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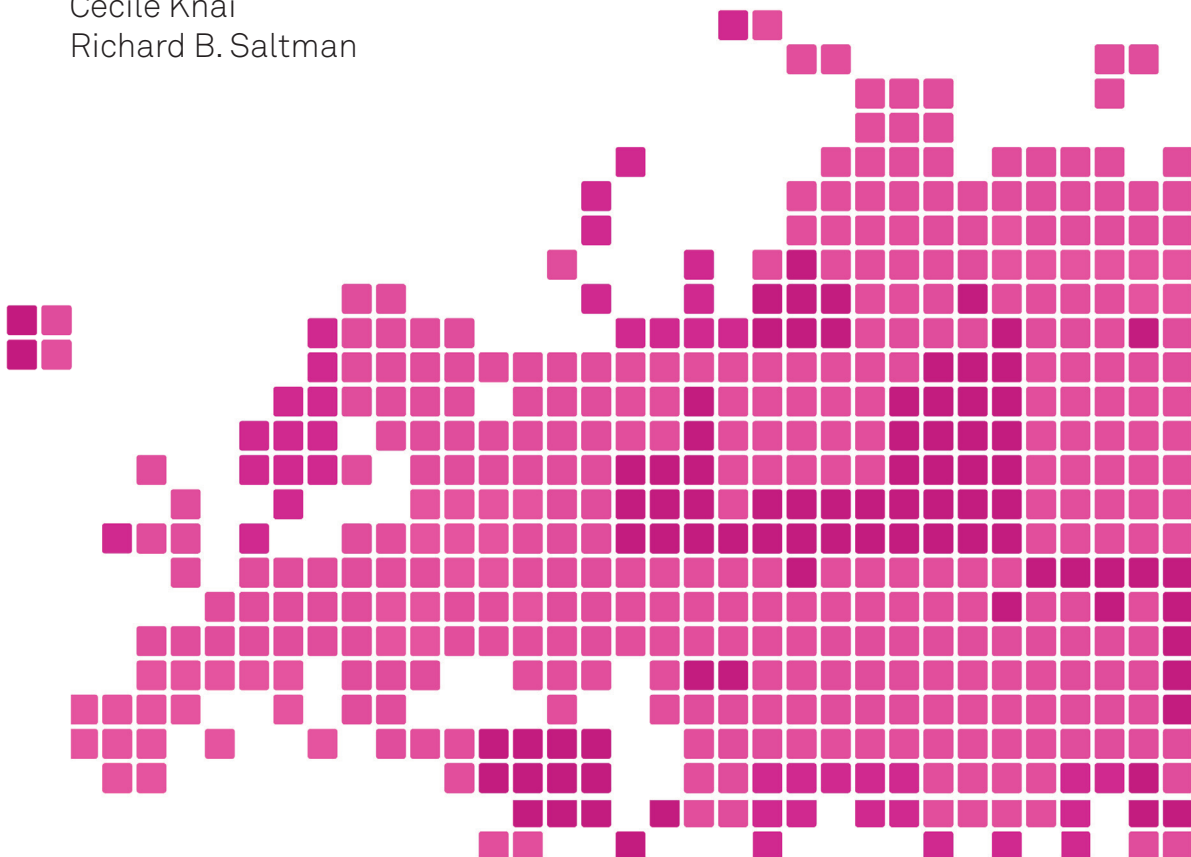
# Assessing chronic disease management in European health systems

37

Observatory  
Studies Series

## Concepts and approaches

Edited by  
Ellen Nolte  
Cécile Knai  
Richard B. Saltman



## **Assessing chronic disease management in European health systems**



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# **Assessing chronic disease management in European health systems**

Concepts and approaches

*Edited by*

**Ellen Nolte  
Cécile Knai  
Richard B. Saltman**

**Keywords:**

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# Preface

This book comprises two volumes and builds on the findings of the DISMEVAL project (Developing and validating DISease Management EVALuation methods for European health care systems), funded under the European Union's (EU) Seventh Framework Programme (FP7) (Agreement no. 223277). DISMEVAL was a three-year European collaborative project conducted between 2009 and 2011. It contributed to developing new research methods and generating the evidence base to inform decision-making in the field of chronic disease management evaluation ([www.dismeval.eu](http://www.dismeval.eu)).

In this book, we report on the findings of the project's first phase, capturing the diverse range of contexts in which new approaches to chronic care are being implemented and evaluating the outcomes of these initiatives using an explicit comparative approach and a unified assessment framework. In this first volume, we describe the range of approaches to chronic care adopted in 12 European countries. By reflecting on the facilitators and barriers to implementation, we aim to provide policy-makers and practitioners with a portfolio of options to advance chronic care approaches in a given policy context.

In volume II (available online at <http://www.euro.who.int/en/about-us/partners/observatory/studies>), we present detailed overviews of each of the 12 countries reviewed for this work and which informed the overview presented in the first volume of the book.

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# List of abbreviations

AIDS	Acquired immunodeficiency syndrome
ASALEE	Health Action by Teams of Self-employed Health Professionals (France)
ASL	Local Health Authority (Italy)
AWBZ	Exceptional Medical Expenses Act (Netherlands)
BRASS	Blaylock Risk Assessment Screening Score
CAPI	Contracts for Improved Individual Practice (France)
CHD	Coronary heart disease
CHF	Swiss franc
CCM	Chronic Care Model
CCP	Care coordination pilot
CMP	Care management programme
CNAM	Caisse Nationale d'Assurance Maladie (France)
COPA	Coordinating Care for Older People (France)
COPD	Chronic obstructive pulmonary disease
CVD	Cardiovascular disease
DBC	Diagnosis and treatment combinations (Netherlands)
DIEP	Diabetes Interactive Education Programme
DDKM	Danish Quality Model (Denmark)
DKK	Danish krone
DMP	Disease management programme
DRG	Diagnosis-related group
EBM	Uniform Assessment Scale (Germany)
EEP	Evaluation of professional practice (France)
EHIF	Estonian Health Insurance Fund
EU	European Union
FFS	Fee-for-service
FIQCS	Intervention Fund for Quality and Care Coordination (France)
GDP	Gross domestic product
GP	General practitioner
HAS	National Authority for Health (France)
HMO	Health maintenance organization
ICC	Integrated care contract
ICP	Integrated care pilot
IGEA	Diabetes Integration, Management and Assistance (Italy)
IHD	Ischaemic heart disease
LKF	Performance-based financing (Austria)
MIGAC	Missions d'intérêt général et à l'aide à la contractualisation (France)

NIHFA	National Health Insurance Fund Administration (Hungary)
ÖDG	Austrian Society of Diabetes
OOP	Out-of-pocket
PbR	Payment by result (England)
PCT	Primary Care Trust (England)
PHC	Primary health care
POPP	Partnership for Older People Project (England)
PPP	Purchasing power parity
PPS	Personalized care programme (France)
QALY	Quality-adjusted life years
QOF	Quality and Outcomes Framework (England)
RCP	Multidisciplinary team meeting (France)
ROSP	Payment based on specific public health objectives (France)
RSA	Risk structure compensation scheme (Germany)
SHI	Statutory health insurance
SIKS	Integrated Effort for People Living with Chronic Disease (Denmark)
SSI	State Serum Institute (Denmark)
SSN	National Health Service (Italy)
URCAM	Regional Unions of Insurance Funds (France)
VerAH	Care assistants in family practice (Germany)
VHI	Voluntary health insurance
WMO	Social Support Act (Netherlands)
ZiO	Care in Development (Netherlands)

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# Chapter 1

## Introduction

*Ellen Nolte, Cécile Knai*

### 1.1 Background

Responding to the burden of chronic disease presents challenges for all health systems. As populations age and advances in health care allow those with once fatal conditions to survive, the prevalence of chronic conditions is rising in many countries (Yach et al., 2004). In the European Union (EU), in 2006, from 20 to over 40% of the population aged 15 years and over reported a long-standing health problem and one in four received long-term medical treatment (TNS Opinion & Social, 2007). Other studies have found the prevalence of common chronic disorders was found to be around 50% among adults aged 18 and over in seven high-income countries, including Germany, the Netherlands and the UK (Schoen et al., 2007).

Although the rising burden of chronic disease is driven, in part, by population ageing it is important to recognize that such conditions are not limited to the older population. Thus, increasing numbers of children and young people are developing some form of chronic health problem (Barnett et al., 2012; Van Cleave, Gortmaker & Perrin, 2010), with over 80% of premature mortality estimated to be attributable to noncommunicable diseases in Europe (Institute for Health Metrics and Evaluation, 2013a).

Assessing the precise level, distribution and nature of the chronic disease burden in Europe remains a challenge (Pomerleau, Knai & Nolte, 2008); yet, it is clear that chronic diseases are important, greatly impacting on the years of life lived in good health. In high-income countries, mental disorders (for example, depression and anxiety disorder), musculoskeletal disorders (for example, lower-back pain), chronic obstructive pulmonary disease (COPD) or asthma, and diabetes, are among the leading causes of chronic disability (Institute for Health Metrics and Evaluation, 2013b), with diabetes projected to rise further in importance during the next two decades, especially against the background



of increasing levels of overweight and obesity (Danaei et al., 2013; Finucane et al., 2011).

The implications for health systems and society as a whole are considerable. Chronic diseases pose a sizeable burden for national economies, with associated costs estimated at up to 7% of a country's gross domestic product (Suhrcke et al., 2006). Societal costs arise partly as a result of direct health care costs, including from health care use, medication and potentially costly interventions, with additional indirect costs deriving from, for example, increased absenteeism, and reduced productivity at work (Suhrcke, Fahey & McKee, 2008). These challenges add to the complexity facing health systems, which require effective measures to prevent disease through reducing the major chronic disease risk factors and addressing influences that drive exposure (Novotny, 2008), while also providing services to meet the requirements caused by chronic health problems, thereby ensuring that people with established disease can participate in society.

The goals of care for those with chronic conditions are not to cure but to enhance functional status, minimize distressing symptoms, prolong life through secondary prevention and enhance the quality of life (Grumbach, 2003). These goals are unlikely accomplished through the traditional acute, episodic model of care, which tends to see the patient as passive recipient of care and where treatment aims at return to normal (Holman & Lorig, 2000). In particular, where people have multiple health problems, creating a range of diverse and sometimes contradictory needs, the conventional care model is insufficient (Piette, Richardson & Valenstein, 2004). Instead, what is needed is a delivery model that involves coordinated inputs from a wide range of health professionals over an extended period of time and that places patients at the centre as co-producers of care to optimize health outcomes (Nolte & McKee, 2008a).

However, service delivery has developed in ways that have tended to fragment care, both within and between sectors, for example, through structural and financial barriers at the interface between primary and secondary care and between health and social care, distinct organizational and professional cultures and differences in terms of governance and accountability (Glasby, Dickinson & Peck, 2006). There is thus a need for new service delivery models that are characterized by collaboration and cooperation among professions and institutions that have traditionally worked separately.

The growing recognition of this need is causing many countries to explore new approaches to health care delivery that can bridge the boundaries between professions, providers and institutions and therefore provide appropriate

support to patients with long-standing health problems. We have previously shown how countries vary in their attempts to do so, with many implementing some form of (chronic) disease management although the nature and scope of related approaches differ (Nolte, Knai & McKee, 2008). We have found that the strategies that are being implemented tend to reflect the characteristics of individual health systems with regard to the relationships between, and the responsibilities of, different stakeholders in the regulation, funding and delivery of health care. In particular, there is a suggestion that those health systems in which patients have traditionally chosen their provider without formal enrolment, paying for services episodically using fee-for-service as the predominant method of reimbursement, may face the greatest challenges in adapting towards providing effective chronic care (Busse & Mays, 2008).

However, there is a need to develop this evidence base further, using an explicit comparative approach and a unified framework for assessment to better understand the diverse range of contexts in which new approaches to chronic care are being implemented, and to evaluate the outcomes of these initiatives. There is also a need to better understand the content of these new models, which are frequently applied from different disciplinary and professional perspectives and are associated with different goals. In this book, we aim to contribute to this process by identifying the range of approaches to chronic care adopted in 12 European countries. By reflecting on facilitators and barriers to implementation we aim to provide policy-makers and practitioners with a portfolio of options to advance chronic care approaches in a given policy context.

## **1.2 Approach to this book**

We build on earlier work which examined the health system context for chronic disease (Nolte & McKee, 2008a), assessed the evidence base for chronic care (Nolte & McKee, 2008b) and reviewed the experience in eight countries in Europe and beyond (Nolte, Knai & McKee, 2008). It seeks to extend this earlier work by drawing on information on approaches to (chronic) disease management and evaluation strategies in a range of European countries that was collected within the DISMEVAL (Developing and validating DISease Management EVALuation methods for European health care systems) project. DISMEVAL was a three-year European collaborative project, conducted between 2009 and 2011, which aimed to contribute to developing new research methods and to generating the evidence base to inform decision-making in the field of chronic disease management evaluation. It was funded under the European Commission's Seventh Framework Programme.

### 1.2.1 Conceptualizing chronic disease and chronic disease management

Chronic conditions or chronic health problems have been described in different ways (Nolte, McKee & Knai, 2008); it is therefore important to briefly set out the terminology we will be using throughout this book. We adopted a general definition, which is principally based on the effects and associated care needs, rather than the cause of the condition in question (Unwin, Epping Jordan & Bonita, 2004). We distinguished acute conditions, which are potentially curable within a short period of time, from chronic conditions, which are either incurable or require prolonged treatment and care, and for which there is a chance of developing intercurrent episodes or acute illnesses associated with the chronic condition (Holman & Lorig, 2000). This differentiation is summarized in Table 1.1.

**Table 1.1** Differentiating acute and chronic conditions

	<b>Acute condition</b>	<b>Chronic condition</b>
Onset	Abrupt	Generally gradual and often subtle
Duration	Limited	Lengthy or indefinite
Cause	Typically single cause	Typically multiple causes with changes over time
Diagnosis and prognosis	Usually accurate	Frequently uncertain
Technological intervention	Usually effective	Often indecisive, adverse effects common
Outcome	Cure possible	No cure
Uncertainty	Minimal	Pervasive
Knowledge	Professionals knowledgeable, patients inexperienced	Professionals and patients have complementary knowledge and experiences

Sources: adapted from Department of Health (2004), based on Holman & Lorig (2000).

This definition includes a range of common, long-term health problems such as diabetes, heart disease or COPD, and progressive mental and neurological disorders. It also includes disabilities and impairments not defined as diseases, such as musculoskeletal disorders, and selected communicable diseases such as human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) (Nolte & McKee 2008a). We also consider cancer, as in some settings approaches to chronic disease management may also target certain cancer sites, for example, breast cancer disease management programmes in Germany or cancer networks in France (Nolte, Knai & McKee, 2008).

We restricted the scope of approaches reported in this book to the management of people with established chronic health problems although we also considered measures of secondary prevention targeted at people at high risk of developing a chronic disabling disease, such as vascular risk management. However, we

excluded measures of primary prevention or health promotion in the context of this work.

Although the DISMEVAL project focused on approaches that can be broadly subsumed under the heading of “disease management”, it is important to acknowledge that definitions of this concept vary widely (Krumholz et al., 2006; Nolte & McKee, 2008b). We discuss this variation in terminology, and its implications for deriving a robust evidence base, further in Chapter 2. At the outset, and for the purposes of the DISMEVAL project, we defined disease management as comprising the following components: (1) an integrated approach to care or coordination of care among providers, including physicians, hospitals, laboratories and pharmacies; (2) patient education; and (3) monitoring or collecting patients’ outcome data for the early detection of potential complications (Krumholz et al., 2006). However, we acknowledge that approaches that are being tested across Europe may not fully meet this definition. Our study sought to capture the range of models that use a subset of disease management interventions or are otherwise conceptualized while pursuing the same objective, that is, to improve the care for those with chronic health problems. We therefore included a wider range of approaches, which we considered as “chronic disease management” or chronic care. Box 1.1 provides an overview of the range of approaches reviewed in this study.

**Box 1.1** Approaches to chronic disease management or chronic care: definition of terms

**Care pathway(s)** (synonyms: clinical pathway; care map; integrated care pathway):

Task-oriented care plan(s) that specify essential steps in the care of patients with a specific clinical problem and describe the patient’s expected clinical course (Campbell et al., 1998).

**Case management:** Intensive monitoring of a person with complex needs by a named case manager – usually a (specialist) nurse – through the development of care or treatment plans that are tailored to the needs of the individual patient who is at high risk socially, financially and medically (Krumholz et al., 2006).

**Chronic care model (CCM):** A conceptual framework that presents a structure for organizing health care comprising of four key components: (1) self-management support; (2) delivery system design; (3) decision support; and (4) clinical information systems (Wagner et al., 1999).

**Coordinated care** (synonyms: care management): Development and implementation of a therapeutic plan designed to integrate the efforts of medical and social service providers, often involving designated individuals to manage provider collaboration.

**Box 1.1** contd

**Disease management (programme) (DMP):** Definitions of disease management (programmes) vary substantially. Common features are: (1) an integrated approach to care/coordination of care among providers, including physicians, hospitals, laboratories and pharmacies; (2) patient education; and (3) monitoring/collecting patient outcomes data for the early detection of potential complications (Krumholz et al., 2006). DM programmes do not normally involve general coordination of care. They also not normally include preventive services such as flu vaccination.

**Integrated care:** Types of collaboration, partnerships or networks between providers of health and social care services that work together to meet the multidimensional needs of an individual patient/client or a category of persons with similar needs/problems (Kodner & Spreeuwenberg, 2002; Nies & Berman, 2004).

**Managed discharge:** Arrangements for the transfer of an individual from hospital to an appropriate setting (primary care; community care) to ensure that any rehabilitation, recuperation and continuing health and social care needs are identified and met.

**Multidisciplinary team(s)/care:** An “extension” of case management that also normally involves the development of treatment plans tailored to the medical, psychosocial and financial needs of patients. Its key feature is the use of a broader range of medical and social support personnel (including physicians, nurses, pharmacists, dietitians, social workers and others) to facilitate transition from inpatient acute care to long-term, outpatient management of chronic illness (Krumholz et al., 2006)

**Nurse-led clinic:** A formalized and structured health care delivery arrangement in which a nurse with advanced competence to practise in a specific health care area (nurse practitioner, clinical nurse specialist, specialist nurse) acts as the first point of contact of care. The nurse manages patients either independently or interdependently with other members of a health care team in at least 80% of their work. The key interventions are: nursing therapeutics, encompassing assessment and evaluation; health teaching/counselling; treatment and procedures; and case management. (NB: Nurse-led clinics are different from nurse-led care insofar as the former describe a formalized and structured delivery arrangement, whereas the latter also includes other arrangements, for example, case management, liaison nurses, discharge nurse, etc.) (Wong & Chung, 2006).

**Provider network(s):** A group of providers bringing together different levels of care (for example, health and social care or primary and secondary care).

*Source:* compiled by the authors

### **1.2.2 Countries included in the review**

We selected 12 countries for review: Austria, Denmark, England, Estonia, France, Germany, Hungary, Italy, Latvia, Lithuania, the Netherlands and Switzerland (the only non-EU country). Five of these countries (Denmark, England, France, Germany and the Netherlands) were reviewed in previous work (Nolte, Knai & McKee, 2008), but as these have further developed existing approaches or have implemented new approaches, their experience can provide important insights into the factors that have made these developments possible (or indeed hindered further advancement).

The review was based on a structured template for the collection of data on approaches to chronic disease management in European systems, which was based on earlier work by Nolte, Knai and McKee (2008), and informed, to great degree, by the Chronic Care Model developed by Wagner and colleagues in the United States (Wagner, 1998). Data collection was undertaken by key informants in the countries under review. It was beyond the scope of this study to provide a comprehensive inventory of all approaches being implemented in a given country; key informants were asked to present a “sample” of approaches considered representative of a given health system in terms of the type and setting of delivery model, providers involved, key strategies employed and the population covered. Data presented here reflect information collected by the summer of 2011, with updates to early 2014 where necessary and appropriate. Country reports formed the basis of the systematic cross-country comparison presented in this book. Further detail on the data collection that informed country reports is provided in the accompanying volume to this book (Nolte & Knai, 2015).

### **1.3 About this book**

We begin in Chapter 2 with a brief review of the peer-reviewed literature on chronic disease management. In Chapter 3, we report on the key observations from our survey of 12 European countries on approaches to chronic care. We conclude with Chapter 4, which provides a summary analysis of findings reported in earlier sections. We suggest that this book should be read in conjunction with a second volume, which presents detailed overviews of each of the 12 countries reviewed for this work and which informed the summary overview presented in this book (Nolte & Knai, 2015).

## Chapter 2

# What we know: a brief review of the evidence of approaches to chronic care

*Ellen Nolte, Emma Pitchforth*

This chapter provides a brief overview of the evidence base for chronic care.<sup>1</sup> Drawing on our earlier work (Nolte & McKee, 2008b; Nolte & Pitchforth, 2014), it summarizes the evidence on approaches to managing care for people with chronic conditions. It begins by briefly reflecting on concepts used in the context of chronic care, reviewing the commonalities and differences between terms such as disease management and integrated care. It then provides an overview of published evidence on the effectiveness of selected approaches to improving the care of people with chronic conditions. It concludes with a section outlining the major gaps in our understanding of effective approaches to chronic care.

