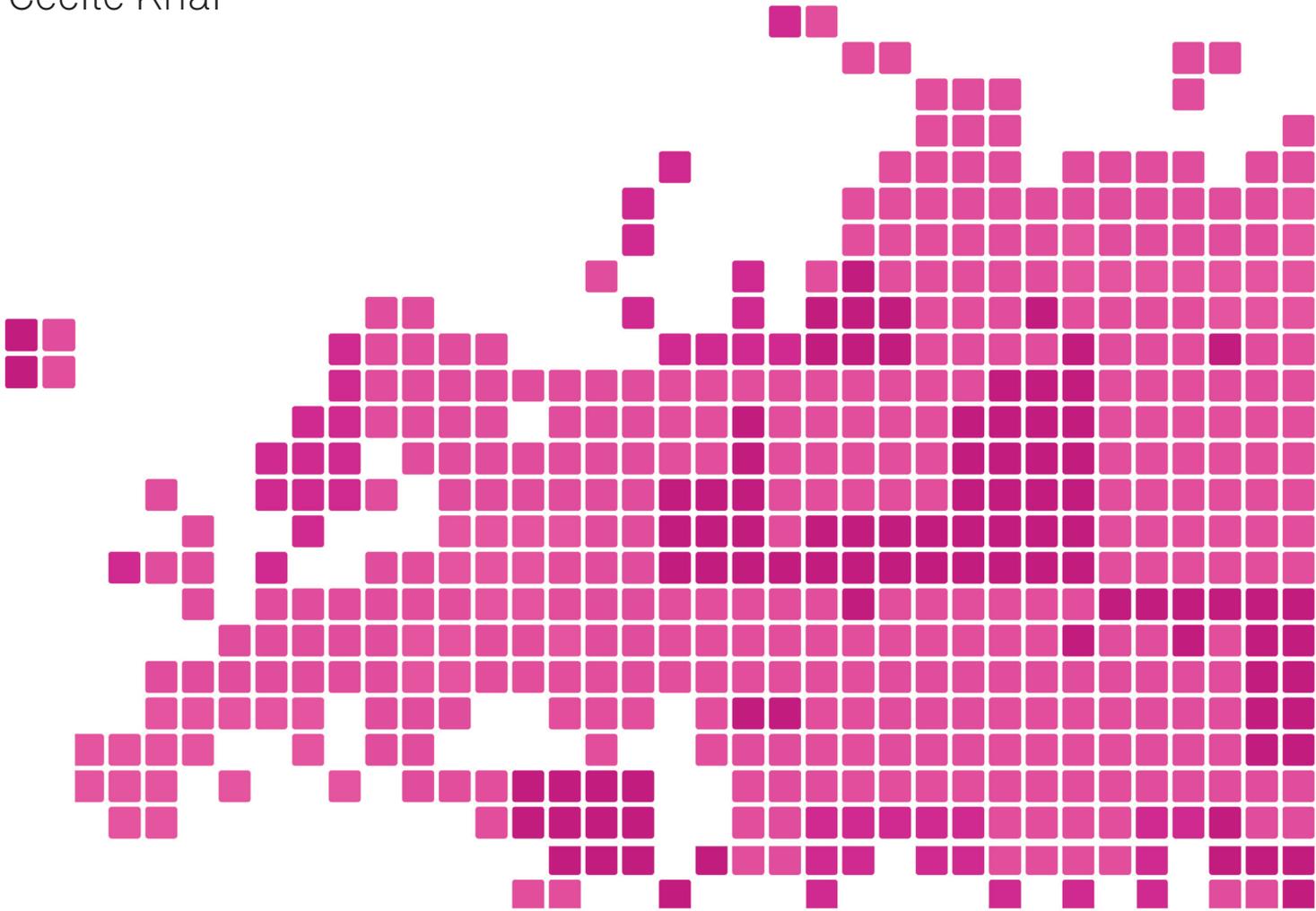


# Assessing chronic disease management in European health systems

## Country reports

Edited by  
Ellen Nolte  
Cécile Knai



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*Edited by:*  
*Ellen Nolte*  
*Cécile Knai*