### **2.1 Managing care for people with chronic conditions: concepts and definitions**

One challenge to identifying effective approaches to managing care for people with chronic conditions remains the absence of common definitions of underlying concepts. There is a plethora of terminologies that have variously been described as integrated care, coordinated care, collaborative care, managed care, disease management, case management, patient-centred care, chronic (illness) care, continuity of care, and others (Nolte & McKee, 2008b). While these may differ conceptually, the boundaries between them are often unclear and terms are frequently used interchangeably (Kodner & Spreuwenberg, 2002),

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<sup>1</sup> This chapter is based on a summary overview of 'Best practice in chronic care', which informed the 2013 International Symposium on Health Care Policy convened by the Commonwealth Fund, New York (unpublished).

reflecting the range of disciplines and professional perspectives involved, along with a diverse set of objectives around “chronic care” (Nolte & McKee, 2008b). This issue is not only of academic relevance but has important implications for practice. Empirical evidence of approaches that can be subsumed under the above terms is often difficult to compare because of a lack in clarity in defining and describing the approach being studied. It thus remains problematic to arrive at conclusions about the relative value of one approach versus another.

Take two common concepts that are frequently used in the context of managing chronic conditions, disease management and integrated care. We have previously argued that these two concepts may reflect two ends of a spectrum of approaches that, ultimately, aim to ensure cost-effective quality care for service users with varied needs (Nolte & McKee, 2008b). Disease management, by definition, traditionally targets patient groups with specific conditions, such as diabetes, while integrated care is typically aimed more broadly at people with complex needs that arise from multiple chronic conditions, coupled with increasing frailty at old age. However, with more recent definitions of disease management explicitly adopting a broader view towards a population-based approach that addresses multiple needs (Population Health Alliance, 2014; Geyman, 2007), boundaries are becoming increasingly blurred.

### **2.1.1 Disease management**

Disease management was first described in the USA in the 1980s, with an initial focus on educational programmes to promote medication adherence and behaviour change among people with specific chronic conditions (Bodenheimer, 1999). From the mid-1990s, in parallel with an emerging body of evidence pointing to the potential for disease management to improve care quality and lead to cost savings, disease management strategies were adopted more widely across the private and public sector in the USA (Krumholz et al., 2006) and, more recently, in several European countries (Nolte & Hinrichs, 2012; Rijken et al., 2014) with related concepts also implemented in Australia (Glasgow et al., 2008). However, as noted in the introduction to this book, approaches vary widely in focus, scope of interventions and populations covered (Nolte & Hinrichs, 2012). In the USA, descriptions range from “discrete programs directed at reducing costs and improving outcomes for patients with particular conditions” (Rothman & Wagner, 2003:257) to “a system of coordinated health care interventions and communications for populations with conditions in which patient self-care efforts are significant” (Population Health Alliance, 2014). This second, comprehensive definition by the US-based Population Health Alliance suggests a shift from a single-disease focus towards a whole person model that addresses the needs of patients with comorbidities and multiple conditions.



Yet, although authors have increasingly adopted this broader definition, as discussed further on in this chapter, variation in what is referred to as disease management has remained (Coleman et al., 2009; Lemmens, Nieboer & Huijsman, 2009; Pimouguet et al., 2011). Importantly, in many settings the focus continues to be on single diseases, albeit with some adjustment to also consider comorbidity (Fullerton, Nolte & Erler, 2011), and there remain concerns overall about the suitability of current approaches to disease management to address the complex needs of those with multiple disease processes (Aspin et al., 2010; Nolte et al., 2012a; Rijken et al., 2014).

### **2.1.2 Integrated care**

In contrast to disease management, the concept of integrated care has traditionally been discussed in the health and social care fields, with reference to linking the cure and care sectors (Kodner & Spreeuwenberg, 2002; Leutz, 1999). The application of the concept of integrated care to health and social care is not, however, clear-cut and different conceptualizations have been put forward, emphasizing, for example, the health care perspective (Gröne & Garcia-Barbero, 2001), or interpreting integration in terms of financing and delivery functions in the context of managed care (Øvretveit, 1998; Shortell, Gillies & Anderson, 1994). The common denominator of integrated care concepts and approaches is their primary aim of improving outcomes for, traditionally, frail older people and other population groups with diverse and complex needs. The focus is on service users with multifaceted problems who require assistance with activities of daily living (Nolte & McKee, 2008b).

From this perspective, the notion of integrated care can be seen to be distinct from disease management. But, with recent conceptualizations of disease management that encompass collaborative care models and broader population groups as advocated by the Population Health Alliance (2014), and an interpretation of integrated care that is often limited to linkages within the health sector, the lines between the two concepts are increasingly difficult to draw. A review of systematic reviews by Ouwens et al. (2005) illustrates this issue. It sought to assess the effectiveness, definitions and components of integrated care programmes for chronically ill patients; however, of the systematic reviews considered, the majority were reviews of disease management programmes.

This latter point highlights the continued challenges associated with differentiating approaches in the field of chronic care. Based on these observations, we argue that concepts of integrated care and narrower, health-sector-specific perspectives of disease management share a common goal of improving outcomes for those with (complex) chronic health problems by overcoming issues of fragmentation through linkage of services of different

providers along the continuum of care (Nolte & McKee, 2008b). However, while concepts of integrated care frequently (aim to) link with the social care sector, disease management programmes are typically limited to linkages within the health care sector. Furthermore, as noted previously, disease management tends to remain restricted to single diseases.

## **2.2 What we do know: a review of the evidence base on approaches to caring for people with chronic conditions**

This section presents a summary overview of key observations from recent rapid evidence reviews of disease management and of integrated care published elsewhere (Nolte, 2015; Nolte & Pitchforth, 2014). Both reviews focused on published systematic reviews and meta-analyses in the relevant field, building on the aforementioned work by Ouwens et al. (2005). The precise scope of our earlier work differed, but in both cases, we limited our search to studies published from 2004 onwards since the review by Ouwens and colleagues (2005) had covered systematic reviews and meta-analyses that had been published during 1996 through to May 2004. Detailed overviews of these reviews are available at Nolte (2015) and Nolte & Pitchforth (2014). Where appropriate, we complement this summary with more recent evidence not captured in our earlier reviews.

### **2.2.1 Disease management**

Our review of the effectiveness of programmes broadly defined as disease management identified 15 eligible systematic reviews or meta-analyses published between January 2004 and October 2012 (Nolte, 2015). A summary of key findings is presented in Table 1.1.

The conditions most frequently considered in the reviews were depression (Neumeyer-Gromen et al., 2004; Thota et al., 2012), heart failure (Drewes et al., 2012; Göhler et al., 2006; Gonseth et al., 2004; Roccaforte et al., 2005), diabetes (Egginton et al., 2012; Knight et al., 2005; Pimouguet et al., 2011), COPD or asthma (Adams et al., 2007; Peytremann-Bridevaux et al., 2008; Lemmens, Nieboer & Huijsman, 2009), or a combination of these (de Bruin et al., 2011; Ofman et al., 2004; Tsai et al., 2005). Definitions of disease management varied among studies, although all adopted a fairly comprehensive conceptualization, drawing, for example, on the definition by Ellrodt et al. (1997:1687), which defines disease management as “an approach to patient care that coordinates medical resources for patients across the entire delivery system”. Others built on the CCM proposed by Wagner (1998), which

**Table 2.1** Review of reviews: evidence of the effect of disease management programmes

Disease	Functional status, clinical outcomes	Health care use	Quality of life	Patient satisfaction	Mortality	Process	Cost
<b>Chronic heart failure</b>							
Gonseth et al. (2004)		↓					(↓)
Roccaforte et al. (2005)		↓	?		↓	+	
Göhler et al. (2006)		↓			↓		
Drewes et al. (2012)		↓	+		↓		
<b>Diabetes</b>							
Knight et al. (2005)	+ / (+)	(↓)	(+)	(+)	=	(+)	
Pimouguet et al. (2011)	+						
Egginton et al. (2012)	+		(+)			(+)	?
<b>COPD</b>							
Adams et al. (2007)	+ / (+)	↓	?		=		(↓)
Peytremann-Bridevaux et al. (2008)	+ / (+)	↓	?	(?)	=	(+)	
Lemmens, Nieboer & Huijsman (2009)	=	↓ / (↓)	+	(+)		(+)	
<b>Depression</b>							
Neumeyer-Gromen et al. (2004)	+		+	+		+	?
Thota et al. (2012)	+		+	+		+	
<b>Combined</b>							
Ofman et al. (2004)	+ / (+)	(↓)	(+)	+	0	+ / (+)	(↓)
Tsai et al. (2005)	+		+ / (+)			+ / (+)	
de Bruin et al. (2011)							(↓)

*Notes:* ↓ = significant reduction in more than half of studies reviewed; (↓) = some evidence of reduction; ↓ / (↓) = significant reduction in some outcomes; + = significant improvement in more than half of studies reviewed; (+) = some evidence of improvement; + / (+) = significant improvement in some outcomes; = no significant change in outcome concerned; ? evidence inconclusive. COPD: chronic obstructive pulmonary disease.

considers six elements as essential for improving chronic illness care (see Box 1.1). Several reviews analysed primary studies that included a minimum of two discrete interventions considered beneficial for chronic illness care, such as patient self-management, provider feedback, structured follow-up or role redesign (Lemmens, Nieboer & Huijsman, 2009; Peytremann-Bridevaux et al., 2008; Pimouguet et al., 2011), or a variation of this conceptualization (Egginton et al., 2012; Göhler et al., 2006; Neumeyer-Gromen et al., 2004; Roccaforte et al., 2005). Typically, around half of primary studies covered by the reviews were set in the USA, followed by Australia, the United Kingdom, Canada, Sweden and the Netherlands. Two reviews focused on studies set in the USA only (Egginton et al., 2012; Neumeyer-Gromen et al., 2004).

Studies reported on a diverse set of outcomes, reflecting the condition being targeted. In brief, available reviews provided fairly consistent evidence of a positive impact of disease management interventions targeting those with depression. These demonstrated, for example, significant improvements in depression severity (Neumeyer-Gromen et al., 2004), as well as depression symptoms, patient adherence to treatment, response to treatment and satisfaction with care, among other outcomes (Thota et al., 2012). One meta-analysis of 102 experimental or quasi-experimental studies targeting 11 conditions found that disease management interventions for those with depression had the highest proportion of studies demonstrating substantial improvements in patient care (48% statistically significant) (Ofman et al., 2004).

A similar consistency was found for disease management interventions targeting heart failure. These showed, for example, statistically significant reductions in the frequency of disease-specific and all-cause readmissions of between 10 and 30% (Gonseth et al., 2004; Roccaforte et al., 2005), with some evidence of a reduction in all-cause mortality (Roccaforte et al., 2005; Göhler et al., 2006; Savard, Thompson & Clark, 2011; Drewes et al., 2012). There was also some evidence that programmes that had incorporated a multidisciplinary team approach had a stronger impact on outcome measures (Roccaforte et al., 2005; Göhler et al., 2006). However, Savard, Thompson and Clark (2011), in a meta-review of meta-analyses of heart failure disease management programmes found the quality of reviews to be moderate and very mixed across reviews, with studies not adequately taking account of programme complexity and heterogeneity.

Evidence for the impact of disease management on diabetes also tended to show beneficial effects overall, with significantly improved glycaemic control among diabetes disease management populations compared to usual care, although the overall clinical significance of observed improvements remains uncertain (Knight et al., 2005; Pimouguet et al., 2011; Egginton et al., 2012). However,

there was evidence that disease management may be more effective for patients with poor glycaemic control (Pimouguet et al., 2011). The review by Knight et al. (2005) further showed that observed effects were larger for studies conducted in the USA, although the number of trials outside the USA considered in the review was small (Knight et al., 2005). Overall there was considerable variation across studies included in individual reviews in terms of intervention delivery methods, duration and populations, and such a variation was also observed in studies that examined the evidence base for disease management targeted at people with COPD or asthma. Among these, there was evidence of reduced health service use, such as hospitalizations, among those receiving disease management (Adams et al., 2007; Peytremann-Bridevaux et al., 2008), while impacts on clinical outcomes were mixed across reviews, with some evidence of a reduction in all-cause mortality among targeted patients (Peytremann-Bridevaux et al., 2008). This last review considered trial evidence from a range of countries, including Canada, the Netherlands, New Zealand, Spain, Sweden and the USA.

### **2.2.2 Integrated care**

Our review of integrated care focused on the economic impacts of relevant approaches (Nolte & Pitchforth, 2014). We identified 19 systematic reviews and meta-analyses published between 2004 and 2012, although it is important to note that of the reviews included, none explicitly defined the term integrated care. Instead, the most commonly used strategies were described as case management (Chiu & Newcomer, 2007; Smith & Newton, 2007; Oeseburg et al., 2009; Pimouguet et al., 2010), collaborative care (Gilbody, Bower & Whitty, 2006; Brink-Huis, van Achterberg & Schoonhoven, 2008; van Steenberg-Weijnenburg et al., 2010), or a combination of these (Phillips et al., 2004; Langhorne et al., 2005; Shepperd et al., 2008; Steffen et al., 2009; Althaus et al., 2011; Smith et al., 2012; Tappenden et al., 2012), alongside notions such as seamless care (Simoens et al., 2011). Four reviews focused on disease management interventions that involved multicomponent approaches (Neumeyer-Gromen et al., 2004; Maciejewski, Chen & Au, 2009; Steuten et al., 2009; de Bruin et al., 2011). Of these, two were also considered in our review of disease management reported previously in this chapter; therefore, we do not report on these two reviews in this section (Neumeyer-Gromen et al., 2004; de Bruin et al., 2011).

Reviews considered a wide range of interventions or initiatives that targeted a diverse group of people or populations. Several studies focused on adults with specific chronic conditions including pain (Brink-Huis, van Achterberg & Schoonhoven, 2008), depression (Gilbody, Bower & Whitty, 2006; van

Steenbergen-Weijnenburg et al., 2010), stroke (Langhorne et al., 2005), asthma (Maciejewski, Chen & Au, 2009), COPD (Steuten et al., 2009), or those with multimorbidity (Smith et al., 2012). Four reviews considered integrated care approaches for older people in the community considered to be frail (Oeseburg et al., 2009) or have long-term medical or social care needs (Tappenden et al., 2012), those with specific chronic conditions, such as heart failure (Phillips et al., 2004), or those who were to be discharged from hospital (Chiu & Newcomer, 2007). Three reviews focused on adults with dementia or memory loss (Pimouguet et al., 2010), those with severe mental health problems (Smith & Newton, 2007), or those who received mental health care services (Steffen et al., 2009), while the remainder addressed populations defined by patterns of health service use (Shepherd et al., 2008; Althaus et al., 2011; Simoens et al., 2011).

Initiatives frequently targeted the interface between hospitals and primary care or community services, most often in the context of discharge planning or care transition (Phillips et al., 2004; Langhorne et al., 2005; Chiu & Newcomer, 2007; Steffen et al., 2009; Althaus et al., 2011; Simoens et al., 2011). Several studies examined initiatives that sought to coordinate primary care and community services, often, although not always, involving medical specialists (Gilbody, Bower & Whitty, 2006; Brink-Huis, van Achterberg & Schoonhoven, 2008; van Steenbergen-Weijnenburg et al., 2010; Smith et al., 2012) or extending further into social care services (Smith & Newton, 2007; Pimouguet et al., 2010; van Steenbergen-Weijnenburg et al., 2010; Tappenden et al., 2012). The latter type of interventions tended to target older people with multiple care needs, those with dementia or with mental health problems. The definition of what constitutes community services or social care differed across the individual studies reviewed, making any generalization of the extent of integration across sectors difficult. This last point also reflects the differences in settings, with typically about half of primary studies considered by reviews set in the USA, followed by the United Kingdom, Australia, Canada, New Zealand, the Netherlands, Spain, Italy and Sweden.

Similar to studies of the effectiveness of disease management, reviews of the impacts of integrated care reported on a diverse set of outcomes that we attempt to summarize here. We should reiterate that our original review focused on the economic impacts of approaches considered as integrated care (Nolte & Pitchforth, 2014). Therefore, our review captured only a subset of relevant studies that included cost measures and that did not necessarily cover the broader range of outcomes. These limitations reflect our selection process rather than an absence of evidence; where appropriate we complement our discussion with evidence from systematic reviews not included in our initial review.

Categorizing reviews by type of integrated care strategy or approach, we found mixed evidence for the impact of case management. One review of case management in mental health, which focused on studies assessing assertive community treatment or intensive case management, reported some limited evidence of increased patient satisfaction (Smith & Newton, 2007). Two reviews, focusing on case management for dementia (Pimouguet et al., 2010) or chronic illness among older or frail people (Oeseburg et al., 2009), reported reduced service use. A more recent review of case management for heart failure patients being discharged from hospitals provided evidence for significant reductions in readmission rates, as well as all-cause mortality at the 12-month follow-up (Takeda et al., 2012). Reviews that assessed interventions targeting interactions between hospitals and primary care or community services through care coordination activities pointed to improved satisfaction among those receiving the intervention (Langhorne et al., 2005; Simoens et al., 2011), as well as improved quality of life (Phillips et al., 2004; Steffen et al., 2009), but not reduced mortality (Langhorne et al., 2005; Chiu & Newcomer, 2007; Simoens et al., 2011).

There was consistency in findings across two reviews examining collaborative care approaches for those with depression, but as with the evidence on disease management approaches reported previously, studies were almost exclusively set in the USA (Gilbody, Bower & Whitty, 2006; van Steenberg-Weijenburg et al., 2010). A more recent Cochrane review of collaborative care for depression and anxiety problems, which also included studies from countries outside the USA, found improvements in outcomes across several studies, but statistically significant improvements were not always maintained over time (Archer et al., 2012). Brink-Huis, van Achterberg & Schoonhoven (2008) reviewed collaborative organizational models in relation to pain management among adult cancer patients, finding that pain intensity and relief improved using integrated care processes.

Evidence from reviews that considered strategies involving a combination of case management, care coordination or collaborative care for a range of patient groups was difficult to summarize. In general, they tended to show improvements in clinical or functional outcomes and, in some cases, a trend towards reduced mortality rates (Shepperd et al., 2008; Tappenden et al., 2012). One review of interventions targeting patients with coexisting, multiple chronic conditions in primary and community care settings found limited evidence for these to impact outcomes, although a number of process indicators, such as provider behaviour did improve (Smith et al., 2012).

### ***2.2.3 Economic impacts of disease management or integrated care***

We report the economic impacts of disease management and integrated care, respectively drawing from our reviews. In the review of disease management, few studies explicitly considered costs, and where they did, the evidence tended to be inconsistent (Ofman et al., 2004). De Bruin et al. (2011) examined the impact of disease management programmes on health care expenditures for patients with diabetes, depression, heart failure or COPD. Of 31 studies considered in their review, 21 reported incremental health care costs per patient per year, and of these, 13 found evidence of cost savings, but these were typically not statistically significant or not tested for statistical significance. The authors noted substantial variation across studies with regard to the interventions (content and type), the economic evaluative approach used, the type of direct health care costs and cost categories considered, alongside a lack of reporting on reliability of estimates, highlighting the need for higher-quality studies. Consequently, the authors concluded that “although it is widely believed that disease management programs reduce health care expenditures, the present study shows that evidence for this claim is still inconclusive” (de Bruin et al., 2011:105), thereby calling for well-designed economic evaluations.

In our review of integrated care approaches, the most common economic outcome measures were use and cost, but reporting of measures was inconsistent and the quality of the evidence was often low (Nolte & Pitchforth, 2014). The majority of economic outcomes focused on hospital use through (re)admission rates, length of stay or admission days and emergency department visits. For example, among reviews that considered care coordinating activities at the hospital–primary care or community services interface reported evidence of reduced hospital use (Phillips et al., 2004; Langhorne et al., 2005; Chiu & Newcomer, 2007; Steffen et al., 2009; Simoens et al., 2011).

Most studies reported cost in terms of health care cost savings, most frequently in relation to hospital costs. There was some evidence of cost reduction in a number of reviews although findings were frequently based on a small number of original studies, or studies that only used a before/after design without control, or both (Phillips et al., 2004; Chiu & Newcomer, 2007; Brink-Huis, van Achterberg & Schoonhoven, 2008; Shepperd et al., 2008; Steffen et al., 2009; Althaus et al., 2011; Simoens et al., 2011). Philips et al. (2004) highlighted the impact of a health system setting on costs, demonstrating how pooled cost differences for comprehensive discharge planning for those with heart failure ranged from US\$359 compared to usual care in non-US-based trials to US\$536 in trials based in the USA. Tappenden et al. (2012) further noted, in a review of structured home-based, nurse-led health promotion, the importance of differentiating between initial and longer-term costs. Thus,



they reported how a community-based nursing programme for patients with Parkinson's disease had initially increased costs, whereas over two years costs were lower.

Neumeyer-Gromen et al. (2004) and van Steenberg-Weijnenburg et al. (2010), both reporting on care approaches targeted at those with depression, reported an increase in costs associated with the intervention, but the cost per successfully treated patient was lower (Neumeyer-Gromen et al., 2004). A review by Jacob et al. (2012) of 30 studies of collaborative care for the management of depressive disorders also provided some evidence of potential cost savings associated with collaborative care compared with usual care. All three reviews drew on primary studies set in the USA.

Reviews also pointed to cost-effectiveness of selected integrated care approaches, although again the evidence base was weak, frequently relying on single trials of a given intervention. For example, one review of approaches targeting frequent hospital emergency department users found one trial that reported the intervention to be cost-effective (Althaus et al., 2011). Another review of structured home-based, nurse-led health promotion for older people at risk of hospital or care home admission concluded, based on three economic studies, that there was a high likelihood of cost savings associated with the intervention (Tappenden et al., 2012). However, one of the three studies suggested that there was little or no evidence for gains in quality-adjusted life years (QALYs) over usual care. Four reviews reported on cost per QALY as a measure of cost utility, providing mixed evidence of increased cost with integrated care approaches (Gilbody, Bower & Whitty, 2006; Steuten et al., 2009; van Steenberg-Weijnenburg et al., 2010; Simoens et al., 2011). Jacob et al. (2012) reported collaborative care for the management of depressive disorders to be cost-effective. Overall the evidence was difficult to interpret.

### **2.3 What we need to know: limitations of the existing evidence base**

This overview of the evidence on approaches to enhance chronic care is arguably limited in that it considers published systematic reviews only. This means that, by necessity, we have had to rely on authors' reporting of findings of original studies, which limits objective assessment, in particular, where observations from original studies were not described in detail. Furthermore, even the most recent reviews will not capture primary studies published over the past 12 months or so, and which might have provided additional insights into the overview presented here. At the same time, and echoing concerns reported by Ouwens et al. (2005) in their assessment of the evidence of integrated care programmes

as described earlier, it remains challenging to interpret the evidence from existing primary studies. Thus, as reviews reported here have shown, studies of what can broadly be subsumed under the heading of chronic care strategies or programmes tend to be very heterogeneous. Lack of precision in reporting of interventions, alongside variation in definitions and components of care, does make arriving at overarching conclusions at what is the best approach difficult. Indeed, as Ouwens et al. (2005) noted, such heterogeneity might lead to inappropriate conclusions about programme effectiveness and the application of findings. This further underlines the continued need for the use of consistent definitions and of better description of the content of interventions to enable comparison.

However, at the same time, and at the risk of simplifying what is inherently complex, we can derive some tentative observations from the evidence presented here. Specifically, what seems to be emerging is the value of targeted approaches to enhance outcomes of those with complex care needs. For example, evaluations that examined the impact of different care components point to an association between the format or modality of the intervention and reported outcomes. Thus, evidence from collaborative care models for the management of depressive disorders suggests that interventions were more effective when based in the community or when they involved nurses as case managers (Thota et al., 2012). Similarly, for persons with heart failure, the impact on outcomes was found to be stronger for those interventions that incorporated a multidisciplinary team approach (Roccaforte et al., 2005; Göhler et al., 2006). These observations concur with other review evidence that examined the effects of different coordinated care interventions (Powell Davies et al., 2008). That review showed that interventions using multiple strategies tended to be more successful in enhancing the health outcomes of patients than those using single strategies only. Specifically, approaches that helped structuring relationships between providers and between providers and patients through, for example, case management or multidisciplinary teams were found to be more likely to be effective.

Other evidence points to the need to develop approaches that more specifically target those who are most likely to benefit. For example, Pimouguet et al. (2011) showed how diabetes disease management may be more effective for patients with poor glycaemic control. Similar findings were recently reported for a large, population-based diabetes care intervention in the Netherlands (Elissen et al., 2012), although requiring further confirmation (Elissen et al., 2013a). Evidence supporting the use of targeted approaches was also provided in the review by Smith et al. (2012) of models of care for those with multimorbidity cited earlier. While highlighting the paucity of research into related strategies, the

review noted that organizational interventions that focus on the management of specific risk factors or that targeted specific areas of concern for patients, such as functional ability or the management of medicines, may be more effective than approaches not similarly targeted.

The review by Smith et al. (2012) further highlighted the need to integrate new interventions with the existing health care delivery structure to enhance their effectiveness. Related observations noted how the evidence of impact tended to be stronger for primary studies undertaken in the USA than for those done elsewhere, as was the case for studies of disease management for diabetes (Knight et al., 2005). Given that much of the available evidence tends to originate from the USA, the findings highlight a need for caution when considering transferring models across countries with different health systems, and for developing a more robust evidence base that takes account of the European context (Nolte & McKee, 2008a). Overall, these findings also point to the need for more systematic evaluation of new models of care as a means to inform the development of efficient and effective interventions to address the growing burden of chronic conditions in Europe and elsewhere.

## **2.4 Conclusions**

In this chapter, we have reviewed the recent evidence on the effectiveness of various approaches to improving care for people with chronic conditions. We have highlighted the difficulties in differentiating and defining terms associated with different models of care. This is not only of academic concern but makes collating evidence to support assessments of best practice in the management of chronic illnesses very difficult.

Furthermore, evidence of the cost–effectiveness of different models is lacking, particularly in the European context. Findings from the USA that suggest certain chronic care approaches may yield cost savings may not be transferable to other health systems. In this context, it is important to note that it is clear from the literature that it is easier to improve processes of care than costs. The assumption that providing better care will save money will need to be scrutinized carefully. Policy-makers and payers need to be clear about whether their goal is quality improvement or cost reduction as these two are not necessarily compatible with one another (Øvretveit, 2009).

We have shown that, overall, strategies that involve multiple organizational strategies that are set in the community, involve nurses as case managers and incorporate a multidisciplinary team approach are more likely to be effective. The evidence that is available tends to be limited to a small set of conditions only, although arguably, by restricting the review reported here to published

systematic reviews, we will have missed more recent evidence from primary studies that have investigated the impact of disease management on a broader range of conditions.

One fundamental issue remains, which is related to the need to develop a system-wide model of care for patients with chronic disease. Disease-specific approaches, such as disease management programmes, are ill-suited to meet the needs of the typical patient in primary care who typically has multiple health problems with complex needs (Nolte & McKee, 2008a). Integrated care, which is most commonly associated with aiming to meet the needs of populations groups with diverse and complex needs, has been associated with improved patient and clinical outcomes. The challenge in this case is that it is not clear for how long initial improvements are sustained. Furthermore, evidence of interventions designed to improve outcomes in patients with coexisting multiple chronic conditions in primary and community care settings suggests that this may be an area with the most inconsistent evidence. Despite the need for more robust evaluations and general strengthening of the evidence base, we have drawn common lessons around modalities of interventions that are likely to be more effective.

## Chapter 3

# Approaches to chronic disease management in Europe

*Ellen Nolte, Cécile Knai*

This chapter provides an overview of the policy context for chronic disease management in 12 European countries and examines approaches to chronic disease management and models of care delivery that have been or are being implemented in these countries. It draws on detailed country reports, which are presented in an accompanying volume (Nolte & Knai, 2015). We begin with a concise overview of selected key features of the health care systems in each of the countries reviewed. We then describe the main types of chronic care approaches countries are employing, the nature and scope of professionals and health care providers involved, the extent to which patients are actively engaged or supported, the use of support structures, such as decision-making tools and guidance, approaches to financing and the use of financial incentives, and population(s) covered.

As noted earlier, it is beyond the scope of this book to provide a comprehensive inventory of all approaches being implemented in a given country; instead we have focused on a sample of approaches considered representative of a given health care system.

### **3.1 Key features of the health care systems in 12 European countries**

Before discussing the specific policy context for chronic disease in the countries reviewed, it is important to understand some of the key characteristics of the health care systems and the principles of health service delivery in each of the countries to help placing into context the efforts to implement chronic care policies as described further on in this chapter.

All countries have a similar commitment to providing universal and reasonably equitable access to health care for their populations, but do so in different ways. Four countries (Denmark, England, Italy and Latvia) operate primarily tax-funded systems, while the health care systems in Austria, Estonia, France, Germany, Hungary, Lithuania and the Netherlands are primarily funded through statutory health insurance. Switzerland operates a mandatory private insurance system (Table 3.1).

Countries reviewed vary in relation to principal health care governance structures, with systems in England, France, Hungary, Latvia and Lithuania characterized by structures that tend to concentrate governance functions at the central (national) level, with decentralization of some functions to bodies at arm’s length from government. Elsewhere, administrative and political responsibility is partly or fully devolved to local or regional authorities (Denmark, Estonia, Italy) or federal states (Austria, Germany, Switzerland). In Austria, Germany and the Netherlands, corporate actors (for example, statutory health insurance (SHI), providers) also play an important role.

**Table 3.1** Principles of health care financing in 12 European countries

Country	Health expenditure (2012)		Main sources of funding for health care (% of total current health expenditure in 2012)
	% of GDP	US\$ PPP	
Austria	11.5	5065	Combination of SHI (40.5) and general taxation (35.0), VHI (4.0), OOP (15.2)
Denmark	11.2	4720	General taxation (85.5), VHI (1.8), OOP (12.6)
England (UK)	9.4	3495	General taxation (82.5), VHI (1.1), OOP (9.9)
Estonia	5.9	1385	National health insurance (69.1), general taxation (10.8), OOP (18.4)
France	11.7	4260	SHI (71.0), VHI (13.8), OOP (7.4), general taxation (5.9)
Germany	11.3	4617	SHI (67.6), general taxation (8.7), VHI (9.5), OOP (12.1)
Hungary	7.8	1729	SHI (52.3), general taxation (11.4), VHI (2.7), OOP (27.1)
Italy	9.2	3040	National and regional taxation (78.2), OOP (20.2)
Latvia	6.0	1188	General taxation (56.7), VHI (2.5), OOP (37.4)
Lithuania	6.7	1426	SHI (60.1), taxation (10.7), OOP (28.5)
Netherlands	12.4	5384	SHI (72.6), taxation (7.3), VHI (5.2), OOP (5.6)
Switzerland	11.3	6062	Mandatory health insurance (43.7), taxation (18.0), VHI (9.4), OOP (28.1)

Source: World Health Organization (2014).

Notes: GDP: gross domestic product; PPP: purchasing power parity/capita (national currency unit per US\$); SHI: statutory health insurance; VHI: voluntary health insurance; OOP: (household) out-of-pocket (expenditure).

Countries also vary in the organization of health care, with differences in the settings within which the different levels of care are being provided (Table 3.2). Focusing on primary care, most countries reviewed here offer a choice of primary care physician, usually a general practitioner (GP) or family physician

operating in independent practice. The only exceptions are Denmark and England where choice of primary care provider is presently restricted to within (small) geographical areas. All but four countries require registration with a primary care provider who typically acts as gatekeeper to specialist services. Exceptions are Austria, France, Germany and Switzerland, which principally offer almost unrestricted access to primary and specialist care providers in the ambulatory care system, with France and Germany recently introducing voluntary GP gatekeeping schemes to enhance care coordination; selected managed care schemes in Switzerland also restrict direct access to specialists.

Where gatekeeping is in place, some direct access to specialists may still be possible, with certain specialties exempted from requiring a GP referral, such as in Denmark, Estonia, Hungary, Italy and Latvia. Also, where registration with a GP (practice) is in place, payment of the primary care provider tends to be based on capitation, frequently in combination with fees for specific services or activities and, less frequently, performance-related elements (for example, England, Estonia, France, Hungary). Systems that do not require patient enrolment typically reimburse their primary care providers on a fee-for-service basis (France, Switzerland), while elements of capitation may also be used (Austria, Germany).

We have previously noted that health care systems in which patients have traditionally chosen their provider without formal enrolment, and where payment for services is mainly based on fee-for-service, may face the greatest challenges in adapting towards providing effective chronic care (Busse & Mays, 2008). These observations provide important context for better understanding the general approaches taken by individual countries to enhance care for people with chronic conditions, and the extent to which existing structures facilitate, or indeed hinder, the implementation of related policies and approaches.

### **3.2 The policy context for chronic care in Europe**

Fragmentation of care, particularly between ambulatory or primary care and hospital or secondary care, and between the health and social care sectors remains a key concern in most health care systems (Nolte, Knai & McKee, 2008; Nolte & McKee, 2008c). In recent years, therefore, many European countries have sought to create a regulatory and policy framework to respond to chronic disease, generally aiming to promote approaches that better integrate care and improve coordination between sectors and levels of care. Detailed descriptions of the policy context in the countries reviewed for this book are provided in its accompanying volume (Nolte & Knai, 2015). In brief, in Germany, for example, the 2000 Health Care Reform Act introduced provisions for the

**Table 3.2** Selected features of health care systems in 12 European countries

Country	Governance of the public health system	Principles of health care provision outside hospital			Payment of providers	
		Provision of primary/generalist and specialist care outside hospital	Choice of provider in primary/ambulatory care	GP gatekeeping		Payment of physicians in primary/ambulatory care
Austria	Shared by central government, nine state governments and corporatist actors; responsibility for hospital sector mainly with the federal states	Office-based primary and specialist care physicians; outpatient clinics	Yes	No	Blended system of fee-for-service (FFS) with capitated element for basic services; determined by payment schemes based on public services or private law and supplemented by bonuses defined by the state	Performance-oriented hospital financing system (LKF) (1997)
Denmark	Shared by central government, regions and municipalities; largely responsible for organizing health care	GPs in private practice	Yes, within specified local area; registration with GP required	Yes; access to specialist care on referral only except for ophthalmologists and dentists	A combination of capitation per patient and FFS, in addition to special fees for out-of-hours services, telephone consultations and home visits	Combination of global budget and activity-based funding using DRGs
England	Central level by government and agencies at arm's length from government; local organizations organize health care delivery	GPs in community-based practices or health centres	Within specified small area only; registration with GP required	Yes	Weighted capitation based on General Medical Services contract, negotiated nationally by Department of Health with NHS Employers and GP Committee of the British Medical Association; plus elements of FFS and performance-related payment	Activity-based payment by results using health resource groups for acute services (2003)
Estonia	Concentrated at the central level with some involvement of local authorities especially in the hospital sector	GPs in independent family practice	Yes; registration with GP required	Yes; direct access to selected specialties and follow-up consultation for chronic disease	Combination of basic allowance, capitation fee, FFS, with additional compensation for those practicing in remote areas; based on negotiations between SHI and Society of Family Physicians for a period of five years	DRGs (2004), complemented by per diem and FFS payments



Country	Governance of the public health system	Principles of health care provision outside hospital			Payment of providers	
		Provision of primary/generalist and specialist care outside hospital	Choice of provider in primary/ambulatory care	GP gatekeeping		Payment of physicians in primary/ambulatory care
France	Traditionally concentrated at the national level with gradual decentralization of (selected) governance functions to regional agencies	Office-based primary and specialist care physicians	Yes	Yes, of a soft-type (preferred doctor scheme), with strong financial incentives for patients	FFS; nationally set coverage of fees based on agreements between professional organizations and SHI administration; extra-billing (concerns 50% of patients); P4P element since 2009 based on individual contracts between physicians and SHI	DRGs (phased in from 2004), supplemented by additional payments for specific areas/services
Germany	Shared by central government, 16 state governments and corporatist actors; responsibility for hospital sector mainly with the federal states	Office-based primary and specialist care physicians	Yes	Voluntary (GP contracts)	Combination of capitation and fee-for-service based on centrally negotiated uniform value scale (EBIM) by the Federal Association of SHI physicians and the National Association of SHI Funds	German DRGs (phased in from 2003)
Hungary	At central level by government and agencies at arm's length from government	Office-based family physician; specialist care in polyclinics and dispensaries	Yes; registration with family physician required	Yes, in principle, but wide range of specialist services are accessible without referral	Weighted capitation plus adjustments based on provider characteristics	DRGs (1993); outpatient specialist services on a FFS basis
Italy	Shared by the central government and the 20 regions, with regions having extensive autonomy	Office-based GPs, typically in solo practice; office-based specialists	Yes; registration with GP required	Yes; direct access to certain specialists, for example gynaecologists	Capitation fee plus a share based on participation in public health interventions (vaccination and screening), based on national contract and regional agreements	DRGs (1995), complemented by capitation or grants for selected services
Latvia	Concentrated at the central level by government and agencies at arm's length from government	Typically GP in independent practice; health centres	Yes	Yes; direct access to certain specialists	Age-weighted capitation plus fees for defined activities, bonus payments and fixed allowances	Case-based payment, per diem plus FFS points

**Table 3.2** cont'd

Country	Governance of the public health system	Principles of health care provision outside hospital			Payment of providers	
		Provision of primary/generalist and specialist care outside hospital	Choice of provider in primary/ambulatory care	GP gatekeeping		Payment of physicians in primary/ambulatory care
Lithuania	Concentrated at the central level	Family physicians in independent practice; specialist outpatient care in health centres	Yes; registration with GP required	Yes	Age-weighted capitation plus payment for people living in rural areas and incentive payments for certain listed services	Global budgets plus case-based payment
The Netherlands	Shared by federal and local authorities and corporatist actors	GPs in group practices	Yes; registration with GP required	Yes; access to specialist care on referral only	Combination of capitation and FFS; maximum remuneration fees for GPs negotiated between National Association of GPs, Health Insurers Netherlands and Ministry of Health, Welfare and Sport	Diagnosis and treatment combinations DBOs (2005)
Switzerland	Shared by the federal and 26 cantonal governments with the cantons having extensive autonomy	Office-based primary and specialist care physicians	Yes	No, except for those enrolled in managed care plans (12% of residents)	Independent health care professionals are generally paid on a FFS basis; some managed care plans operate capitation models	Per diem plus Swiss DRGs (from 2009)

Sources: Ertel & Nolte (2010), Ertel et al. (2008); Thomson, Foubister & Mossialos (2009); the authors.

Notes: GP: general practitioner; FFS: fee-for-service; LKF: Leistungsorientierte Krankenanstaltenfinanzierung (performance-based financing); DRG: diagnosis-related groups; NHS: national health service; SHI: statutory health insurance; P4P: pay-for-performance; EBM: Einheitlicher Bewertungsmaßstab (Uniform Assessment Scale); DBC: diagnose behandelnde combinaties (diagnosis and treatment combinations).

development of integrated care structures, linking the ambulatory care and hospital sectors (Busse & Riesberg, 2004). In Austria, the 2005 health reform led to the creation of a financial pool at the federal state level (reform pool) to promote coordination of and cooperation between ambulatory and hospital care (Hofmarcher & Rack, 2006). In England, the 2004 NHS Improvement Plan explicitly placed the care for those with chronic conditions at the centre of successive and ongoing reform efforts, emphasizing the need to strengthen the integration between providers and sectors (Nolte et al., 2015). This objective was also central to recent efforts in Hungary and Lithuania to strengthen chronic care (Gaal et al., 2015; Lai et al., 2015). Other reform efforts have aimed at supporting care coordination through the introduction and further development of nurse-led strategies in most countries reviewed here, although the degree to which relevant efforts have been implemented has varied, from nurses forming an integral part of primary care, such as in England and the Netherlands (Elissen et al., 2015; Nolte et al., 2015), or their deployment within defined areas of care delivery, such as in Austria, France and Germany (Chevreul et al., 2015; Erler, Fullerton & Nolte, 2015; Sönnichsen, Flamm & Nolte, 2015).

Several countries have introduced fundamental reforms which, although not necessarily implemented to specifically address chronic disease or indeed targeting the health care sector as such, have impacted on the ability of systems to develop an integrated policy response to the rising burden of chronic illness. Most notable are reforms of national administrative structures, as in Denmark and Italy (Frølich, Jacobsen & Knai, 2015; Ricciardi et al., 2015). For example, the 1992 Law 502 in Italy introduced the gradual decentralization of administrative and financial functions to regions and local authorities, which was further strengthened and expanded on by the 2001 constitutional reform and 2009 legislation stipulating fiscal autonomy of regional institutions. This has provided regions with the means to organize health care according to local need, but it has also meant that centrally planned policies tend to be fragmented and uncoordinated, resulting in considerable variation among (and within) regions. In Denmark, the 2007 administrative reform changed the way health care is funded and organized, with most responsibilities moved to regions while municipalities were made responsible for the cofinancing of health services. This sought to encourage municipalities to improve preventive services and so reduce use of hospital care, which is organized at the regional level.

Ideally, such reforms will pave the way for the development of a consistent and comprehensive policy response to chronic diseases, with elements of health promotion and primary prevention, early detection and treatment, to the management of co- and multimorbidities and complications to palliative

and end-of-life care. However, countries reviewed differ with regard to their vision for controlling and managing chronic disease, ranging from overarching strategies for chronic disease control, to specific policies addressing the various components along the care continuum, to a lack of explicit policy focus on chronic diseases altogether. Instead, the majority of countries considered here have implemented a range of policies targeting specific elements on the care continuum.

### **3.3 Overview of approaches to chronic disease management in 12 European countries**

We reviewed some 50 approaches and groups of approaches to chronic disease management in 12 European countries. Given the highly selective nature of the types of approaches identified, we have refrained from attempting to quantify observed features, such as providing counts or proportions. Instead, we provide a narrative account of key observations, summarized in tabular format. Detailed information on each approach is included in the relevant country report presented in an accompanying volume to this book (Nolte & Knai, 2015).

Table 3.3 provides an overview of the type and aims of approaches that have been or are being implemented, the target populations addressed and the principal providers involved. Because the focus of this work has been specifically to identify and describe approaches that broadly seek to improve the care for those with chronic health problems, the stated aims of the various approaches typically have the improvement of the quality of care at their core. Frequently, approaches also consider some form of coordination or integration between providers or sectors as a further aim, alongside enhancing efficiency and, in some instances, reducing (hospital) use.

Importantly, the majority of approaches focus on care models for populations with defined conditions, most frequently targeting type 2 diabetes, followed by asthma/COPD, cardiovascular disease (mainly chronic heart failure, ischaemic heart disease, cardiovascular risk and stroke), cancer and mental health problems. However, several countries reviewed here are also implementing approaches with a broader focus, typically centring on older people. These tend to be available in selected regions only or are operated as pilot studies. Examples include the Integrated Care Pilot (ICP) programme and the Partnership for Older People Project (POPP) in England, the Coordinating Care for Older People programme (COPA) in Paris, France, selected integrated care contracts in Germany and the Care Coordination Pilot (CCP) in Hungary. Where care models have been implemented as a pilot, some have been adapted for implementation in other regions (for example, the COPA programme in

France) or are sustained beyond completion of the pilot phase (for example, selected POPP projects in England) (Table 3.3).