**Keywords:**

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# List of abbreviations

A&E	Accident and emergency	DBC	Diagnosis treatment combinations ( <i>Diagnose behandel combinaties</i> )
AFSOS	French national association of supportive care in cancer ( <i>l'Association francophone pour les soins oncologiques de support</i> )	DCC	Cancer patient records ( <i>dossier communiquant de cancérologie</i> )
ALD	Long-term disease ( <i>affections de longue durée</i> )	DDKM	Danish Healthcare Quality Programme ( <i>Danske Kvalitetsmodel</i> )
ANCREd	National Association for the Coordination of Diabetes Networks ( <i>Association nationale de coordination des réseaux diabète</i> )	DIEP	Diabetes Interactive Education Programme
ARS	Regional health agencies ( <i>Agence Régionale de Santé</i> )	DISMEVAL	Developing and validating DISease Management EVALuation methods for European health care systems
ASALEE	Health Action by Teams of Self-employed Health Professionals	DMP	Disease management programme
ASL	Local health enterprise ( <i>Azienda Sanitaria Locale</i> )	DNDR	National fund for the development of provider networks ( <i>Dotation Nationale de Développement des Réseaux</i> )
AVOS	Working group preventive medicine Salzburg ( <i>Arbeitskreis Vorsorgemedizin Salzburg</i> )	DRG	Diagnosis-related group
AWBZ	Exceptional Medical Expenses Act ( <i>Algemene Wet Bijzondere Ziektekosten</i> )	EDISSE	Evaluation of Dutch Integrated Stroke Service Experiments
BMI	Body mass index	EHIF	Estonian Health Insurance Fund
CAPI	<i>Contrats d'Amélioration des Paratiques Individuelles</i>	EU	European Union
CBO	Dutch Institute for Healthcare Improvement	FAQSV	Fund for the quality improvement of ambulatory care ( <i>Fonds D'Amélioration De La Qualité Des Soins De Ville</i> )
CCG	Clinical commissioning group	FGÖ	Healthy Austria Fund ( <i>Fonds Gesundes Österreich</i> )
CCIV	Competence Centre for Integrated Care ( <i>Competence Center integrierte Versorgung</i> )	FIQCS	Quality and coordination of care funds ( <i>Fond d'Intervention pour la Qualité et la Coordination des Soins</i> )
CCM	Chronic Care Model	GDP	Gross domestic product
CCO	Care coordination organization	GÖG	Austria Health Corporation ( <i>Gesundheit Österreich GmbH</i> )
CCP	Care coordination pilot programme ( <i>Irányított Betegellátási Rendszer</i> )	GP	General practitioner
COPA	Coordination of Professional Care for the Elderly	HAS	National Authority for Health ( <i>Haute Autorité de Santé</i> )
COPD	Chronic obstructive pulmonary disease	HIF	Health Insurance Fund
CQC	Care Quality Commission	HMO	Health maintenance organization
		IGEA	Integration, Management and Treatment

	for Diabetes (project/strategy) ( <i>Integrazione, Gestione e Assistenza per la Malattia Diabetica</i> )	POPP	Partnerships for Older People Projects
		PRADO	Hospital discharge programme for patients with heart failure
INCa	National Cancer Institute	PSRS	Regional strategic health plans ( <i>plan stratégique régional de santé</i> )
ISS	National Institute of Health ( <i>Istituto Superiore di Sanità</i> )	QOF	Quality and Outcomes Framework
IT	Information technology	RCP	Multidisciplinary team meeting ( <i>Réunion de concertation pluridisciplinaire</i> )
IVS-OÖ	Integrated stroke care Upper Austria ( <i>Integrierte Versorgung Schlaganfall in Oberösterreich</i> )	RHZ	Regional General Practitioners Association ( <i>Regionale Huisartsenzorg</i> )
MIGAC	<i>Missions d'intérêt général et d'aide à la contractualisation</i>	RIVM	National Institute for Public Health and the Environment
MUMC	Maastricht University Medical Centre	ROSP	<i>Rémunération sur les objectifs de santé publique</i>
NHIF	National Health Insurance Fund (Lithuania)	SGB	Social Code Book V ( <i>Sozialgesetzbuch</i> )
NHIFA	National Health Insurance Fund Administration (Hungary)	SHI	Statutory health insurance
NHP	National Health Plan (Estonia)	SIKS	Integrated effort for people living with chronic diseases project
NHS	National Health Service	SSFA	Social Security Financing Act
NICE	National Institute for Health and Care Excellence	SSN	National Health Service (Italy) ( <i>Servizio Sanitario Nazionale</i> )
NSF	National Service Framework	SSI	State Serum Institute
OECD	Organisation for Economic Co-operation and Development	USL	Local health authority ( <i>Unità Sanitaria Locale</i> )
OOP	Out-of-pocket (payment)	VHI	Voluntary health insurance
ÖSG	Austrian National Health Care Plan ( <i>Österreichischer Strukturplan Gesundheit</i> )	Wmo	Social Support Act ( <i>Wet maatschappelijke ondersteuning</i> )
PCT	Primary Care Trust	ZonMw	Netherlands Institute for Health Research and Development
PHE	Public Health England	Zvw	Health Insurance Act ( <i>Zorgverzekeringswet</i> )
PNP	National plan for prevention ( <i>Piano Nazionale della Prevenzione</i> )		

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# Introduction

## 1.1 Introduction

This book presents detailed accounts of the experiences of 12 countries in Europe in their efforts to enhance the care for people with chronic conditions. It accompanies Volume I, which provided a summary overview of the current state of policy thinking across Europe to more effectively address the requirements associated with chronic and long-term conditions (Nolte & Knai, 2014). Both volumes 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). The present volume 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 project (Developing and validating DISease Management EVALuation methods for European health care systems). DISMEVAL was a three-year European collaborative project, conducted between 2009 and 2011, which aimed to contribute to developing new research methods and to generate 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 Summary overview of findings from Volume I

In Volume I we have reviewed the policy context for, and approaches to, chronic disease management in 12 European countries in place during 2009–2011 (and updated to 2014). This showed that 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. While not presenting a comprehensive inventory of all approaches that have been or are being implemented in a given country, and acknowledging new developments that we have been unable to capture during the project, a number of general observations can be made.

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

The most frequently targeted conditions were type 2 diabetes, asthma/chronic obstructive pulmonary disease (COPD), cardiovascular diseases (chronic heart failure, ischaemic heart disease, stroke), cancer, and mental health problems. These conditions are typically targeted by means of structured disease management to enhance coordination, which are 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 nonmedical staff is involved in care delivery. Commonly, the general practitioner (GP) or family physician tends to act as principal provider or ‘care coordinator’.

*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 practice 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.

*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 those 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 Projects (POPP), both in England, or the Improving intersectoral collaboration pilot in Lithuania as examples. The “SIKS” (Integrated effort for people living with chronic diseases) 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.

*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 targeting individual providers or physicians, such as within disease management programmes (DMPs) 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 United Kingdom. Incentives for patients are also being used, but these are less common.

#### *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 so 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.

### 1.3 Methods

#### Conceptualizing chronic disease and chronic disease management

Chronic conditions or chronic health problems have been described in different ways (Nolte & McKee, 2008a). 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 short period, from chronic conditions, which are 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).

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, in its core, on approaches that can be broadly subsumed under the

heading of ‘disease management’, we recognize that definitions of this concept vary widely (Krumholz et al., 2006; Nolte & McKee, 2008b), and we discuss this issue in detail in Volume 1 (Nolte, Knai & Saltman, 2014). In the present volume, we defined disease management as comprising the following components: (a) an integrated approach to care or coordination of care among providers, including physicians, hospitals, laboratories and pharmacies; (b) patient education; and (c) monitoring or collection of patient outcomes data for the early detection of potential complications (Krumholz et al., 2006).

#### Selection of countries

As many countries in Europe are in the process of experimenting with or implementing various approaches to chronic care, the selection of countries for detailed review was of necessity pragmatic. Country selection was guided by three main criteria in order to capture (1) the range of approaches to funding and governing health care across Europe; (2) the range of stages of economic development; and (3) geographical spread across the European Union (EU).

On this basis, 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, McKee & Knai, 2008). However, renewed inclusion was justified as all have developed existing approaches further or have implemented new approaches and can so provide important insights into the factors that have made these developments possible (or indeed hindered further advancement).

All of the countries reviewed in this book 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 systems in Austria, Estonia, France, Germany, Hungary, Lithuania and the Netherlands are primarily funded through statutory social health insurance. Switzerland operates a mandatory private insurance system (Table 1.1).