Three countries, Estonia, Latvia and Lithuania, have not (yet) established chronic disease management as a distinct concept (Lai & Knai, 2015; Lai, Knai & Taube, 2015; Lai et al., 2015). Instead, chronic care is seen to be embedded within the primary care system, which all three countries newly introduced in the 1990s, with the GP or family physician at the core. However, within this framework, these countries are implementing strategies specifically targeting (complex) chronic conditions.

Most approaches were introduced in the 2000s, with some in an ongoing process of implementation or pilot stage. Only a small number of service models described here date back to the 1990s or earlier; examples include an ambulatory after-care service for stroke in the State of Salzburg, Austria (1989), a stroke service in Delft, the Netherlands (1997), and the Delta physician network in Geneva, Switzerland (1992) (Table 3.3). This illustrates that chronic disease care has only relatively recently become the focus of health policy-makers, regulators, funders and other stakeholders, as noted in the introduction to this book. It also reflects the health care literature around approaches to, and models of care for chronic health problems, which has emerged from the mid-1990s onwards, largely evolving from accumulating evidence of the effectiveness of structured disease management in the USA (Nolte & McKee, 2008b). At the same time, it is important to recognize, as indicated here, that countries have experimented with new models of care well before the current chronic care debate, usually in the context of care for the frail older population at the interface between the cure and care sectors (shared care). Indeed, the Matador model of diabetes care described for the Maastricht region in the Netherlands has evolved from a shared care approach implemented in 1996 (Klein-Lankhorst & Spreuwenberg, 2008).

As described in Table 3.3, the approaches implemented in the countries reviewed can be broadly categorized as care coordination, managed discharge, multidisciplinary team working, case management and nurse-led care. These distinctions do overlap, with case management and managed discharge frequently, although not always, led by (specialist) nurses, while care coordination and multidisciplinary team working tend to refer to a coordinated approach to providing care across different professions or disciplines, in some cases also involving different providers, for example, in the form of provider networks. Our simplified typology is largely driven by the principal coordinator or provider of patient care identified for each of the approaches described here. In most cases, this is the GP or family physician (DMPs in Austria and Germany; care groups in the Netherlands). Where multidisciplinary teams act

as principal coordinator, these are frequently led by a GP or other physicians, for example: selected integrated cure pilots in England; provider networks and local cancer networks in France; integrated cure contracts in Germany; treatment protocols and CCPs in Hungary; the “From On-Demand to Proactive Primary Care” programme in Tuscany, Italy; the DiaBaid diabetes care network and Delta physician network in Switzerland). Several countries also use nurse-led approaches, although it should be noted that these tend to be limited to a selected set of countries only, including England (nurse-led case management; selected integrated care pilots), Hungary (asthma and diabetes disease management), Italy IGEA diabetes care programme; Leonardo and Raffaello projects), and the Netherlands (Matador diabetes management programme; stroke service Delft).

Several countries have introduced enhanced roles for specialized nurses in a coordinating function or in case management, such as Denmark (integrated clinical pathways), the COPA coordination of professional care for the elderly programme and the ASALWW project in France, and Lithuania (case management pilot HIV/AIDS). The Sophia diabetes care programme in France uses trained nurses to lead on the main intervention to support patients; however, the patient’s GP remains the principal care coordinator. Similarly, the Kardiomobil home care for patients with chronic heart failure programme in Salzburg, Austria, involves a nurse-led intervention to support patient self-management of chronic heart failure. Although nurses act as the principal coordinators, they do so in collaboration with the patients’ GPs. Germany has introduced nurse-led projects based on the concept of a community nurse, with different formats being tested and implemented. The predominant model is that of a care assistant in family practice (for example, VerAH), with selected medical tasks delegated to the practice nurse but legally assigned and performed under the supervision of a GP.

A small number of approaches use care coordinators with a non-medical and non-nursing background. These approaches tend to focus on after-care, rehabilitation and general support schemes. Those involved include allied health professionals (for example, a team of therapists in the ambulatory after-care of stroke patients in Salzburg, Austria), social or hybrid (health and social care) workers (Partnership for Older People Project, England), volunteer organizations (Partnership for Older People Project, England) or skilled key workers (selected integrated care pilots, England). The care coordination/interface management programme in Styria, Austria, offered by the regional SHI fund, uses an employee of the fund as the principal coordinator for discharge management; similar approaches in other parts of Austria use nurses or social workers.

**Table 3.3** Overview of approaches to chronic disease management or their equivalent in 12 European countries

Name	Aim/general description	Type of approach	Target population	Year implemented	Principal coordinator	Providers involved
<b>Austria</b>						
'Therapie aktiv' disease management programme	To improve the quality of life and extend life for people with chronic disease, to place the patient at the centre of care and to make efficient use of health care resources and also reduce hospitalizations	Care coordination	Type 2 diabetes patients	2006	DMP physician (GP/family physician)	GPs, specialists, diabetes advisers
Integrated stroke care Upper Austria	To improve care for patients with stroke both in relation to acute care and at the interface to rehabilitation	Managed discharge	Stroke patients	2005	GP	GPs, specialists in/outside hospital, emergency services, rehabilitation
Care coordination/interface management Styria	To improve the continuity of care following discharge from hospital using a care coordinator	Managed discharge	Patients in hospital	2002–2003 (pilot)	Care coordinator at the regional SHI fund	Care coordinator liaises with hospitals and GPs
Ambulatory after-care of stroke patients, Salzburg	To facilitate access to specialized ambulatory care for stroke patients and thereby enable timely rehabilitation and reduce hospital costs through early discharge	Managed post-discharge care	Stroke patients	1989	Team of therapists (neurorehabilitation team)	Occupational, speech and physiotherapists; GPs
Kardiomobil – Home care for patients with chronic heart failure	To support patients with chronic heart failure to enhance disease (self)management, reduce hospital (re)admissions and complications and improve quality of life	Nurse-led care	Chronic heart failure patients	2004 (pilot)	Trained nurse	GPs, specialists, nurses, hospitals, home care services
<b>Denmark</b>						
SIKS project – integrated effort for people living with chronic disease	To support people with chronic conditions (COPD, type 2 diabetes, chronic heart failure, IHD, balance problems) through coordinated rehabilitation	Care coordination	Type 2 diabetes, asthma/COPD, chronic heart failure, IHD, balance problems among older people	2005	Multidisciplinary team at health care centre/hospital (determined by severity of condition)	GPs, specialists in hospital, (specialist) nurses, physiotherapists, dietitians in hospital and community services

**Table 3.3** cont'd

Name	Aim/general description	Type of approach	Target population	Year implemented	Principal coordinator	Providers involved
Denmark cont'd						
Regional disease management programmes	A combined, interdisciplinary, intersectoral and coordinated effort for a specific chronic condition that ensures the use of evidence-based recommendations, a precise description of tasks and coordination of and communication between all parties involved	Care coordination	Type 2 diabetes, COPD, CVD, dementia, musculoskeletal disorders, depression, schizophrenia, cancer	2009, ongoing	DMP GP	GPs, municipal health care centre, hospital specialists
Integrated clinical pathways	To ensure fast and optimal treatment and management of patients with cancer/heart disease	Care coordination	Heart disease, cancer patients	2008 (cancer), 2010 (heart disease)	Care (pathway) coordinator (specialist nurse)	GPs, specialists, nurses, hospitals, multidisciplinary teams
England						
Case management/ community matron	To enable intensive, home-based case management for older people at risk of hospitalization and other high-intensity service users	Case management	Older people at risk of hospitalization	2004	Specialist nurse	GPs, specialists, nurses, hospitals, community care and social care services
Quality and outcomes framework (QOF)	To make the GP profession more attractive, reduce the wide variation in payments to practices, fairly link reward to workload, and help reduce health inequalities	GP-led system	Generalist	2004	GP	GPs, nurses, pharmacists, specialists
Partnerships for older people project (POPP)	To provide person-centred and integrated services for older people, encourage investment in care approaches that promote health, well-being and independence, and prevent/delay the need for higher intensity or institutional care	Integrated care/provider networks/case management/managed discharge	Older people (> 65 years)	2005–2010	Varied: multidisciplinary team (health and social care); social or hybrid worker; volunteer organization	GPs, hospitals, nurses, community services, social care, other public and voluntary and community organizations



Name	Aim/general description	Type of approach	Target population	Year implemented	Principal coordinator	Providers involved
England cont'd Integrated care pilot programme	To improve the quality of care and outcomes for patients, enhance partnerships on care provision and make more efficient use of scarce resources	Integrated care/provider networks/case management/managed discharge	Generalist and disease-specific (for example, diabetes, COPD, dementia)	2009–2011	Varied: GP-led care; multidisciplinary team working; nurse-led case management; skilled key worker-led care coordination	GPs, hospitals, nurses, allied health professionals, community services, social care, other public and voluntary services
Estonia	Chronic disease management as a concept not established but indirectly embedded in the overall structure and organization of the health care system	GP-led care	Type 2 diabetes, cardiovascular disease (chronic heart failure, IHD)	2003 (completion of GP system)	GP	GPs, specialists, nurses, allied health professionals (for example, physiotherapists), social care
Chronic disease management at the primary/secondary care interface	Chronic disease management as a concept not established but indirectly embedded in the overall structure and organization of the health care system	Specialist-led care	Multiple sclerosis, Parkinson's disease, schizophrenia, COPD	Various	Specialist (centre); comorbidities managed by GP in coordination with specialist	GPs, specialists, nurses, allied health professionals, hospitals, social care, specialist centres (multiple sclerosis)
France Provider networks	To improve the quality of care for people with type 2 diabetes	Multidisciplinary team	Type 2 diabetes	2001	Pathway coordinator: GP or nurse	GPs, specialists, nurses, allied health professionals (dietitians, therapists), hospitals, laboratories

**Table 3.3** contd

Name	Aim/general description	Type of approach	Target population	Year implemented	Principal coordinator	Providers involved
<i>France contd</i>						
<i>Provider networks</i>						
For example, Coordination of professional care for the elderly (COPA)	To better integrate service provision between health and social care; to reduce inappropriate health care use, including emergency department and hospital use; to prevent long-term nursing home institutionalization	Case management	Frail older people (> 65 years)	2006	Specialist nurse as case manager	GPs, specialists, nurses, hospitals, allied health professionals (psychologists, therapists), social services
<i>Specific programmes</i>						
Sophia diabetes and asthma care programme (by SHI)	To improve self-management, efficiency and quality of diabetic care; nationwide	Care coordination	Type 1 and 2 diabetes, asthma	2008 (diabetes), 2014 (asthma)	GP in collaboration with nurse	GPs, nurses
Health Action by Teams of Self-Employed Health Professionals (ASALEE)	To improve health care quality by delegating selected tasks to nurses	Nurse-led care	Diabetes, CVD	2004–2007	Trained nurse	GPs, nurses
Hospital discharge programme for heart failure patients (PRADO)	Adapt and improve follow-up care after hospital discharge	Care coordination/managed discharge	Patients hospitalized for heart failure	2013	Discharge manager	GPs, cardiologists, nurses
Specific payment based on public health objectives (ROSP)	Reward achievement of objectives in the fields of prevention, chronic disease care and prescription	Physician-led system	GPs and specialist physicians	2009 (pilot: CAPI) 2012 (full roll-out)	Physician	GPs and specialist physicians
<i>Measures in the 2003–2007 Cancer Plan</i>						
Protocol for disease communication and promotion of shared decision-making (Dispositif d'annonce)	To improve the organization of processes and competencies in discussing a cancer diagnosis, and promoting shared decision-making between professionals, patients and their carers	Care protocol	Cancer	2004	Specialist	GPs, specialists, nurses, allied health professionals (for example, psychologists), social workers

Name	Aim/general description	Type of approach	Target population	Year implemented	Principal coordinator	Providers involved
France contd <i>Measures in the 2003–2007 Cancer Plan contd</i> Multidisciplinary team meeting (RCP)	To promote the systematic use of a multidisciplinary team in the development of the Cancer Care plan so as to improve the quality of cancer diagnosis, treatment and support	Multidisciplinary team	Cancer	2004	Médecin référent (doctor's referral, frequently surgeon)	Specialists, hospitals; multidisciplinary team comprises as minimum surgeon, radiologist and oncologist
Regional cancer networks	To coordinate all relevant actors and levels of care in the management of cancer, and to guarantee quality and equity of care across all regions	Care coordination/provider network	Cancer	2004	As in RCP	Specialists, nurses, pharmacists, hospitals
Local cancer or local multiple pathology networks	To facilitate the local management and monitoring of cancer patients through better integration of GPs into networks of cancer care	Care coordination	Cancer	2004	GP	GPs, specialists, nurses, allied health professionals, pharmacists, hospitals, social workers
Germany						
Disease management programmes	Organizational approach to medical care that involves the coordinated treatment and care of patients with chronic disease across boundaries between individual providers on the basis of scientific and up to date evidence	Care coordination	Type 1 and 2 diabetes, IHD (+ heart failure), breast cancer, asthma/COPD	2002	DMP physician	GPs, specialists, hospitals
GP contracts	To improve the coordination of care and strengthen the role of primary care in the German health system	Care coordination	Generalist (some contracts target the over 65s)	2004	GP/family physician	GPs, nurses
Integrated care: Healthy Kinzigtal	To establish more efficient and organized health care for the residents of the Kinzigtal area	Care coordination	Generalist	2005	Care coordinator (physician/psychotherapist)	GPs, specialists, psychotherapists, hospitals, pharmacists, allied health professionals; coordinated by management organization

**Table 3.3** contd

Name	Aim/general description	Type of approach	Target population	Year implemented	Principal coordinator	Providers involved
Germany contd Community nurses: care assistant in family practice (for example, VerAH)	To support GP services in underserved areas	Nurse-led care	Generalist (although typically targeting the over 65s)	2005	Practice assistant	GP, practice assistant
Hungary Treatment (and financing) protocols	To control costs of treatment, such as those for expensive drugs in the case of cancer care	Use of treatment guidelines	Asthma/COPD, CVD (heart failure, IHD, stroke), cancer	2005 (cancer)	Varies by disease (for example, GP for hypertension; specialist for cancer dispensary, pulmonary dispensary)	GPs, specialists, nurses, hospitals, specialist centres (cancer dispensary, pulmonary dispensary)
Care coordination pilot (CCP)	To incentivize providers to take responsibility for the spectrum of services (primary to tertiary care) for an enrolled population in a defined area	Care coordination	Generalist	1998/99–2008	Care coordination organization: GPs/ groups of GPs, polyclinic or hospital	GPs, specialists, nurses, allied health professionals, hospitals, pharmacists
Multifunctional community centres	To improve efficiency in the health care system through better quality of care at lower costs	Multidisciplinary teams	Generalist	Ongoing	Community centre	GPs, specialists, nurses, pharmacists, social care
Asthma disease manage- ment programme	To enhance the quality of asthma care	Nurse-led care	Asthma	2004	Specialist (asthma nurse)	Nurses, specialists, dispensaries
Diabetes care management programme	To improve the care of patients with type 2 diabetes through a range of measures, with nurse-led care at its core	Nurse-led care	Type 2 diabetes	Various	Diabetes specialist (physician, nurse)	Specialists, nurses, hospitals, specialist diabetes outpatient units
Italy Diabetes integration, management and assistance (IGE)	National strategy to support the implementation of disease management for type 2 diabetes at the regional level	Multidisciplinary team and case management	Type 2 diabetes	2006	Multidisciplinary team/nurse (case management)	GPs, specialists, nurses, allied health professionals (for example, dietician, psychologist), hospitals

Name	Aim/general description	Type of approach	Target population	Year implemented	Principal coordinator	Providers involved
Italy cont'd						
"From On-Demand to Proactive Primary Care" programme, Tuscany	A three-year strategy towards the development of a new organizational approach to health care that emphasizes proactive patient care	Multidisciplinary team	Hypertension, diabetes, chronic heart failure, COPD, stroke	2009	Multi-professional teams (module) (GP lead, community health doctor, specialist nurse)	GPs, specialists, nurses, allied health professionals (for example, dietitian, psychologist), social services
Leonardo pilot project, Puglia	To improve the quality and effectiveness of health care for those with chronic conditions and to facilitate systematic integration into the existing organizational framework set by local health agencies	Nurse-led care	Type 1 and 2 diabetes, chronic heart failure, high cardiovascular risk	2004–2007	Specialist nurse	GPs, nurses, specialists
Raffaello project, Marche and Abruzzo	Research project to assess the effectiveness of an innovative model of patient care for the prevention of cardiovascular disease on the basis of disease and care management in general practice	Nurse-led care	Type 1 and 2 diabetes, cardiovascular risk	2007	Specialist nurse	GPs, nurses
Latvia						
General primary health care system	Not applicable	Not applicable	Generalist	1996–1998 (primary health care reform)	GP	GPs, doctor's assistant (feldsher), nurse, midwife, dentist, dentist's assistant, dental nurse and dental hygiene specialist
Lithuania						
Improving intersectoral collaboration	To improve collaboration between health and social care	Case management (pilot)	Generalist and disease-specific (diabetes, CVD, cancer, chronic renal failure, multiple sclerosis, depression, HIV/AIDS)	From 2004	Nurse	GPs, specialists, providers of educational and social services

**Table 3.3** cont'd

Name	Aim/general description	Type of approach	Target population	Year implemented	Principal coordinator	Providers involved
<b>Lithuania cont'd</b>						
Clinical guidelines	To control medication costs; to improve collaboration between primary and secondary care	Use of clinical guidelines	Diabetes, CVD, breast cancer, chronic renal failure, multiple sclerosis, depression; high-intensity users	From 2002	GP/specialist (depending on health problem)	GPs, specialists, nurses, allied health professionals, hospitals
<b>Netherlands</b>						
Mator DMP/ Maastricht-Heuvelland	Builds on a pilot scheme established in 1996, which used specialized diabetes nurses to reduce the number of patients seen by medical specialists in outpatient care	Multidisciplinary team	Type 2 diabetes	2000–2006	Core team of GP specialist diabetes nurse and endocrinologist	GPs, specialists, nurses, hospitals
Primary care group ZIO (Maastricht-Heuvelland)	The primary care group describes the whole continuum of care for diabetes patients and is financed on the basis of the bundled payment system	Care coordination	Type 2 diabetes (more recently also asthma/COPD, cardiovascular disease)	From 2007	GP	GPs, specialists, nurses, allied health professionals, hospitals
Stroke service Delft	Evolved from a pilot project for improving stroke care initiated in 1997 and funded by the Netherlands Institute for Health Research and Development	Multidisciplinary team	Stroke	1997 (pilot)	Shared care nurse	GPs, specialists, nurses, hospitals, allied health professionals, nursing homes, rehabilitation centres, home care organization
National care standard for vascular risk management	Describes the minimum requirements for appropriate, patient-centred care along the care continuum from prevention and early detection to treatment and rehabilitation (there are similar standards for diabetes and asthma/COPD)	Multidisciplinary team	Vascular risk	From 2010	Central caregiver (determined by programme)	GPs, specialists, nurses, hospitals, allied health professionals, municipal health services, pharmacists, rehabilitation services

Name	Aim/general description	Type of approach	Target population	Year implemented	Principal coordinator	Providers involved
Switzerland DiaBaid diabetes care network	Developed from an inventory of the needs of diabetic patients in the region of Nyon–Morges, Canton de Vaud and the creation of a working group of health care stakeholders involved in diabetes care	Multidisciplinary team	Type 1 and 2 diabetes	2004	Endocrinologist–diabetologist	Specialists, nurses, allied health professionals (dietitian, podologist)
Breast cancer clinical pathway, Lausanne University Hospital and Lausanne University	To improve the quality and efficiency of health care	Multidisciplinary team	Breast cancer	2008–2009	Hospital (oncology)	Specialists, nurses, allied health professionals (physiotherapists, psychologists), social workers
Delta physician network, Geneva	Physician networks form part of the service structure in ambulatory care; Delta was conceived as an HMO and in 2004 transformed into a physician network	Managed care	Generalist: DMs for diabetes, heart failure and asthma under development	1992	Primary care physicians/GPs	Primary care physicians, pharmacists, psychologists

*Sources:* Austria: Sonnichsen, Flamm & Nolte (2015); Denmark: Frølich, Jacobsen & Knai (2015); England: Nolte et al. (2015); Estonia: Lai & Knai (2015); France: Chevret et al. (2015); Germany: Erler, Fullerton & Nolte (2015); Hungary: Gaal et al. (2015); Italy: Ricciardi et al. (2015); Lithuania: Lai et al. (2015); Latvia: Lai, Knai & Tāube (2015); the Netherlands: Elissen et al. (2015); Switzerland: Peyremann-Bridevaux et al. (2015).

### **3.4 Financing, distribution and uptake of approaches to chronic disease management**

The majority of approaches reviewed are funded within the public health care system, frequently supplemented by additional resources made available through (time-limited) funds earmarked for care coordination and integration initiatives, for example: reform pool projects in Austria, such as the Therapie aktiv diabetes management programme; regional diabetes management programme in Denmark; the quality management framework for diabetes and chronic CVD care in Estonia; the FIQCS intervention fund for quality and care coordination in France to support provider networks; integrated care contracts in Germany; and the ministry of health 'special programmes' fund in Italy (Table 3.4). In several cases, additional funding has provided a one-off start-up grant to support project implementation; examples include the two major pilot programmes in England (Partnership for Older People Projects; integrated care contracts) and, until 2009, integrated care contracts in Germany. There are examples of additional funding provided by the pharmaceutical industry, including, in Hungary, the asthma disease management and diabetes care programmes, and in Italy, the Leonardo and Raffaello diabetes disease and care management projects.