**Table 1.1** Principles of health care financing in twelve countries in Europe

	Health expenditure (2012)		Main sources of funding for health care
	% GDP	US\$ PPP	(% of total current health expenditure in 2012)
Austria	11.5	5 065	Combination of SHI (40.5) and general taxation (35.0), VHI (4.0), OOP (15.2)
Denmark	11.2	4 720	General taxation (85.5), VHI (1.8), OOP (12.6)
England (United Kingdom)	9.4	3 495	General taxation (82.5), VHI (1.1), OOP (9.9)
Estonia	5.9	1 385	National health insurance (69.1), general taxation (10.8), OOP (18.4)
France	11.7	4 260	SHI (71.0), VHI (13.8), OOP (7.4), general taxation (5.9)
Germany	11.3	4 617	SHI (67.6), general taxation (8.7), VHI (9.5), OOP (12.1)
Hungary	7.8	1 729	SHI (52.3), general taxation (11.4), VHI (2.7), OOP (27.1)
Italy	9.2	3 040	National and regional taxation (78.2), OOP (20.2)
Latvia	6.0	1 188	General taxation (56.7), VHI (2.5), OOP (37.4)
Lithuania	6.7	1 426	SHI (60.1), taxation (10.7), OOP (28.5)
Netherlands	12.4	5 384	SHI (72.6), taxation (7.3), VHI (5.2), OOP (5.6)
Switzerland	11.3	6 062	Mandatory health insurance (43.7), taxation (18.0), VHI (9.4), OOP (28.1)

NOTE: PPP: Purchasing power parity/capita (national currency unit per US\$); GDP: gross domestic product; OOP: household out-of-pocket expenditure;

SHI: statutory health insurance; VHI: voluntary health insurance

SOURCE: WHO, 2014.

### Survey of approaches to chronic disease management

We developed a common template for the collection of data on approaches to chronic disease management in European systems. The development of the template was based on a structured questionnaire used in the framework of a previous study (Nolte, Knai & McKee, 2008) and informed, to a great degree, by the Chronic Care Model (CCM) developed by Wagner and colleagues in the United States (Wagner, 1998). The CCM comprises four interacting components that are considered key to providing high-quality care for those with chronic health problems: self-management support, delivery system design, decision support and clinical information systems. These are set within a health system context that links an appropriately organized delivery system with complementary community resources and policies.

Accordingly, the template sought to gather information on (i) the health system and policy context and (ii) the type and format of approaches to managing chronic disease, examining nature and scope of the four components identified by the CCM as crucial to effective chronic care. The template was amended further to include a third section on the evaluation of existing approaches and a final section exploring system markers of success or failure for organizational approaches to chronic disease management, including an analysis of the strengths, weaknesses, opportunities and threats of the current system context and the critical success factors for chronic disease management in the country under review.

The template used simple checkboxes as well as open-ended questions. Where appropriate and relevant, sections included a glossary of definitions of terms, for example, of approaches to chronic disease management, and guidance for completion, including examples and checklists. A draft template was circulated among partners of the DISMEVAL project to ensure that definitions appropriately reflect different health systems contexts and the overall applicability of the instrument.

Data collection using the finalized template was undertaken by key informants in the countries under review. Of the 12 countries considered for review, six were represented by DISMEVAL project partners (Austria, Denmark, England, France, Germany and the Netherlands) who were invited to complete the template. For countries not represented in DISMEVAL, key informants were identified through existing professional networks of the lead editors, based on an established network of country experts in eight European countries (the International Healthcare Comparisons Network) (Nolte et al., 2008). Key informants thus identified had to demonstrate expertise in the area of chronic disease or an understanding of the health policy and system context of the country in question as shown by relevant publications in the academic literature or roles in relevant governmental advisory bodies.

Project partners and key informants were asked to adopt an evidence-based approach by making use of the best available data, using all relevant sources including ongoing or completed research projects, policy

documents and routine statistics, surveys and census data related to chronic disease. They were further asked to compile data in consultation with organizations involved in the management of chronic disease such as central government departments, health authorities (or their equivalent), arm's-length bodies or subordinate agencies and academic and training organizations. Where appropriate and necessary, additional information was to be gathered through interviews with key stakeholders and reviews of work in progress such as pilot projects, green or white papers, consultation documents, committee reports, parliamentary hearings and proposals.