Several approaches use financial incentives, usually targeted at physicians. These typically involve additional reimbursement for documentation, patient enrolment or regular assessment (for example, the DMPs in Austria and Germany; the Sophia diabetes and asthma care programme in France) or for quality improvement activities (quality management in primary health care in Hungary; GP contracts in Germany; the Delta physician network in Switzerland). Selected approaches also involve elements of pay-for-performance or financial risk sharing of providers. Examples include the CCP in Hungary; "From On-Demand to Proactive Primary Care" programme in Tuscany, Italy; the Leonardo project in Puglia, Italy; and the primary care group/bundled payment systems in the Netherlands.

Given that most of the approaches reviewed here are funded within the statutory system, patient access is typically granted in line with access to usual care. Indeed, the majority of approaches are free of charge. Only a small number require co- or full payment by patients to enable access, for example, ambulatory after-care for stroke patients in Salzburg, Austria (with exemption from co-payments for those on low incomes). Some approaches offer explicit incentives for patients to participate. These typically include exemption from co-payments for usual care services they would otherwise have to pay for (for example, provider networks in France).



**Table 3.4** Financing, distribution and uptake of approaches to chronic disease management or their equivalent in 12 European countries

Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
<b>Austria</b>					
'Therapie aktiv' disease management programme	Regional SHI fund and federal state at about 50% each; programme development funded by regional SHI funds	Targeted at DMP physicians; patient sign-up and quarterly fee for treatment and documentation	Free access for participating patients to education classes and materials	Implemented in six of nine states, involving about 1000 GPs (2014); three states do not currently provide Therapie aktiv but offer diabetes education programmes	About 39 500 patients enrolled in DMP across the five states that have implemented Therapie aktiv (18% of all people with type 2 diabetes) (2014)
Integrated stroke care, Upper Austria	Regional SHI fund Upper Austria and Upper Austria health fund (50% each)	Not specified	Not applicable	Implemented across Upper Austria and involving all hospitals that provide acute stroke care, medical emergency services and three rehabilitation centres; transferred into routine care from the end of 2010	There are no published data on the number of stroke patients who have benefited from the programme so far
Care coordination/ interface management Styria	Regional SHI fund Styria; Graz model also supported by Styria health fund (2009)	Not applicable	Not applicable	Introduced as pilot project in one locality, the approach was gradually extended across Styria; Graz model to be transferred into usual care	There are no published data on the number of patients covered by the programme
Ambulatory after-care of stroke patients, Salzburg	Salzburg health fund (95%) plus 3% patient co-payment (deductible for home visit)	Not applicable	Not applicable	Service principally accessible to all stroke patients across Land Salzburg; lack of therapists in remote areas reduces access	In 2009, the service covered approximately 450 patients who can access service on referral only
Kardiomobil – Home care for patients with chronic heart failure	Regional SHI fund and Land Salzburg at about 50% each	Not applicable	Not applicable	Programme comprises five trained nurses operating across Land Salzburg	Access to the service is through referral; there are no published data on the number of patients covered
<b>Denmark</b>					
SIKS project – Integrated effort for people living with chronic disease	Combination of usual sources and government grant for 2005–2007 project period; full funding from usual sources from 2007	Not applicable	Networking and peer pressure through steering committee, project group and working groups throughout project period	Implemented as a pilot project in the Østerbro health care centre and Bispebjerg hospital in Copenhagen for a period of three years; subsequently a part of DMP for COPD, type 2 diabetes and CVD in the Capital Region of Denmark	During 2005–2007, about 700 patients participated in the SIKS project; access is through referral following diagnosis (approximately 90% of participating physicians refer patients on)

**Table 3.4** cont'd

Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
Denmark cont'd Regional disease management programmes	Central government funding pool for the development of DMPs of DKK 436 million during 2010-2012	Not planned	Not specified	DMPs for COPD and type 2 diabetes, CVD, dementia and musculoskeletal disorders implemented in Capital Region (end 2010); DMPs for COPD, type 2 diabetes, CVD, depression and lower-back pain developed in the Central Denmark Region; DMPs for COPD, type 2 diabetes, CVD and skeletal disorders developed and, from 2010, implemented in southern Denmark; DMPs for COPD, type 2 diabetes, dementia, schizophrenia and back problems developed in Region Zealand	It is anticipated that the programmes will cover all targeted patients across the country
Integrated clinical pathways	Funded from usual sources (taxation)	Not applicable	Not specified	As a national programme, integrated clinical pathways are implemented across Denmark	It is anticipated that the integrated clinical pathways will cover approximately 40 000 CVD patients per year and all cancer patients
<b>England</b>					
Case management/ community matron	Funded from usual sources within the NHS	No	Not specified	2004 policy foresaw implementation of case management and appointment of 3000 community matrons by all PCTs in 2007; there are now between 620 and 1350 community matrons	In principle, all NHS patients in England should have access to community matron services
Quality and outcomes framework (QOF)	Funded from usual sources within the NHS	Yes: award of achievement points for practices demonstrating that they have met several stages in the management of a given, usually chronic condition, for a proportion of the relevant population	Peer pressure: performance results are published by the Health & Social Care Information Centre	Voluntary for GP practices; most practices have joined. Currently, more than 8000 practices have signed up to the schemes, covering some 54 million people in England	The scheme initially applied to across the United Kingdom and principally covers all patients registered with a given practice participating in the scheme; from 2013, QOF has differed across the four countries of the United Kingdom

Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
England contid Partnership for older people project (POPP)	Services delivered by pilots funded from usual sources (health services: NHS; social services: local authorities)	Government grant to support pilot set-up	Recognition as a government-sponsored pilot site	POPP ran a total of 146 projects involving 522 organizations including the police and housing associations; 85% of projects secured funding beyond the pilot phase into usual care	Around 264 000 people were covered by the services provided by projects
Integrated care pilots	Services delivered by pilots funded from usual sources (health services: NHS; social services: local authorities)	Government grant to support pilot set-up (grants of between GBP600 000 and GBP3.9 million per site over two years)	Recognition as a government-sponsored pilot site	The pilot programme involved 16 Primary care trusts	Population coverage of schemes varied; access to services limited to (target) populations in pilot sites
<b>Estonia</b>	Funded from usual sources (EHIF); additional funding within quality management framework for diabetes/CVD care	Targeted at GP practices within quality management framework	Networking among providers	Quality management framework for diabetes and chronic CVD implemented across Estonia and covering all GP practices	Principally, all persons with diabetes/chronic CVD are covered by virtue of SHI; access to care is free of charge
Chronic disease management at the primary/secondary care interface	Funded from usual sources; additional funding for Parkinson's association for patient education and support	Not applicable	Networking among providers	Implemented across Estonia as part of usual care	Principally, all persons with diagnosed disease covered by virtue of SHI; access to care is free of charge
<b>France</b>	<i>Provider networks</i>	Fees for various providers in the network, for example, GPs (annual assessment), education, dietitians	Free access for patients to certain services that would otherwise have to pay for (for example, foot care)	REVESDIAB is based in three departments (départements) in the Paris region, involving, in 2007–2008, around 500 health professionals in the Essonne department; Overall, in 2007, there were 72 diabetes networks, involving 14 000 health professionals	REVESDIAB is based in the Paris region covering about 3000 patients with diabetes; overall, in 2007, around 60 000 people with diabetes were enrolled in diabetes networks (approximately 2.5% of diabetic patients in France)

**Table 3.4** cont'd

Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
<p>France <i>Provider networks</i> cont'd For example, FIQCS fund established by the 2007 health reform Coordination of professional care for the elderly (COPA)</p>	<p>Funded from usual sources (Statutory health insurance (CNAM))</p>	<p>Not specified</p>	<p>Not specified</p>	<p>The network is established in one district of Paris only and in 2007 involved 79 out of 200 primary care physicians practising in the area</p>	<p>By the end of 2007, approximately 250 older people had been referred to COPA; it is being implemented in other parts of Paris and there is interest in other regions of France and Belgium also</p>
<p>Specific programmes</p>	<p>Funded from usual sources (Statutory health insurance (CNAM))</p>	<p>GPs involved are paid EUR 66 per patient per year</p>	<p>Provides patients with free access to telephone-based intervention by trained nurse following enrolment with SHI fund</p>	<p>Experimental phase targeted patients of 6000 GPs (6.4% of all GPs) in 10 departments; expanded in 2010 to reach 17 500 GPs in 19 departments; roll-out across France in 2013</p>	<p>Experimental phase aimed at reaching 136 000 patients with diabetes; by the end of 2010, 62 000 had joined (approximately 2.5% of all people with diabetes)</p>
<p>Health Action by Teams of Self-Employed Health Professionals (ASALEE)</p>	<p>URCAM (regional SHI fund); usual sources</p>	<p>No</p>	<p>Professional motivation (project was set up by local GPs)</p>	<p>ASALEE is a non-profit organization which, as of 2007, brought together 41 GPs and eight nurses in 18 GP practices</p>	<p>The project covered around 1500 patients</p>
<p>Hospital discharge program for heart failure patients (PRADO)</p>	<p>Funded from usual sources (Statutory health insurance (CNAM))</p>	<p>GPs authorized to bill a long consultation for coordination efforts</p>	<p>Dedicated training for home follow-up by nurses</p>	<p>Pilot phase in five departments</p>	<p>The pilot phases concerns an estimated 60 000 patients per year</p>
<p>Specific payment based on public health objectives (ROSP)</p>	<p>Statutory health insurance (CNAM)</p>	<p>Yes: additional remuneration takes into account the population size and 29 quality indicators with intermediate and final targets</p>	<p>Physicians can follow the evolutions of their quality indicators on a dedicated website</p>	<p>Voluntary participation</p>	<p>In 2012, more than 75 000 physicians participated in the programme, representing a majority of eligible GPs</p>

Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
France contd					
<i>Measures of the 2003–2007 Cancer Plan</i>					
Protocol for disease communication and promotion of shared decision-making (Dispositif d'annonce)	Funded from regional budgets within MIGAC envelope (specific budget to finance activities of public utility) as part of usual care (hospital reimbursement) within SHI	Some regions supplement usual payment to physicians for time dedicated to patients within dispositif d'annonce	Networking has been made obligatory for the management of cancer patients	As part of the national Cancer Plan, principally rolled out across the country within the time frame of the 2003–2007 Cancer Plan; by 2006, only half of the funds set aside by regions had been used for this purpose and accessible to all newly diagnosed cancer patients	By 2007, more than 92 000 patients had been supported through a dedicated dispositif d'annonce (approximately 30% of all patients newly diagnosed with cancer); approximately 23 000 had received a personalized care programme (PPS) (approximately 7% of patients)
Multidisciplinary team meeting (RCP)	Funded from regional budgets within the MIGAC envelope (specific budget to finance activities of public utility) as part of usual care (hospital reimbursement) within SHI	Not specified	Not specified	As part of the national Cancer Plan, principally rolled out across the country within time frame of 2003–2007 Cancer Plan and accessible to all newly diagnosed cancer patients	By 2007, approximately 500 000 RCPs had been recorded while the number of newly diagnosed cancer patients was 345 000 (partly reflecting repeat RCP for some patients pre/post-treatment); approximately 45% of cancer cases were recorded by RCPs
Regional cancer networks	FIQCS fund established by 2007 health reform	Not specified	Networking has been made obligatory for the management of cancer patients; possibility of provider monitoring through EEP	As part of the national Cancer Plan rolled out across the country within the time frame of the 2003–2007 Cancer Plan and accessible to all cancer patients	Not known

**Table 3.4** cont'd

Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
France	<i>Measures of the 2003–2007 Cancer Plan</i> cont'd				
Local cancer or local multiple pathology networks	GPs and nurses funded from usual sources within SHI; networks funded through FIQCS established by the 2007 health reform	Physicians; possibility to receive additional reimbursement for time/expertise dedicated to cancer patients; Patients may benefit from financial support for household assistance	Networking has been made obligatory for the management of cancer patients; possibility of provider monitoring through EEP	As part of the national Cancer Plan, principally rolled out across the country within the time frame of the 2003–2007 Cancer Plan and accessible to all cancer patients	Not known
Germany					
Disease management programmes	Funded from usual sources (SHI)	DMP physicians: additional payment for documentation, education	Free access for participating patients to education classes and materials; physicians; peer pressure; SHI funds legally required to offer DMP	DMPs are offered by SHI funds across Germany; in 2013 there were 1700–1800 DMPs for each condition; the number of participating physicians varies; approximately 65% GPs act as DMP physician for type 2 diabetes (57% for CHD)	By the end of 2013, a total of 6.4 million individuals were enrolled in one or more DMPs, from 122 214 in breast cancer DMP to approximately 3.8 million in type 2 diabetes DMP
GP contracts	Principally from usual sources (SHI) but with contract arrangements permitting flexible GP payment different from usual care GP reimbursement	GPs: additional payment for aspects such as quality improvement and rational prescribing. Patients: exemption from practice fee	GPs: Peer pressure in some regions; SHI funds legally required to offer GP contracts	By the end of 2007, 55 GP contracts had been concluded with GP participation varying among regions; more recent data are not documented	Proportion of SHI insured people enrolled varies between 5.9 million (8.5% of all SHI insured) in 2007 to 19% in 2010

Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
Germany cont'd Integrated care: Healthy Kinzigtal	Principally funded from usual sources (SHI) but with contract arrangements permitting flexible reimbursement; start-up funds (time-limited to end of 2008)	Physician reimbursement involves pay-for-performance (P4P) element	Physicians: networking; patients: access to free check-ups, prevention/treatment plans, case conferences, with specialists, etc.	By the end of 2008, approximately 6400 integrated care contracts had been concluded; content and scope varies widely and their number has stagnated since; Healthy Kinzigtal involves over 90 providers (52% of all providers in the region in 2013)	By the end of 2008, approximately 4 million SHI members were enrolled with an integrated care contract (approximately 6% of all SHI insured); Healthy Kinzigtal covers over 9000 people (30% of the relevant SHI members in the region) (2013)
Community nurses: care assistant in family practice (VerAH)	Principally funded from usual sources (SHI) within GP contracts	GPs: services provided by practice assistants reimbursable through SHI	Practice assistant: professional development	Incorporated in selected GP models, see above	Incorporated in selected GP models, see above
Hungary Treatment (and financing) protocols	Funded from usual sources (SHI)	No	Not specified	As part of the main system, coverage, in principle, is 100%. In practice, the adherence to treatment protocols is rarely audited	In principle, all diagnosed patients should be covered by treatment protocols; access is likely to vary across regions, reflecting inequalities in overall access to care
Care coordination pilot	Principally funded from usual sources (SHI); additional funding for administrative costs and prevention programmes (capitation for care coordinator)	Physicians: risk sharing with savings achieved at end of financial year redistributed to providers	Providers: peer pressure; networking	The CCP gradually expanded from nine care coordinators in 1999 to 16 care coordinators in 2005 when 1500 GP practices participated; established in the Veresegyház region, the CCP was closed down in 2008	Gradual expansion of the project covering 160 000 residents in the region of Veresegyház in 1999 to 2 million in 2005

**Table 3.4** cont'd

Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
Hungary cont'd Multifunctional community centres	Principally funded from usual sources; infrastructure investments from European Union funds; additional funding from local government determined by services provided	Not specified	Not specified	Programme implementation is ongoing; it is anticipated that 50–60 centres/projects will be established	Centres are not yet in operation; it is anticipated that 30–35% of small regions, and their residents, will be covered by the programme
Asthma disease management programme	Principally funded from usual sources with nurse training and payment as well as equipment (for example, spirometer for patients) and printed materials funded by pharmaceutical companies	Nurse payment is covered by pharmaceutical companies	Not specified	The programme has evolved into a formal national network of asthma nurses. By January 2010, there were around 850 trained asthma nurses across Hungary; the number of pulmonary dispensaries is around 160 (2007)	Precise data on population coverage are lacking; in theory the coverage should be 100%
Diabetes care management programme	Principally funded from usual sources with pharmaceutical and medical devices companies covering extra costs including payment to doctors and nurses, equipment and operational costs	Diabetes specialist payments covered by pharmaceutical/device companies	Not specified	Extent to which programme has been implemented by specialist diabetes outpatient units is not well understood; in 2008, there were 176 specialist diabetes units, including 41 in Budapest	Approximately 20 000 patients with type 2 diabetes in Budapest are covered by approximately 40 specialist diabetes outpatient units; not all units provide all programme components
Italy	Funded from usual sources (SSN), complemented by national and regional funds earmarked for prevention	Use of incentives for GPs to participate varies among regions	Physicians: networking, information sharing, access to guidelines, peer pressure	Implementation at regional level has been a gradual process; 35% of GP practices in Piedmont participate (2009); as a government-sponsored programme involvement of all GPs anticipated	Because of gradual implementation of the programme, patient enrolment is ongoing; there are no precise figures on the proportion of the population covered by IGEA



Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
Italy cont'd "From On-Demand to Proactive Primary Care" programme, Tuscany	Funded from usual sources (SSN) with regional regulation stipulating allocation of resources to project implementation of EUR 8 883 000 over of three years	GPs: incentive payment depending on level of involvement (team lead; participant) and against performance (P4P)	GP: programme supported by Tuscany's GP association, and thus creating peer pressure to participate	Two-stage implementation: initial phase in 2010 involved the establishment of approximately 50 modules with addition of modules ongoing; further implementation ongoing	Approximately 50 modules cover approximately 500 000 residents; initially targeting diabetes and heart failure; other conditions to be added; expected coverage with full implementation: 1.1 million with chronic disease in Tuscany
Leonardo pilot project, Puglia	Funded jointly by regional funds, Ministry of Health Special Programmes fund, local health system and Pfizer Italy (contributing InformaCare™ software)	GPs: lump sum at project start, to incentivize participation, plus variable payment at the end, based on performance	Not specified	Total of 85 GPs in Puglia region (approximately 2.5% of GPs practising in the region), working with some 30 care managers	Project covered just under 1160 patients for a project duration of 18 months at the Lecce ASL
Raffaello project, Marche and Abruzzo	Jointly funded by regional funds allocated to health care; additional funds by Ministry of Health Special Programmes fund and cofinancing by Pfizer Italy	Financial incentives for GPs participating in the project (not further specified)	Not specified	The research project involves 16 clusters of GPs participating in the experimental arm of the study	The research project is limited to a defined group of patients recruited for participation, a total of 900 patients in the regions of Marche and Abruzzo
Latvia	Funded from usual sources (taxation)	Not specified	Not specified	Chronic disease management embedded within primary care and as such involves all GPs; a 2010 evaluation of the primary care system found low levels of quality of chronic care as assessed by regular examination of patients with type 2 diabetes (25% of all GPs) or asthma (5%)	Chronic disease management embedded within primary care and therefore covering virtually the entire population; severe financial pressures have, however, meant that approximately 45% of the population cannot access services because of required co-payments (2008)

**Table 3.4** contd

Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
Lithuania					
Improving intersectoral collaboration	Funded from usual sources (SHI), social care funded by local government; plans to introduce more coordinated financing of multidisciplinary team activities	Patients: incentive to remain in the community rather than becoming institutionalized	Not specified	Principally implemented in all 60 municipalities of Lithuania	Precise data on population coverage are lacking; access to case management varies by condition and likely across municipalities
Clinical guidelines	Funded from usual sources (SHI)	GPs: additional payment, for example, for confirmation of early diagnosed cases (for example, cancer) and certain prioritized services	Not specified	In principle, clinical guidelines should be implemented across health services in Lithuania; precise data are not available	In principle, all diagnosed patients should be covered by care plans based on clinical guidelines
<b>Netherlands</b>					
Matador DMP/ Maastricht–Heuveland	Usual sources for providers including GPs, specialists, dietitians and other health professionals; specialist diabetes nurses funded under previous General Exceptional Medical Expenses Act	Not specified	Not specified	In 2006, a total of 63 of 90 GPs (70%) in the Maastricht region participated in the Matador programme	In 2006, about 3000 patients with diabetes in the Maastricht region were covered by the Matador programme
Primary care group ZiO (Maastricht–Heuveland)	Funded from usual sources (mandatory insurance), principal contractor is the health insurer Coöperatie VGZ on the basis of a bundled payment contract	Physicians: bundled payment for defined package of care. Insurer: to negotiate low price for care chain	Presence of an academic hospital; profiling of ZiO as director of regional primary care sector	All regional GPs are members of ZiO Heuveland and as such participate in the diabetes care programme (just under 90 GPs by the end of 2009); there were 97 care groups in March 2010 with bundled payment contract with a health insurer, mostly for diabetes care	By the end of 2009, the programme covered some 7600 patients with type 2 diabetes in the Maastricht–Heuveland region

Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
Netherlands cont'd					
Stroke service Delft	Funded from usual sources: basic health insurance (GP and hospital services); AWBZ (for example, rehabilitation centre; nursing home) and WMO (home care); shared care nurse is funded by all three schemes	Not specified	Not specified	Following the experiences of pilots, the government actively promoted further implementation through breakthrough projects and benchmarking of stroke services; as result, by 2003, each region had developed at least one stroke service (a total of 69 in 2003)	Precise number of patients receiving care within stroke services not known; however, according to the Dutch Heart Foundation, the 69 stroke services present in the Netherlands since 2003 are distributed to a level that should sufficiently cover all stroke patients (around 191 000 in 2007)
National care standard for vascular risk management	Funded from usual sources (mandatory insurance) on the basis of a bundled payment contract	Physicians: bundled payment for defined package of care. Insurer: to negotiate low price for care chain	Not specified	Compared with diabetes, there are relatively few care groups for the provision of vascular risk management; of 55 care groups surveyed in early 2010, two had a bundled payment contract in place for vascular risk management, whereas 17 were preparing to contract	Precise number of patients receiving care within vascular risk management not known; limited to those receiving services through the three established standards
Switzerland					
DiaBaid diabetes care network	Funded by the Canton of Vaud (approximately 50%) and from care activities charged to the patients and reimbursed by their health insurers (approximately 50%)	No	Not specified	Jointly run by the Association des réseaux de soins de la Côte (one of the five care networks operating in the Canton of Vaud) and two regional hospitals	DiaBaid was to cover 30% of the estimated population with diabetes in the Nyon–Morges region (approximately 6000). By 2009, 720 patients (12%) had been reached (approximately 100–150 new patients per year)

**Table 3.4** cont'd

Name	Funding	Use of financial incentives	Other incentives	Distribution	Uptake
Switzerland cont'd					
Breast cancer clinical pathway, Lausanne University Hospital and Lausanne University	Financed by Lausanne University Hospital	No	Peer pressure; competition from other (hospital) providers	Currently offered by Lausanne University Hospital only but there are plans for it to be extended to other regional hospitals in the Canton of Vaud	Programme currently covers approximately 35% of new breast cancer patients in the Canton of Vaud; aim is to treat 40% of new breast cancer patients, with a minimum of 150 patients to be included each year
Delta physician network, Geneva	Financed within the Delta network insurance scheme principally following usual fee-for-service reimbursement but within a capitated scheme with reinsurance for expensive cases	Physicians receive a lump sum of CHF 200 each time they participate in a quality circle	Professional commitment to improving the quality of care	In 2013, the Delta network comprised 260 physicians (10–20% generalists, internists, GPs); in the Canton of Vaud, the network comprised 140 physicians	Accessible to any resident opting for the Delta network insurance scheme; in 2013, Delta covered about 100 000 insured members across the cantons of Geneva and Vaud

*Notes:* Austria: Sönnichsen, Flamm & Nolte (2015); Denmark: Frølich, Jacobsen & Knai. (2015); England: Nolte et al. (2015); Estonia: Lai & Knai (2015); France: Chevrel et al. (2015); Germany: Erler, Fullerton & Nolte (2015); Hungary: Gaal et al. (2015); Italy: Ricciardi et al. (2015); Lithuania: Lai et al. (2015); Latvia: Lai, Knai & Taube (2015); the Netherlands: Elissen et al. (2015); Switzerland: Peytremann-Bridevaux et al. (2015)

*Notes:* DMP: disease management programme; SHI: statutory health insurance; GP: general practitioner; COPD: coronary obstructive pulmonary disease; NHS: National Health Service; CVD: cardiovascular disease; FIQCS: Fonds d'intervention pour la qualité et la coordination des soins; CNAM: Caisse Nationale d'Assurance Maladie; PPS: parcours personnalisé des patients (personalized care programme); RCP: réunion de concertation pluridisciplinaire (multidisciplinary team meeting); MIGAC: Missions d'intérêt général et à l'aide à la contractualisation; EEP: évaluation des pratiques professionnelles; CHD: coronary heart disease; VERAH: Versorgungssassistentin in der Hausarztpraxis (care assistants in family practice); CMP: care management programme; SSN: Servizio Sanitario Nazionale (National Health Service); P4P: pay-for-performance; ASL: Azienda Sanitaria Locale (Local Health Authority); PHC: primary health care; ZIO: Zorg In Ontwikkeling (Care In Development); AWBZ: Algemene Wet Bijzondere Ziektekosten; WMO: (Social Support Act); CHF: Swiss franc.

A number of approaches have been implemented at national level; these include: the care management programme and the Quality and Outcomes Framework in England; quality management in primary health care and management at the primary/secondary care interface in Estonia; disease management programmes in Germany; treatment (and financing) protocols in Hungary; and the improving intersectoral collaboration programme in Lithuania. Several approaches have been implemented at the regional level but are being (gradually) rolled out towards countrywide coverage. These have frequently, although not always, evolved from pilot or experimental projects. Examples include: the diabetes disease management programmes in Austria; the Sophia diabetes and asthma care programme and cancer networks in France; the asthma disease management programme and (possibly) the diabetes care programme in Hungary; the IGEA diabetes disease management programme in Italy; and care groups and standards as well as stroke services in the Netherlands. In Denmark, the regional DMPs and integrated clinical pathways are expected to cover the entire resident population in due course. Some approaches are fairly localized but are being considered for implementation elsewhere, such as the previously described COPA in Paris.

### **3.5 Components of chronic disease management**

As noted in the Introduction, data collection on approaches to chronic disease management in Europe has sought to examine the extent to which these make use of the four components considered key to providing high-quality care for those with chronic health problems as identified by the chronic care model. These components are:

- self-management support
- delivery system design
- decision support
- clinical information systems.

For each of the approaches reviewed, Table 3.5 provides an overview of the nature and scope of these four interacting components. We find that the large majority provides some form of patient self-management support, although the level of support offered varies considerably, for example, involving the provision of information material, such as through brochures (for example, Integrated stroke care Upper Austria; Delta physician network, Switzerland), routine assessment of clinical indicators (for example, clinical guidelines in Lithuania) or access to coaching and face-to-face or telephone follow-up (for example, the Raffaello project, Italy), lifestyle intervention training (for example, the

Matador diabetes disease management programme, the Netherlands) and counselling techniques (for example, National care standard for vascular risk management, the Netherlands). Most approaches involve patients in the development of a care or treatment plan and goal setting, and provide regular assessment of patient needs and problems. The extent to which these support mechanisms are implemented in practice is, however, often unclear.

In the majority of cases, self-management support is provided by health professionals including physicians (for example, diabetes disease management programmes in Austria and Germany; chronic disease management at the primary/secondary care interface in Estonia), or, more frequently, trained nurses (for example, selected integrate care pilots in England; quality management in primary care in Estonia; the Sophia diabetes and asthma care programme and provider networks in France; Care Coordination Pilot, asthma disease and diabetes care management programmes in Hungary; IGEA, Leonardo and Raffaello projects in Italy; care groups and stroke services in the Netherlands; the breast cancer clinical pathway in Lausanne, Switzerland). Self-management support provided by others including lay groups appears uncommon; examples include selected projects implemented within the Partnership for Older People Project set-up in England.

Most approaches reviewed here involve some form of delivery system design, but as with self-management support the nature and scope of related strategies varies. Common elements include a clear definition of roles, the development of (individualized) care or treatment pathways and patient follow-up. Several approaches use case-finding or risk stratification (for example, care coordination/interface management Styria, Austria; Partnership for Older People Project and integrated care pilots, England; France; selected integrated care contracts, Germany; Care Coordination Pilot, Hungary; Raffaello project, Italy; care groups, the Netherlands). These approaches also tend to involve case management, or indeed constitute dedicated case management approaches, such as within the Partnership for Older People Project and integrated care pilots in England; the COPA Coordinates of professional care for the Elderly in France; and the improving intersectoral collaboration approach in Lithuania, with case management elements also incorporated within selected GP contracts in Germany; the Care Coordination Pilot in Hungary; the “From On-Demand to Proactive Primary Care” programme in Tuscany, Italy; and the Matador diabetes disease management programme in the Netherlands.

These strategies are commonly supported by decision support tools, such as guidelines and protocols, developed at organizational, regional, national or international level with some strategies also incorporating training in translating national or regional guidelines to the local level, as, for example,

**Table 3.5** Components of chronic disease management used in 12 European countries

Name	Self-management support	Delivery system design	Decision support	Clinical information systems
Austria				
‘Therapie’ aktiv disease management programme	Education through group instruction; involvement in goal setting and timelines, with agreed targets signed jointly; regular follow-up	Patient management through coordinating physician with conditions for referral between levels of care; regular patient follow-up (in person)	Care pathways developed by the Austrian Society of Diabetes (ODG); mandatory provider training programmes for DMP physicians; annual advanced training sessions and quality circles	Standardized documentation of clinical and diagnostic measures and treatment; nationwide monitoring is planned, but regular feedback reports to participating physicians have yet to be established
Integrated stroke care Upper Austria	Information (stroke awareness campaigns, brochures distributed in GP practices and hospitals, dedicated website, targeted lectures)	Development of integrated care pathways; regular (peer group) meetings; defined roles for participating providers	Practice guidelines (for example, stroke checklist for GPs); development of integrated care pathways based on evidence-based guidelines	Common data warehouse that compiles information on stroke patients collected by participating organizations; provider feedback to monitor and improve processes and outcomes
Care coordination/ interface management Styria	Involvement of patients and their caregivers in planning of discharge and subsequent care arrangements including information and practical assistance, such as arrangement of devices and services	Care coordinator acts as key contact for the patient, hospital and the patient’s GP; regular meetings of the coordinator with providers outside hospital; case-finding	Checklist to identify patients requiring support by the care manager; use of the BRASS index in Graz for case-finding	Not specified
Ambulatory after-care of stroke patients, Salzburg	Access to team of occupational therapists, speech therapists and physiotherapists in one-to-one and group settings; social activities; information through events	Team of therapists led by senior therapist and physician in each district acting as programme lead; regular team meetings and meetings of project leaders	Continuing education and training of therapists; access for therapists to monthly group supervision meetings	Not specified
Kardiomobil – Home care for patients with chronic heart failure	Education about the disease, instruction in self-monitoring and in handling emergency situations by trained nurse; follow-up assessment of patient self-management competences and needs	Support of patients along defined protocol of three home visits by trained nurse; nurse also acts as key point of contact for patients and as care coordinator in collaboration with GP and specialist outpatient clinic	Continuing education for Kardiomobil nurses on aspects of medication, quality assurance, communication with clinicians, information technology	Not integral part of the programme; plans to implement an electronic information system that allows for the sharing of patient data within the programme

**Table 3.5** cont'd

Name	Self-management support	Delivery system design	Decision support	Clinical information systems
Denmark				
SIKS project – integrated effort for people living with chronic disease	Education and regular documentation of self-management needs and activities; involvement in developing individualized treatment plans and goal setting; access to physical exercise intervention; information	Clear definition of roles and tasks of participating health professionals; multidisciplinary team supports the delivery of rehabilitation; regular patient follow-up; regular interorganizational meetings	Evidence-based clinical guidelines developed by SIKS working groups; regular provider education and training	Monitoring of practice team performance; systematic collection of clinical and other data; use of municipal IT platform Sundhedsportat; providers may operate their own database
Regional disease management programmes (generic model as proposed in 2008 by the then National Board of Health)	Structured (disease-specific and general) education; information; involvement in developing care treatment plan and goal setting including agreeing timeline and methods for evaluation of goals; regular assessment and follow-up of problems and needs	Clearly defined roles of participating health professionals; development of individualized integrated care plans; GP is principal care coordinator with support by specialist and by case manager (usually specialist nurse) for complex patients; regular follow-up	Clinical guidelines developed by a working group and based on national and international clinical guidelines; provider training in relevant disciplines of chronic disease, including lifestyle interventions, self-management support and in education competencies and motivation techniques	National administrative registers and clinical quality databases allow for data sharing and communication, as well as consistent data collection; quality monitoring according to the Danish Quality Model (DDKM) and the National Indicator System
Integrated clinical pathways	Not specified	Clear definition of responsibilities (diagnosis, treatment, rehabilitation); development of individualized care plans; designated care coordinator; regular follow-up with intervals depending on condition	National clinical guidelines	From 2012, the State Serum Institute (SSI) coordinates the National Patient Registry and the Cancer Register; established specific codes for the monitoring of the integrated clinical pathways, with reporting made mandatory for Danish hospitals from October 2012. Similar codes were also established for integrated clinical pathways for heart disease; reporting of these became mandatory in July 2013



Name	Self-management support	Delivery system design	Decision support	Clinical information systems
England Community matron	Education provided by specialist nurse; involvement in development of care plan and goals; regular assessment and documentation of needs and activities	Clear definition of roles with specialist nurse as case manager; coordinating with GP; community and social care services; medicines management; case-finding using standardized risk assessment	Training of nurses within national competency frameworks and guidance	May include use of risk stratification tools to identify patients at risk of rehospitalization; availability of IT support/information sharing variable across commissioners
Quality and outcomes framework	n/a	Varies at practice level; may include regular staff meetings, patient follow-up (usually by phone or post), and medicines management	Use of clinical guidelines and training of practice nurses on the basis of individual learning plans	Automated mechanism for the collection of data for clinical quality indicators from GP electronic medical records, including disease registration and performance monitoring, through national IT system; data extracts are accessible to the Health and Social Care Information Centre to support publication
Partnership for older people project (POPP)	Varied: involvement of older people in project development, operation and evaluation; peer support, including EEP; staff and volunteers acting as "navigators" to helping older people through the system; follow-up; expert carer programme;	Varied: community-based multi-agency teams; development of integrated care pathways; multidisciplinary health and social care teams; designated roles, including community matrons and case workers (social/"hybrid" workers); case-finding; regular follow-up	Varied: health or social care staff training; volunteer training; skill sharing and training; access to specialist expertise	Varied: integrated IT systems connecting primary and secondary care, or primary and social/community care; use of telehealth technology and case-finding software; use of wireless technology for mobile units
Integrated care pilots	Varied: patient education and provision of self-management tools by senior nurses; training in self-management of medicines	Varied: development of care pathways; managed discharge; case management, led by senior/specialist nurses; use of integrated community teams providing a single point of access for patients	Varied: health or social care professional training, particularly regarding generic skills that enable more effective work on multidisciplinary teams or in a rapid-response capacity; access to specialist expertise	Varied: case-finding software; a few sites aimed to establish a single integrated IT system for primary and community care, while others make use of telecare services and remote health monitoring

**Table 3.5** cont'd

Name	Self-management support	Delivery system design	Decision support	Clinical information systems
Estonia				
Quality management in primary health care	Education provided by GP/family nurse; involvement in development of care plan; regular assessment and follow-up; additional support by home care nurse or social worker where necessary	Case-finding; development of individualized care and treatment plans; routine follow-up	Evidence-based diagnosis, treatment and disease management guidelines; provider education as part of continuing professional development in primary and specialist care; quality management activities	GP practice information system according to mandatory guidelines including electronic medical records, booking and reminder systems; IT system linked to countrywide patient and treatment system of all health care providers (available online from 2009)
Chronic disease management at the primary/secondary care interface	Education (specialist); involvement in development of care plan; regular assessment and follow-up; mentoring/peer support through patient associations (for example, multiple sclerosis, Parkinson's disease); support at home by nurse or social worker where necessary	Case-finding; development of individualized care and treatment plans; routine follow-up	Evidence-based diagnosis, treatment and disease management guidelines; provider education as part of continuing professional development in primary and specialist care	GP practice information system according to mandatory guidelines including electronic medical records, booking and reminder systems; IT system linked to countrywide patient and treatment system of all health care providers (available online from 2009)
France <i>Provider networks</i>				
For example, (diabetes networks): REVESDIAB	Information and education (for example, diet); coaching by nurses; involvement in developing treatment plan towards a formal agreement between patient and network; regular assessment and follow-up including patient logbook completed with doctor consulted	Clear definition of roles of multidisciplinary health care team; development of individualized care plan by core team; discussion forum and quality circles; regular follow-up	Evidence-based guidelines and care protocols; provider training within continuous medical education	Shared information system involving a database collecting routine clinical indicators and used for evaluation and quality control; patient-held care folder to support monitoring; some systems operate reminder functions; GPs do not have routine access to centralized patient information
Coordination of professional care for the Elderly (COPA)	Involvement in developing treatment plan and goal setting	Clearly defined roles with trained nurse as case manager; development of individualized care plan; occasional multidisciplinary team meetings (GP, geriatrician, caregivers); case-finding	Provider training in geriatric assessment (InterRAI) to inform care plan and case-finding	Database for evaluation and documentation; to be integrated in the clinical routine in the future

Name	Self-management support	Delivery system design	Decision support	Clinical information systems
France cont'd				
<i>Specific programmes</i>				
Sophia diabetes and asthma care programme (by SHI)	Advice and information on self-management of disease and health behaviour; facilitating communication with health professionals; access to dedicated programme website	Clear definition of roles: regular individualized (need-based) phone intervention by trained nurse with GP remaining care coordinator; stratification of patients according to risk to determine frequency of intervention	Evidence-based guidelines	Risk stratification software
Health Action by Teams of Self-employed Health Professionals (ASALEE)	Education about disease provided by trained nurse	Clearly defined roles for staff with nurses responsible for screening for cognitive problems and cardiovascular risk factors in individuals over 75 years	Not specified	Reminder systems on patient notes and monitoring systems
Hospital discharge program for heart failure patients (PRADO)	Weekly home visit by nurse during two months to deliver patient education; support brochures for patients	Organization and coordination of follow-up consultations by the discharge manager	Care algorithms for the participating health professionals	Paper-based logbook for the patient, containing physiological information to be shared among all health professionals
Specific payment based on public health objectives (ROSP)	Not applicable	Not applicable	Incentives for set-up of prescription aid software; (indirect) adherence to guidelines via the quality indicators for remuneration	Incentives for infrastructure related to electronic patient record and data transmission (mostly with SHI)
<i>Measures of the 2003–2007 Cancer Plan</i>				
Protocol for disease communication and promotion of shared decision-making (Dispositif d'annonce)	Access to dedicated time informing about the illness and support; involvement in decision-making; access to psychological and social support; regular assessment of patient needs; follow-up	Roles of staff are clearly defined with support provided by nurse, psychologist or social worker; personalized follow-up	National recommendations on patient communication developed by the HAS/INCa	Systems have been established to enable sharing of cancer patient records (Dossier communiquant en cancérologie); however, implementation has varied across regions

**Table 3.5** cont'd

Name	Self-management support	Delivery system design	Decision support	Clinical information systems
<p>France  <i>Measures of the 2003–2007 Cancer Plan</i> cont'd                      Multidisciplinary team meeting (RCP)</p>	<p>As implemented within dispositif d'annonce</p>	<p>Development of individualized care plans (PPS); staff roles are clearly defined with médecin référent (referring doctor) preparing draft treatment plan for discussion with team; weekly team meetings for each cancer speciality and every two weeks to discuss individual cancer patients</p>	<p>Regional guidelines/recommendations on cancer practice based on national recommendations issued by HAS/INCa</p>	<p>Systems have been established to enable sharing of cancer patient records (Dossier communiquant en cancérologie); however, implementation has varied across regions</p>
<p>Regional cancer networks</p>	<p>As implemented within dispositif d'annonce</p>	<p>As implemented within RCP; in addition: regular (monthly, six-monthly) meetings of providers in the form of workshops for each group of specialities of regional importance, for example, variation in practice, regional guidelines</p>	<p>As implemented within RCP</p>	<p>Systems have been established to enable sharing of cancer patient records (Dossier communiquant en cancérologie); however, implementation has varied across regions</p>
<p>Local cancer or local multiple pathology networks</p>	<p>As implemented within dispositif d'annonce</p>	<p>Participation of GPs in multidisciplinary consultation; development of monitoring plan by GP covering episodes between hospitalizations, treatment at home and monitoring after-care</p>	<p>As implemented within RCP with an element of provider education at local level (GPs, home care nurses) as means to implement regional guidelines; access to specialist expertise in hospital</p>	<p>Access of GPs to electronic patient records of participating patients</p>

Name	Self-management support	Delivery system design	Decision support	Clinical information systems
Germany				
Disease management programmes	Education programme in group sessions; involvement in agreeing treatment goals; regular follow-up, with patient reminders for missed sessions; some SHI funds also offer telephone services to further support their members participating in DMPs	Coordination of three care levels according to specified conditions for referral between levels of care; regular patient follow-up	Evidence-based guidelines as developed by the German Network for Evidence-based Medicine and Institute for Quality and Efficiency in Health Care; participating physicians have to meet defined training standards and may have to attend further training; further training or quality circles on a regular basis	Standardized electronic documentation of treatment, patient's condition and test results, medication regime and agreed treatment goals; central data analysis to produce quality reports, and provider feedback on performance and for benchmarking
GP contracts	Annual check-ups; advice on preventive measures and information; assessment of cardiovascular risk factors (arriba software) supports shared decision-making on treatment options	GP acts as gatekeeper to specialist care; case management led by qualified nurses/practice assistants is encouraged	Treatment guidelines by association of family physicians; requirement to participate in (continuous) professional training, selected DMPs and in at least four quality circles per year; training in psychosomatic medicine and rehabilitation care	(Optional) use of electronic medical record (patient passport); externally created feedback reports for physicians; requirement to implement a quality management system
Integrated care/ Healthy Kinzigtal	Regular check-ups and risk assessments; involvement in the development of individual treatment/prevention plans and goal setting; representation through patient advisory board and a patient ombudsman	Clearly defined roles with identified care coordinators; integrated provider network and designated management organization responsible for provider coordination; case-finding	Treatment guidelines for over 15 diseases; providers and experts from the participating SHI funds collaborate in working groups to develop guidelines and care pathways	Quality management system and electronic patient records; regular analysis of patient data using predictive modelling to identify high-cost risks
Community nurses: care assistant in family practice (VerAH)	Access to trained case managers	Delegation of tasks to practice assistants and performed under the supervision of the GP; usually forms part of GP contract	Part of GP contract as described above under GP contracts	Part of GP contract as described above