A number of countries were characterized by a wide range of frequently small-scale approaches at the local or regional level, in some cases conceptualized as pilot studies intended for subsequent rollout to larger geographical areas (examples include Austria, Denmark, Italy and Switzerland). As 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.

Principal data collection was carried out from June 2009 to December 2009. Each completed template formed the basis for a country report with a follow-up to complete missing information and clarify data. Draft country reports were reviewed by the key informant leading template completion for each country in 2011 and again in early 2014 to ensure accuracy and allow for the update of information where necessary and appropriate. Country reports formed the basis of the systematic cross-country comparison presented in Volume I.

#### 1.4 Structure of country reports

Each of the country reports in this book comprises the following four sections:

- (i) Setting the health system context, including a description of the key features of health care governance, organization and financing and

regulatory framework, and the principles of delivery of primary and secondary care. This section also includes a brief review of recent health care reforms of relevance to chronic disease, and a summary overview of current legal, regulatory and policy frameworks for chronic disease.

- (ii) A detailed description of selected approaches to chronic disease management considered to be representative or illustrative for the country under review. This includes a description of key components of each approach, following the elements identified by the CCM to be core to chronic illness care: self-management support, service delivery design, decision support and clinical information systems (Wagner, 1998). The review also includes a summary of financing modes, distribution and uptake of approaches among the population, and an assessment of the evidence of effectiveness of the individual approach.
- (iii) A description of a “typical” patient journey for a hypothetical patient, outlining the pathway to diagnosis, access to specialist care and access to medication and self-management tools, contrasting the journey for “usual care” with structured care or disease management where appropriate. Patient journeys are provided for two hypothetical patients: (a) A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy and is also slightly overweight. She lives on her own, has been unemployed for three years and receives social assistance benefits; and (b) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure who lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing block and are increasingly housebound due to their illness. They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.
- (iv) A concluding section, summarizing key observations and achievements, alongside continued challenges and future perspectives for chronic disease management.

# 2 Austria

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## 2.1 The health care system

The Austrian health care system is largely funded through statutory health insurance (SHI) contributions (2012: 40.5%), complemented by taxation (35.0%), out-of-pocket (OOP) payments (15.2%) and voluntary health insurance (VHI) (4.0%) (WHO, 2014). In 2012, national health expenditure was 11.5% of gross domestic product (GDP). SHI in Austria is granted on the basis of occupation and residence, covering over 99% of the population (Hauptverband der österreichischen Sozialversicherungsträger, 2013). SHI members do not have the option to choose among funds. SHI contributions are calculated on the basis of income (2012: 7.65% of annual gross income) and are shared between employers and employees (50% each). Dependants are covered free of charge while those receiving unemployment benefits are covered by the state. Individuals further contribute to health care through varied forms of co-payments, mainly prescription fees and co-payments for therapeutic products.

The health care system is characterized by Austria's federal structure, with governance shared by the federal and nine state (*Land*) governments and corporatist actors (SHI and health professionals' associations). The federal government is responsible for almost all areas of the system, the only exception is the provision of hospital care, which is delegated to the states, with the federal government setting the overarching framework as per basic law while the states regulate implementation and enforcement (Hofmarcher, 2013). Ambulatory care outside hospital is negotiated between the 19 health insurance funds and the Federation of Austrian Social

Security Institutions (*Hauptverband der österreichischen Sozialversicherungsträger*, HVSV), the Austrian Medical Association (*Österreichische Ärztekammer*) and associations of other health professions.

Health care services are provided by a mix of public and private providers. The delivery of outpatient care is organized in four ‘pillars’: office-based primary and specialist care physicians who typically work in solo practice; outpatient clinics (*Ambulatorien*), operated by social health insurance or private practice; hospital outpatient departments (*Spitalsambulanzen*); and group practices, which were introduced from 2010 (Hofmarcher, 2013). Remuneration of office-based doctors is through a blended system based on fee-for-service payments plus a capitated element for basic services (Mossialos, Allin & Ladurner, 2006). The relative proportion of the two components varies by specialty, with remuneration of highly specialized physicians such as radiologists almost entirely on a fee-for-service basis while GPs’ reimbursement is largely through flat rates per case, basic practice allowances and fees for home visits, with fee-for-services accounting for one-fifth of total reimbursement only (Hofmarcher, 2013).