**Table 3.5** cont'd

Name	Self-management support	Delivery system design	Decision support	Clinical information systems
Hungary				
Treatment (and financing) protocols	Information material on cancer, hypertension and other CVD; self-management support by patient associations and by health care staff predischARGE for hospitalized patients (cancer, CVD)	Not applicable	Use of treatment guidelines/protocols developed by professional associations on the basis of best available evidence with variation in quality of guidelines; provider education for some conditions, organized at the national level and frequently supported by pharmaceutical companies	National disease registries are in place for cancer, asthma/COPD, cardiovascular disease
Care coordination pilot	Education by specialized nurses; involvement in developing treatment plan and goal setting; access to self-management tools; regular assessment of problems/ accomplishments	Care coordination organization responsible for care delivery to an enrolled population; regular meetings of providers; medicines management; case-finding and follow-up; case management; systematic screening	Use of local care pathways and of evidence-based guidelines developed by care coordination organization and discussed with local providers	NIHFA database on health care use to analyse provider performance and feedback; create patient profiles to identify need
Multifunctional community centres	Patient education may be provided	Community centre integrates primary, specialist care and social care; development and use of integrated care pathways	Not applicable	Implementation of integrated information system is a requirement
Asthma disease management programme	Patient education on asthma; access to self-monitoring tools; involvement in treatment plan, goal setting, decision-making; regular assessment of problems/ accomplishments	Asthma nurse is patient's first point of contact, and case manager; regular staff meetings; responsibility of all care decisions remain with treating physician	Use of treatment plans based on evidence-based guidelines and training of providers, in particular asthma nurse	Use of a national registry of asthma patients maintained by National Koranyi Institute of Tuberculosis and Pulmonology; nurses keep detailed records of each patient

Name	Self-management support	Delivery system design	Decision support	Clinical information systems
Hungary cont'd Diabetes care management programme	Education provided by a diabetes nurse; access to self-monitoring devices (glucometer); regular follow-up to routinely assess problems and accomplishments, both in person and by telephone	Clear definition of roles of health care staff; regular staff meetings to discuss problematic cases; regular follow-up of patients; use of discharge social nurses who coordinate social support (cash and in kind)	Evidence-based treatment guidelines developed and regularly updated by the Hungarian Diabetes Association and the training of health care staff, in particular specialist diabetes nurses	Planned; strategies envisaged include reminder systems, electronic booking system and provider feedback
Italy	Structured diabetes education by trained staff (specialists, nurses, GPs); involvement in developing care plan; access to self-management tools; routine assessments of problems and accomplishments	Use of integrated care pathways; specialist nurse develops individualized care or treatment plans; team composition varies in accordance with individual patient's needs	Evidence-based guidelines for the management of type 2 diabetes and two-stage provider training: training-the-trainers stage at national and regional level and individual provider education with feedback for programme improvement	Registries of patients with diabetes enrolled in the programme although format varies by region; document "The information system" sets out the principles for the development of information systems
"From On-Demand to Proactive Primary Care" programme, Tuscany	Education and counselling; instruction in self-monitoring activities; involvement in developing and consent to care plan; regular assessments of problems and needs; support by social workers where needed	Clinical pathways delivered by GP-led teams; periodic meetings with community health doctor at the local health authority (ASL); staff roles clearly defined including flowcharts; staff nurse for case management and counselling	Evidence-based guidelines to inform clinical pathways and comprehensive programme of peer education for all professionals involved and single groups of professionals on specific issues; access to specialist expertise; nurse training	Databases on enrolled patients to monitor performance of practice team in regular meetings; information sharing among team members through lead GPs electronic system; electronic booking system in place
Leonardo pilot project, Puglia	Education based on the eight priorities approach defined by Lorig & Holman; systematic assessment of patient needs (in person/by telephone) and follow-up	Care manager works with GP to deliver individual patient's care plan; staff roles are clearly defined; regular staff meetings; flowcharts describe activities set out in the care plan; medicines management	Evidence-based principles of care management and scoring systems and training of staff (care managers in counselling and communication techniques; GPs in use of the programme software); specialist expertise is available where required	Software, InformaCare™; reminders for providers; data collection for performance assessment; continuous monitoring of progress; information sharing. Electronic booking system in place

**Table 3.5** cont'd

Name	Self-management support	Delivery system design	Decision support	Clinical information systems
Italy				
Raffaello project, Marche and Abruzzo	Participation in devising care plan and decision-making; access to coaching and follow-up activities by telephone, doctor's office or patient's home; access to information material on disease, services availability and lifestyle	Care manager works with GP to deliver individual patient's care plan; staff roles are clearly defined; use of case-finding through measures of primary prevention	Provider education (training-the-trainers and individual provider training for GPs and care managers); access to specialist expertise and experience is mentioned, but specialists do not play an active role in the team; preimplementation simulation to assess impact of proposed care strategy on existing organization	Software developed for care managers: regular reminders for GPs on scheduled tests and appointments; communication between patient and staff members; ensure adherence to evidence-based guidelines; evaluation of clinical outcomes
Latvia				
General primary health care system	Not specified	Plans to second nurses to work with GP in chronic care; education about self-management; health promotion and disease prevention; development of home health care	Quality criteria for general practitioners are defined by law; these include indicators on the periodic assessment of patients with conditions such as asthma or diabetes	Not specified
Lithuania				
Improving intersectoral collaboration	Routine assessment of problems and accomplishments; access to psychosocial rehabilitation services in some cases (mental health)	Case-finding by nurse; case management pilot (HIV/AIDS, some mental health problems)	Access to specialist expertise	Not documented
Clinical guidelines	Routine assessment of clinical indicators	Development of individualized care plans common for diabetes and depression, required for cardiovascular disease	(Evidence-based) clinical guidelines; provider education in cases (for example, depression) with support from private sector (pharmaceutical companies); access to specialist expertise	Electronic booking systems piloted; provider feedback on service delivery through database held by territorial patient fund (SVEIDRA)



Name	Self-management support	Delivery system design	Decision support	Clinical information systems
Netherlands				
Matador disease management programme	Access to Diabetes Interactive Education Programme (DIEP), comprising lifestyle intervention training component for providers to engage patients in the development of treatment plan and goals; DIEP website; systematic patient follow-up	Stratification of patients into three levels of care intensity and clinicians (GP, diabetes specialist nurse, endocrinologist); staff roles clearly defined; specialist diabetes nurse liaison between hospital and primary care for all patients; regular core team meetings	Use of Matador protocol; access to specialist expertise with endocrinologist supervising specialist diabetes nurse and acting as consultant to GP, plus training	Not integrated; data on patient contacts and outcomes collected on GP and hospital information systems
Primary care group ZIO (Maastricht–Heuveland)	Regular check-ups that include education on self-management by practice nurses/specialized diabetes nurses, depending on the level of need	Stratification of patients into four regular modules plus two modules for (complex) problems; staff roles and responsibilities are defined; GP oversees referral to secondary care and ensures follow-up	Nationally defined standards for diabetes care and multidisciplinary care protocol; referral criteria to other care providers; internist acts as consultant to specialized diabetes nurse on patients with (complex) problems	Disease-specific electronic patient record (Medix) contains check-up and referrals data within care programme, allows for information sharing and automatization of care protocols, and can be linked to laboratory data and functional measurements
Stroke service Delft	Education adapted to the wishes and needs of individual patients and their carers (verbal or written; communicated in group meetings alternating with individual sessions or through media such as Internet or DVD)	Common elements: hospital stroke unit; specialist multidisciplinary team of caregivers; protocol-based care; agreements about patient referral; regular multidisciplinary staff meetings in the various settings; structured follow-up by specialist nurses of stroke patients following discharge to their home	Shared care protocols and national multidisciplinary care for stroke guideline developed by over 70 professionals and representing 26 societies or institutions dealing with stroke patients; special staff training	Electronic patient record Portavita Stroke Service; permits documentation and sharing of information; tracking and registering of medications; requesting, planning and registering of (complementary) examinations; workflow support

**Table 3.5** cont'd

Name	Self-management support	Delivery system design	Decision support	Clinical information systems
Netherlands cont'd				
National care standard for vascular risk management	Involvement in shared decision-making; development of care plan and goal setting; acquire self-management competencies through task-oriented interviewing; or motivational communication	Defined staged process; staff roles and responsibilities clearly defined; central caregiver is first point of contact and coordinator of care; is trained in vascular risk management and skilled in supporting self-management and oversees referrals	Multidisciplinary care standard for vascular risk management; if necessary, experts can be consulted	IT systems are used to register, share and interpret patient data as part of vascular risk management, both at individual and group level
Switzerland				
DiaBaid diabetes care network	Information material; customized face-to-face self-management education and follow-up; regular assessment of problems and needs; involvement in goal setting and developing a treatment plan	Clear definition of staff roles and tasks; monthly team meetings and weekly coordination meetings; development of care plans; scheduled patient follow-up including telephone contact at least once a year	Care protocols are developed according to international and Swiss guidelines; specialist physicians are involved in the programme	Shared electronic medical record permitting (restricted) information sharing among health professionals (customized access); includes an electronic booking system
Breast cancer clinical pathway, Lausanne University Hospital and Lausanne University	Written information; regular reassessment of the patient's situation; shared decision-making; support by trained nurses and social workers; possible access to peer support groups	Detailed description of clinical pathway; regular meetings with staff and project leads; planned, predetermined and structured face-to-face consultations; regular assessments of pathway implementation	Adapted (inter)national guidelines; provider education of physicians and nurses involved in the programme; hospital specialists are entirely integrated in the programme; further support through written documentation detailing care pathway	Database and biobank; providers feedback on delays, number of new cases per month, volume of reoperation, or frequency of a given surgeon acting as main operator in relation to the total number of breast cancer operations

Name	Self-management support	Delivery system design	Decision support	Clinical information systems
Netherlands cont'd				
Delta physician network, Geneva	Regular information (two information letters per year), detailing provisions for access to health promotion and disease prevention consultations and activities; website	Primary care physicians act as gatekeepers to specialist care; chronic disease management for diabetes, heart failure and asthma under development	Organization of regular quality circles for all physicians participating in the network	Not specified
<p><i>Sources:</i> Austria: Sönnichsen, Flamm &amp; Nolte (2015); Denmark: Frølich, Jacobsen &amp; Knai (2015); England: Nolte et al. (2015); Estonia: Lai &amp; Knai (2015g); France: Chevreul et al. (2015); Germany: Erler, Fullerton &amp; Nolte (2015); Hungary: Gaal et al. (2015); Italy: Ricciardi et al. (2015); Lithuania: Lai et al. (2015); Latvia: Lai, Knai &amp; Taube (2015); the Netherlands: Elissen et al. (2015); Switzerland: Peytremann-Bridevaux et al. (2015).</p>				
<p><i>Notes:</i> DMP: disease management programme; GP: general practitioner; BRASS: Blaylock Risk Assessment Screening Score; IT: information technology; EEP: évaluation des pratiques professionnelles (evaluation of professional practice); SHI: statutory health insurance; HAS: Haute Autorité de Santé (National Authority for Health); INCa: Institut National Du Cancer (National Cancer Institute); RCP: reunion de concertation pluridisciplinaire (multidisciplinary team meeting); CVD: cardiovascular disease; COPD: coronary obstructive pulmonary disease; NIHFA: National Health Insurance Fund Administration; HIV: human immunodeficiency virus; AIDS: acquired immunodeficiency syndrome; DIEP: Diabetes Interactive Education Programme; ZIO: Zorg In Ontwikkeling (Care In Development); DVD: digital versatile disc.</p>				

within local cancer networks in France. Dedicated staff training tends to be common for those strategies that involve (the delegation of tasks to) non-medical professionals, such as nurses (for example, asthma disease management and diabetes care management programmes in Hungary; IGEA, Leonardo and Raffaello projects in Italy; breast cancer clinical pathway in Lausanne, Switzerland), practice assistants (for example, VerAH care assistant in family practice, Germany) or allied health professionals (for example, therapists in ambulatory after-care of stroke patients in Salzburg, Austria). Physicians acting as coordinators in Austria, Denmark, Germany and Italy are required to undergo additional training; in other settings, this is provided within the framework of continuing medical education (for example, Estonia, France, Hungary).

A number of approaches also provide training in the use of specific programmes designed to support case-finding (for example, care coordination/interface management Styria, Austria; COPA, Coordination & professional care for the Elderly, France). However, overall the use of clinical information systems tends to be the least developed strategy in most approaches. Exceptions include England and Estonia, with both employing standardized, electronic medical records and electronic booking and reminder systems throughout the primary care system.

### **3.6 Conclusions**

In this chapter, we have reviewed the policy context for, and approaches to, chronic disease management in 12 European countries in place during 2009–2011. Countries have sought to create a regulatory and policy framework to respond to chronic disease during recent years. These generally aim to promote approaches that better integrate care and improve coordination between sectors and levels of care, but countries differ with regard to their vision towards controlling and managing chronic disease.

As noted earlier, our review did not attempt to present a comprehensive inventory of all approaches that are being implemented in a given country. Also, as we have focused on published evidence, it is likely that we have missed innovative approaches that are currently being developed or implemented. However, there are a number of general observations that we have identified.

#### ***3.6.1 The majority of approaches tend to focus on populations with defined conditions***

The most frequently targeted conditions were type 2 diabetes, asthma/COPD, cardiovascular disease (chronic heart failure, IHD, stroke), cancer and mental

health problems. These conditions are typically targeted by means of structured disease management to enhance coordination, which are typically implemented at the national level, or, in decentralized systems, at regional level. There is wide variation in the nature and scope of approaches and the extent to which non-medical staff is involved in care delivery. Commonly, the GP or family physician tends to act as principal provider or “care coordinator”.

### ***3.6.2 There is a trend towards strengthening the role of nurses in care delivery and coordination***

The use of nurses in care delivery and coordination is common in systems that have a tradition in multidisciplinary team working (Nolte & McKee, 2008a). Examples include nurse-led clinics and nurse-led case management as established in countries such as England, Italy and the Netherlands. Conversely, the introduction of nurse-led approaches in primary care has remained challenging in systems where primary care is traditionally provided by doctors in solo practices with few support staff. However, there are moves in these countries towards enhanced functions of nurses in care coordination or case management, as, for example, in Denmark, France and Lithuania. Countries are also seeking to strengthen the role of nurses in providing patient self-management support or the delivery of selected medical tasks, although most often such tasks have remained under the supervision of the GP or family physician, such as in Austria, France and Germany.

### ***3.6.3 Approaches that seek to reduce barriers between sectors remain less common***

Many of the observed approaches seeking to enhance the care for people with chronic or long-term conditions tend to be implemented within existing organizational and governance structures without necessarily overcoming existing structural or sectoral boundaries. Such approaches may still be effective in enhancing coordination, through, for example, the use of structured referral pathways, but structural barriers between sectors remain, potentially impeding further progress in advancing service delivery towards one better suited to meet complex chronic care needs.

Approaches that seek to more specifically reduce or eliminate these structural or sectoral barriers were less common. Typically, such approaches would focus on managing the primary–secondary care or the secondary care–rehabilitation interface. Examples include some provider networks in France, a range of integrated care contracts in Germany, or the stroke service Delft in the Netherlands as one specific example of an integrated care service. Frequently,

although not always, approaches that perhaps challenge the established ways to service delivery by overcoming sectoral boundaries through, for example, new ways of contracting between funders and providers, were implemented as pilot projects, with the integrated care pilots and the Partnership for Older People Project, both in England, or the improving intersectoral collaboration pilot in Lithuania as examples. The SIKS project in Copenhagen, Denmark, provides an illustration of an integrated care 'pilot' that ended following completion of the project phase but that crucially informed policy development for coordinated care approaches across Denmark more widely.

### ***3.6.4 The implementation of approaches frequently involves financial incentives***

In a number of countries, the introduction of new approaches to enhance the care for people with chronic conditions involved additional funding in the form of start-up funding to support infrastructural development (for example, administrative structures). These can be targeted at payers, for example, municipalities in Denmark, integrated care pilots in England, or integrated care contracts in Germany, or, in some cases, support providers, such as in the case of provider networks in France.

Typically, however, new approaches would involve some form of financial incentive, most frequently targeted individual providers or physicians, such as within disease management programmes in Austria and Germany, GPs (diabetes care) in Denmark, provider networks in France, care groups in the Netherlands and Italy or GP practices in the England. Incentives for patients are also being used, but these are less common.

### ***3.6.5 Levels of patient and clinician support vary***

Patient access is typically granted in line with access to usual care. Many approaches are being implemented in selected geographical regions and may therefore potentially limit access to defined population groups. The majority of approaches provide some form of patient self-management support, although the level and scope of support offered varies. The use of clinical information systems for chronic disease management tends to be the least developed strategy in most approaches.

# Chapter 4

## Looking ahead

*Ellen Nolte, Cécile Knai, Richard B. Saltman*

Chronic disease as a core challenge to health care systems is now firmly on national and international agendas (United Nations General Assembly, 2011; Council of the European Union, 2013; World Health Organization, 2013). In Europe, chronic disease is the greatest challenge to the goal that the EU has set itself of contributing to the achievement of an increase by two years in the number of years spent by the EU population in good health (Council of the European Union, 2013). Achieving this ambition will require effective measures of disease prevention (Novotny, 2008), while also ensuring that those with established illness will be able to participate in society.

We have shown that while policy-makers in European health systems have recognized these challenges, and have acknowledged both the fiscal and social importance of more effectively addressing the requirements associated with chronic and long-term conditions, they often have had considerable difficulty translating this recognition into effective policy programmes (Nolte & McKee, 2008a).

There are several reasons for these continued translational difficulties, but the core challenge is that strategies that would address the complexity arising from the changing burden of disease sit at policy intersections between several different subsystems involving public health, health care and social care, and the wider regulatory framework within which these are embedded. The approaches implemented by countries described in Chapter 3 pursue a wide range of goals, often seeking to simultaneously:

- improve the quality of care and health outcomes for people with complex care needs;
- strengthen primary care and community services, and optimize their interface with secondary care;
- make more efficient use of scarce resources, and reduce spending on health services;

- empower people with chronic and long-term conditions to help define treatment and care modalities.

This list of objectives would be a tall order for any single set of policy innovations to achieve. It is especially difficult to attain where complex care needs created by people with multiple chronic conditions are concerned, the long-term nature of their requirements, alongside the complex set of interests and priorities of those involved in the delivery and financing of care services. These are likely to differ at the different tiers of the system, from the primary process of patient care and the organizational context, to the financing and policy context at system level, each with distinct rationales and perspectives concerning the delivery of health care (Plochg & Klazinga, 2002). Even where innovative approaches addressing the various objectives may be possible, the likelihood of their successful implementation will be determined, to a considerable degree, by the specific political, economic and cultural context within which they are being introduced.

This volume presents the current state of policy thinking across Europe about how to respond to this set of multiple policy objectives. By exploring different approaches in the studied countries, patterns can be identified and their innovative potential and likelihood of success, or indeed failure, noted. It is important to emphasize that strategies to address chronic disease are constantly evolving and this volume could, in the space available, only provide a brief illustration of the many approaches that are being tested and implemented in countries in Europe. It is likely that some approaches presented here will have experienced further modification, roll-out or indeed termination while new strategies will be in the process of implementation at the time of publication of this volume. Further, as we have noted previously, different systems are at different stages of the process and with different degrees of comprehensiveness (Nolte & McKee, 2008c), and evidence presented in this volume confirms this observation. It is against this background that our discussion of the main observations drawn from the presentation of findings has to be set.

#### **4.1 Learning from existing approaches**

Our review of approaches seeking to improve the care for those with chronic conditions in Europe found a tendency among countries to implement change within existing provider structures while models that aimed to reduce barriers between providers, institutions or sectors through service redesign were less common. Where such approaches have been implemented, these are likely to be in the form of pilot projects, or, where they form part of routine care, they tended to be confined to a particular locality or region.



One such example is the *Gesundes Kinzigtal* (Healthy Kinzigtal) model of integrated care in Germany (Hildebrandt et al., 2010). Introduced in 2006, the model is considered the only long-term public health and population-based integration approach in Germany. It uses an innovative shared health gain contract between a health care management company, involving a local physicians' network, and two regional SHI funds in south-west Germany, alongside P4P elements and a share of the company's profit on the basis of individual provider performance. The approach was associated with a proportionally smaller increase in health care expenditure compared to other regions in the same state, and a comparative saving of 17% of total costs during a four-year period between 2006 and 2010 (Hildebrandt, Schulte & Stunder, 2013).

The Healthy Kinzigtal service delivery model took advantage of start-up funding, a provision made possible by the government from 2004 to encourage selective contracting of SHI funds with individual providers towards the development of more integrated care (Erler, Fullerton & Nolte, 2015). This option created substantial activity, with some 6500 integrated care contracts concluded by 2008, covering a total of around 6% of patients insured under SHI (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen, 2012). However, the number of integrated care contracts has remained stagnant since, coinciding with the discontinuation of start-up funding from 2009; for example, during 2008 and 2009, around 20% of contracts were terminated or not renewed because of funding discontinuation. Importantly, an assessment of the experience of integrated care contracts published in 2012 found that although a number of anticipated benefits from integrated care contracts had been met, such as improved patient satisfaction with care, or the ability to enter into selective contracts, others were not, such as cost savings and reduced service use (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen, 2012). The Healthy Kinzigtal model did continue, however, and, as indicated previously, showed potential for cost savings. Although there are efforts to roll out this and other models of more integrated care across Germany, overall their uptake has remained slow.

The Healthy Kinzigtal example is not unique to Germany; indeed similar observations can be made for other countries that have examples of successful models of innovative delivery models but have thus far failed to roll out these models more widely (Curry & Ham, 2011). Where the wider diffusion of models has been possible, this typically required some modification of a given approach to enable take up, which might mean that innovative elements may have to be adapted. The Dutch primary care groups may serve as an example for the scaling up of a care model that was developed locally, and which served

to inform the development of a countrywide approach while retaining the core innovative features of the local model, the Matador disease management programme in Maastricht (Elissen et al., 2015).

Innovative components of the Matador model included: a team approach with the diabetes nurse linking primary and secondary care and taking on some of the tasks previously performed by doctors only; the use of protocols setting out the primary responsibilities for three subgroups of patients to a medical specialist (highly complex), a diabetes nurse (intermediate or stable) or the GP and a practice supporter (low complex) and support of self-management. The redesign of the model towards the one implemented in the form of diabetes care groups included a redefining of the role of the GP and of primary care in general, tasked with the primary responsibility for the subgroup of patients with intermediate to complex care needs. Further adaptations included employment by GPs of practice supporters, who may or may not have a nursing background. This implied a different role for the diabetes nurse, who became a consultant for primary care and a caregiver for patients with highly complex care needs. The wider uptake of the programme was further stimulated and facilitated by the introduction of bundled payments. In a similar vein, the SIKS (Integrated effort for people living with chronic disease) project in Copenhagen, Denmark, served to inform the development of disease management programmes for COPD, type 2 diabetes and CVD in the Capital Region of Denmark (Frølich, Jacobsen & Knai, 2015).

Against this background, it is apparent that, to elevate innovative models of service delivery that provide promising results to a level beyond pilot project or best practice, there is a crucial need for better understanding of specific local conditions that influence the implementation and sustainability of a given approach, so that identified processes can be translated to other contexts and settings. In the context of integrated care in particular, Goodwin (2013) highlighted the need to draw more firmly on implementation science that would enable evidence to be used to support health care policy and practice. It also seems necessary to better understand what Greenhalgh et al. (2004) have referred to as 'system readiness' for innovative approaches, that is, the steps that need to be taken to enable wider adoption of new care models. More fundamentally perhaps, there is a need to better understand existing approaches to service delivery to identify those components that present the greatest obstacles to the delivery of high-quality care and that are most likely to act as barriers to change. This issue was highlighted by Epstein and Sherwood (1996); they identified a number of factors for the successful implementation of chronic care management processes, noting that this would require understanding of:

- existing inefficiencies in health care delivery;

- disincentives for the patient or the provider to receive or deliver the highest quality care (such as access or cost);
- the relative cost–effectiveness of alternative treatments; and
- the success of different interventions in modifying individual behaviour (for example, adherence).

Lack of understanding of current context, structures and processes, and of the potential for change in the way services are being staffed and delivered to lead to improvement in patient outcomes, might result in the implementation of approaches that are, ultimately, ill-equipped to achieve the desired outcomes. Returning to the example of Germany, among the factors that Amelung, Hildebrandt and Wolf (2012) identified as important barriers to the wider uptake of more coordinated or integrated care approaches within the German health system, the lack of appropriate incentives for key actors to engage in the process was one such barrier. For example, they argued that, for health insurers, the risks to do so currently outweigh the benefits: innovative forms of care typically require investments, yet, stipulations require that where insurers exceed their income (that is, contributions from their members), they have to impose higher premiums on their members, which in turn may threaten their competitiveness in the insurance market. Thus, to encourage insurers to engage in integrated care approaches there may be a need to establish incentive structures that have the potential to better balance the risk–benefit ratio for insurers. Clearly, the specific enablers and barriers for the various actors in the system to engage in change will differ in different settings and it will be important to unpack these various factors in the specific context within which they operate.

In addition to the need to better understand the how and why a given approach works, and its potential for scaling up, there is also a need to better understand the differential impacts of new models of care and what works for whom. We have argued elsewhere how lack of evidence of improved outcomes (however conceptualized) of a given intervention might simply reflect that programme components were not suitable to lead to health improvement in the first place (Nolte et al., 2012b). Likewise, where evidence finds that a given care approach improves outcomes for a subgroup of participants only, this might indicate that the intervention was suboptimal or not sufficiently targeted at those who would benefit most. Indeed, as discussed in Chapter 2, existing research points to the value of targeted approaches to enhance outcomes of people with complex care needs, focusing on those who are most likely to benefit. For example, an evaluation of Dutch primary care groups found that diabetes patients with poorly controlled blood sugar levels saw notable improvements, but there

was little additional benefit for the majority of patients who were already adequately controlled (Elissen et al., 2012). Although these findings require further confirmation (Elissen et al., 2013a), similar observations were reported by a systematic review of diabetes care programmes (Pimouguet et al., 2011).

Likewise, the evaluation of a diabetes disease management programme in Salzburg, Austria, which was implemented as a cluster randomized controlled trial, found only small effects of the intervention on the primary outcome metabolic control (Flamm, Panisch & Sönnichsen, 2012). It concluded that the intervention approach might have taken insufficient account of patient self-management support. Informed by these findings, in a subsequent trial, the patient education module was enhanced through introducing peer support for diabetes patients in the same region (Sönnichsen, Flamm & Nolte, 2015). However, preliminary findings of that trial suggest that the enhanced programme did not significantly improve clinical outcomes, risk profile or quality of life in the intervention group after two years of follow-up (Johansson et al., 2014). Similar to the Dutch primary care groups described earlier, the authors attributed this absence of a significant effect to the observation that both intervention and control groups had already adequate metabolic control, so leaving little room for further substantial improvement.

Overall, these findings point to the need for a more systematic evaluation of new models of care as a means to inform the development of efficient and effective interventions to address the growing burden of chronic conditions in Europe and elsewhere. Evaluation may help identify where a given intervention is likely to lead to inequities in health care delivery. For example, where participation in a novel care approach relies on voluntary enrolment, this might lead to only those with higher health literacy actually benefiting from the programme (selection bias) (Craig et al., 2008). Furthermore, evaluation findings might also highlight issues around programme implementation; for example, where a given intervention is characterized by high drop-out rates of participants this might indicate problems with programme set-up, while also suggesting that the intervention might overall be ill-suited to the needs of the target population.

Arguably, interventions that address the needs of people with chronic conditions should be developed systematically, are based on the best available evidence and appropriate theory, and are tested using a phased approach to inform further development, alongside evaluation. However, as Craig et al. (2008) have pointed out, in practice, interventions emerge from various sources, which may include theory, but may also be based on weak evidence, depending on the drivers behind the intervention. However, even if models and programmes are informed by, say, political imperatives, there are programme design requirements about assessing performance and permitting mid-course corrections that are equally

important if programme outcomes are to match expectations. Elsewhere, we have shown that countries can face considerable barriers to the systematic evaluation of new care models (see Box 4.1), reflecting, to considerable extent, lack of evaluation culture and related shortage of capacity as well as a reluctance of payers or providers to engage in evaluation (Knai et al., 2013).

**Box 4.1** Reported barriers to evaluation in five European countries

In 2010, as part of the DISMEVAL project, we carried out a range of semi-structured interviews with key informants from Austria, Denmark, France, Germany and the Netherlands, who were involved in the decision-making process as it relates to various aspects of chronic disease management in a given health care system context. Interviews sought, among other things, to explore perceived barriers to developing, implementing and evaluating chronic care approaches.

Focusing on evaluation, key informants highlighted a lack of overall interest in wanting to know whether a given innovation does result in improvements in processes or outcomes. This reluctance can be driven by a range of factors. For example, in Germany, until recently, SHI funds (commonly referred to as sickness funds), which offer structured disease management to their enrolled population, received additional funding for every patient registered in a disease management programme (Erlor, Fullerton & Nolte, 2015). As a consequence, for those SHI funds that have a high proportion of members with chronic disease, there may have been low interest in identifying whether or not disease management works because of the risk of losing this additional funding. Yet, conversely, for those SHI funds with a high proportion of relatively healthy members, who benefited less from the financial incentive, proof of DMP effectiveness was equally undesirable:

*There were clear political reasons. [...] So for some sickness funds it was a very attractive idea to have DMPs because they had more chronic[ally] ill patients who are eligible for those programmes. They earned a lot of money [from this system]. [...] Other sickness funds [...] calculated that they would lose a lot of money because they had not so [many registered] chronic[ally] ill patients. [...] And those sickness funds tried to stop the programmes on a political basis.[...] This was a big battle. They wanted to stop the connection of those DMPs to the RSA [risk structure compensation scheme], so they had no interest in proof of success of those programmes. And this is a big political issue (Germany).*

Other informants from Germany highlighted a historical lack of interest among funders in “*what is done with their money*” although this has changed over the years, with an increasing “*consensus about the necessity to have evaluation of the effectiveness of money spent by the State or by the sickness funds*”.

**Box 4.1** contd

Several key informants also pointed to a perceived or real reluctance of providers in supporting evaluation, for example, as a result of the additional administrative burden this entails. There may be uncertainties about the range of relevant indicators and the feasibility to collect them, alongside questions, among providers, about the validity of metrics used for evaluation; such metrics were commonly perceived as not necessarily representing the true quality of care provided. This notion was reported in several countries, with interview participants noting that making available such data (for example, to health insurers) may be interpreted by providers as a compromise on their freedom of practice to the extent that this would likely involve subjecting their practice to more external scrutiny:

*[...] some doctors [say] that they don't want to collect data because they are afraid about the 'big brother' syndrome, [...] of being judged on their data. In Denmark there are many small units of GPs: one-third of GPs are alone in their own practice and therefore it is easier to blame them if the data are not good enough (Denmark).*

This reluctance of physicians to disclose patient data and outcomes to payers and other stakeholders may also reflect the importance that providers assign to their professional independence. The underlying concern seems to be that if treatment and outcomes are made transparent this might interfere with the doctor–patient relationship and thus impact on patient care.

Against this background, respondents highlighted the need to engage clinicians in the process more actively so as to come to a common understanding about the purpose of the evaluation, and thereby strengthen support, as noted for Germany:

*Ambulatory [care] physicians have a lot of work with these DMPs, about the evaluation. They have to give a lot of information but this information is more or less used for regulatory purposes [only] and is not a good feedback for the practices. For example, they don't know what happens to the patient, they have got very bulky reports. [...] They are not very happy that they have to write a lot of data, a lot of work with that, and the results of the evaluation are not quite transparent and usable. (Germany)*

*Source:* Knai et al. (2013)

#### **4.1.1 Incorporating the patient perspective**

A growing body of evidence points to the potential benefits of actively involving patients with chronic conditions in their own care (Wagner, 1998; Holman & Lorig, 2000). Supporting self-management has been associated with more appropriate use of health services and the potential to improve health outcomes, although the precise benefits will vary according to the conditions involved (Coulter, 2006; Rijken et al., 2008). The concept of active engagement has a

persuasive appeal, building on the notion of what Dieterich (2007) referred to as the “modern patient”, who has a legal or moral right to autonomy and self-determination and who can, with the appropriate knowledge and information, make decisions and help improve the system through making informed choices (Greenhalgh, 2009). However, as Bate and Robert (2006:307) observed “[i]n most countries, despite the longevity of the “patient involvement” concept, health care systems are still not putting patients first”. Indeed, as we have shown in Chapter 3 in relation to self-management support for people with chronic conditions, the implementation of such approaches in practice remains weak (Elissen et al., 2013b). Although patient support has moved beyond the mere distribution of information materials towards those that provide access to coaching, lifestyle intervention training and counselling techniques, as well as lay-led programmes, such as the Expert Patients Programme in England, the extent to which these support mechanisms reach wider groups of patients in practice is often unclear.

Experiences of the diabetes disease management programme in Salzburg, Austria, cited earlier point to the challenges of self-management support programmes in demonstrating evidence of effect on clinical outcomes (Johansson et al., 2014). Systematic reviews of self-management support interventions for people with chronic disease have pointed to some improvements in selected outcomes, such as self-efficacy (Foster et al., 2007), or moderate improvements in a range of symptoms such as pain, fatigue, health distress, as well as self-rated health and health-related quality of life, but these were often short-term only and their clinical relevance remains uncertain, as does their impact on service use (Franek, 2013; Kroon et al., 2014). There are many possible explanations for the apparent failure of self-management support programmes to lead to sustained improvement in outcomes; examples include that the length of the evaluation, typically of around 12 months, might be insufficient to demonstrate tangible change in health outcomes, or indeed, resource use (Nolte et al., 2012b). Reflecting on our discussion in the preceding section, it is also likely that programme design may have been inadequate to lead to the desired effect, because it was too narrowly focused and reliant on the clinical setting, and targeted those groups which were less likely to benefit.

An evaluation of the Dutch primary care groups provides further illustration of this point (Elissen et al., 2013b). It found that although Dutch guidelines for type 2 diabetes (care standard) stipulate that patients should play a central role in their care, the practice of diabetes care has remained highly paternalistic. Thus, in its current format, the care group motivates providers to deliver highly standardized care based on performance indicators as stipulated in the national diabetes care standard (Nederlandse Diabetes Federatie, 2007). These

indicators, which are monitored by health insurers, prescribe a defined intensity of service delivery, regardless of patients' health, demographic or social status. Although frequent monitoring was shown to be especially useful for improving clinical values in poorly controlled diabetic patients, patients in relatively good health could be managed equally effectively in a less physician-guided way that emphasizes self-management. The authors thus argued that there was potential for a more tailored approach to disease management that proactively considers patient characteristics in determining care processes, including self-management support, benefiting a relatively healthy population of diabetic patients for whom intensive monitoring may be inappropriate (Elissen et al., 2012).

Importantly, however, there is a need for initiatives seeking to support people with chronic conditions to self-manage to account for the social and cultural context and norms within which they live (Greenhalgh, 2009). Chronic illness confronts patients with a spectrum of needs that requires them to alter their behaviour and engage in activities that promote physical and psychological well-being, to interact with health care providers and adhere to treatment regimens, to monitor their health status and make associated care decisions, and to manage the impact of the illness on physical, psychological and social functioning (Clark, 2003). This means that any intervention seeking to support people with chronic conditions to self-manage will have to consider their changing needs over time, in particular where they have multiple care needs. Thus, increasing responsibility taken by patients for self-management can create particular challenges for those with multiple conditions, as they may experience aggravation of one condition by treatment of another. For example, a patient with chronic respiratory disease may struggle to adhere to exercise programmes designed for their diabetes (Bayliss et al., 2003). Furthermore, as we have argued previously, patients vary in their preferences for care and the importance they place on health outcomes (Nolte & McKee, 2008a). While the ability of patients to develop individualized treatment plans will be of critical importance to aide effective care, this is unlikely to be sufficient when patients are not considered partners in a care process that is sensitive to the contexts within which people make decisions (Dubois, Singh & Jiwani, 2008).

Failure to take account of patient preferences may lead to suboptimal outcomes of an otherwise innovative service delivery model that seeks to enhance patient care. An illustrative example is that of the national integrated care pilot programme in England, which was carried out from 2009 through to 2011 as described in Chapter 3 (Nolte et al., 2015). A three-year evaluation of six of the 16 pilot sites that used intensive case management for older people at risk of emergency hospital admission, found that staff involved in the delivery of



the care believed that the quality of patient care had improved, while patients receiving care in the pilots reported that they found it significantly more difficult to see a doctor or nurse of their choice and felt less involved in the decisions about their care (Roland et al., 2012). Although it is difficult to say whether these perceptions were linked to the change in service delivery as such, this observation highlights that patients need to be consulted on what they actually need and how new delivery models are to be structured to be acceptable to patients and so more likely to be successful. Patient preferences, rather than expert determinations, will need to drive policy formulation.

This latter point is receiving increasing attention under the notion of “experience-based co-design”, which is being tested in patient safety initiatives (Bate & Robert, 2006). It goes beyond mere consultation using user views and perceptions collated through focus groups, patient surveys and other feedback mechanisms. Instead, it is conceived as a joint venture that involves users and professionals working together and throughout the change process as co-designers of a service, based on the experiences of patients (and professionals). This concept has been tested in the area of cancer care (Tsianakas et al., 2012), and may present a useful way forward for improving service design for people with chronic conditions.

## **4.2 Providing the (regulatory) context to enable innovation**

We have previously noted that the policy context within which services are being designed and delivered will be crucial to encourage innovation (Nolte & McKee, 2008c). One area of tension we highlighted was the need to strike a balance, in a given country context, between centrally defined requirements and local autonomy. For example, the creation of a strict national regulatory framework for disease management in Germany has been viewed as beneficial in ensuring that disease management programmes meet an appropriate standard, but it has also been challenged on grounds that it might impede further improvements that take account of local circumstances (Siering, 2008). Tensions also arise in relation to weighing top-down versus bottom-up approaches. Actors operating at the different levels of the health care system are faced with different pressures and consequent priorities that are not necessarily compatible or may even be contradictory (Plochg & Klazinga, 2002). There are particular challenges for organizations that arise from policies initiated by health care reformers on the one hand and established ways of delivery, on the other, which are likely to result in a gap between policy intent and actual implementation (Ham, 2003). We have observed such tensions in our review of approaches to chronic disease management, highlighting the need to create a policy environment that

provides the means for those who are asked to implement change to acquire the actual capacity and competence to do so to be critical for success (see Box 4.2).

**Box 4.2** Balancing the gap between policy intent and actual implementation: evidence from the DISMEVAL project

As part of the DISMEVAL project, we sought to further explore the barriers to successful implementation of chronic care, and ways of overcoming these barriers, by means of interviews with key informants in a range of countries. These revealed a range of challenges, such as a perceived failure to integrate risk minimization and disease prevention along the spectrum of care; the persistence of care fragmentation hindering better coordination; and a lack of structures suitable to promote proactive engagement with patients in the management of their own condition. Key informants further discussed the challenge arising from a perceived mismatch between intent, at national level, to enhance coordination and integration, and the ability at regional or local level to translate these ambitions into practice.

For example, in Denmark, the 2007 administrative reform led to the reorganization of regions and municipalities, giving municipalities more responsibility for health. Specifically, the reform required municipalities to contribute 20% to health care funding so as to encourage them to increase preventive services and, ultimately, reduce hospitalizations. However, it was reported that municipalities lacked a coherent framework to guide them in their new tasks, as well as support to develop competencies in health care. There was concern that many of the resulting projects might not be sustainable and measurable:

*[Following the administrative reform] the municipalities had a central place in [solving] problems of the health care sector. The municipalities [have the responsibility] to create new health centres [...] [designed to overcome] barriers to coordination [...] [However] municipalities do not have the competence and knowledge about health care. And there is no systematic development in this area; [...] it is dependent on learning from the regional level. [...] [Moreover] the Regions got most of the [earmarked] 600 million DKK. [...] We have ended up with a lot of different projects and I am not sure how they will evaluate the projects and [...] implement the best. (Denmark)*

Such disjoint between intent, at national level, to enhance coordination and integration, and ability at regional or local level to translate these ambitions into practice was also reported by French participants. For example, the 2009 reform in France stipulated that patient education should form a mandatory component of chronic illness care. However, this stipulation was not accompanied by adequate resources to implement relevant initiatives on the ground:

*Funding for patient education has only got limited or ad hoc financing [...] usually allocated for one year, and then [once the funding runs out] it is always put into*

**Box 4.2** contd

question. The law now says that patient education is mandatory. However where the financing comes from is still not clear [...] The nursing profession is collectively in agreement with [...] developing and implementing patient education programmes but this is based on the assumption that they have money to do it and at the moment they don't. (France)

Furthermore, the creation in 2010 of regional health agencies was aimed at ensuring that health care provision meets the needs of the population by improving coordination between ambulatory and hospital care and between health and social care services. Yet, respondents highlighted that this recent decentralization tended to result in unclear responsibilities, further fragmented decision-making and disjointed care.

Source: Knai et al. (in press)

Fundamentally, however, it is important to come to an understanding as to whether approaches to better coordinate care for those with chronic conditions is to be considered as a series of interventions that, by implication, ought to be cost-effective and support financial sustainability. Alternatively care coordination and integration could be interpreted, and evaluated, as a complex strategy to innovate and implement long-lasting change in the way services in the health (and social care) sectors are being delivered and that involve multiple changes at multiple levels. Evidence presented here and elsewhere strongly points to the latter, and initiatives and strategies under way will require continuous evaluation over extended periods of time that will enable assessment of their impacts on both economic and health outcomes. This will mean investment in research alongside investment in the development and implementation of service reconfiguration initiatives to ensure that evaluation will inform service development, in particular if we are to generate appropriate conclusions about programme effectiveness and the application of findings to inform decision-making.

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The rising burden of chronic illness, in particular the rapid increase in the number of people with multiple health problems, is a challenge to health systems globally. Associated premature mortality and reduced physical functioning, along with higher use of health services and related costs, are among the key concerns faced by policy-makers and practitioners.

There is a clear need to redesign delivery systems in order to better meet the needs created by chronic conditions, moving from the traditional, acute and episodic model of care to one that better coordinates professionals and institutions and actively engages service users and their carers. Many countries have begun this process but it has been difficult to reach conclusions about the best approach to take: care models are highly context-dependent and scientifically rigorous evaluations have been lacking.

*Assessing chronic disease management in European health systems* explores some of the key issues, ranging from interpreting the evidence base to assessing the policy context for, and approaches to, chronic disease management across Europe. Drawing on 12 detailed country reports (available in a second, online volume), the study provides insights into the range of care models and the people involved in delivering these; payment mechanisms and service user access; and challenges faced by countries in the implementation and evaluation of these novel approaches.

This book builds on the findings of the DISMEVAL project (Developing and validating DISEase Management EVALuation methods for European health care systems), led by RAND Europe and funded under the European Union's (EU) Seventh Framework Programme (FP7) (Agreement no. 223277).

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