Patients principally have free choice of any office-based doctor contracted with a SHI fund or they may choose between outpatient clinics and hospital outpatient departments offering outpatient care. There is also the option to consult non-contracted health care providers (*Wahlärzte*), whereby insured people may claim for a refund of up to 80% from their SHI.

Hospitals are owned and operated by a variety of public (regional hospital corporations or SHI: 55%), private for-profit (19%) and private non-profit-making organizations (24%) (2010) (Hofmarcher, 2013). Since 1997, about half of the running costs of hospitals have been covered through activity-based funding, the performance-oriented hospital financing system (*Leistungsorientierte Diagnosefallgruppen*, LKF), a modified version of diagnosis-related groups (DRGs). Capital investment is mainly decided on and financed by the owners and/or hospital operators. Physicians working in hospitals (60% of all Austrian physicians) are salaried employees.

### Health care reforms of relevance to chronic disease

A key defining feature of the Austrian health care system is the large number of actors involved in the

funding or provision of services. In consequence of this fragmentation there is a considerable lack of continuity of care at all levels and a lack of communication between them. However, recent years have seen increased efforts to enhance the effectiveness of decision-making and financing flows across the different sectors. One important move has been the 2005 health reform that aimed at improving the coordination of the planning, control and financing of the entire health care system and which involved a commitment to securing and enhancing the quality of health care (Hofmarcher & Rack, 2006). It recognized the need for the implementation of nationwide standards for chronic care and, in 2006, established health funds in each of Austria’s nine federal states (*Landesgesundheitsfonds*), with state health platforms as their executive agency. This also involved the creation of a financial pool at state level (reform pool) as a means to promote the coordination of and cooperation between ambulatory and hospital care. This cooperation formed part of the legislation of the 15a Federal Constitution agreements and most of current (novel) approaches to chronic care such as structured disease management have evolved from reform pool projects (see below). The reform pool and its projects are funded through the state health funds, with statutory health insurance and the state each contributing about half.

The Federal Health Agency (*Bundesgesundheitsagentur*, BGA) was established in 2005 as a fund under public law and as a separate legal entity. It is responsible for developing the framework for planning health service provision in all sectors; it is also responsible for the management of the interface between various sectors including the reform pool sector. At state level, the state health platforms and health funds mentioned above were established to implement these plans and to monitor trends. Health platforms also undertake joint pilot schemes for the integrated planning, implementation and financing of specialist medical care provided through hospital outpatient care and by office-based doctors, in addition to overseeing resource coordination between health care and long-term care. The latter is regulated within the 1993 national Long-term Care Act. Long-term care is financed through the budget of the federal government, with those requiring long-term care receiving cash benefits depending on their needs (Hofmarcher & Rack, 2006).

The year 2005 also saw the introduction of an e-card to replace the paper-based health insurance voucher as a means to improve continuity of care and efficiency

in the delivery of health care services. The e-card infrastructure links all physicians in Austria electronically and in future should fulfil a variety of purposes such as the establishment of a standardized electronic health record. This was followed by an initiative, in 2007, to establish ambulatory care centres aimed at enhancing the integration of service delivery with a particular view to improving allocative efficiency and of quality of care for those with chronic disease (Eichwalder & Hofmarcher, 2008). However, the proposal was unsuccessful. Only recently has there been a renewed attempt to establish ambulatory care centres as part of a wider policy development that includes agreements between the medical profession and health insurance funds to establish group practices. The 2008–2013 government programme made improving patient access to ambulatory care services a priority as part of an overall move to increase the effectiveness and efficiency of integrated health care services in the Austrian health system (ÖVP, 2008). It also set out plans to develop nationwide health targets in particular regarding myocardial infarction, stroke, cancer, dementia and diabetes. The Federal Act to Strengthen Public Ambulatory Health Care Provision, which came into effect in 2010, introduced multidisciplinary group practices (*Ärzte-GmbHs*) from 2011, which are anticipated to reduce reliance on the hospital sector although their establishment has remained slow (Hofmarcher, 2013).

The most recent 2013 health reform introduced a new approach involving target setting to enhance the steering of the structure, organization and financing of the Austrian health care system (*Gesundheits-Zielsteuerungsgesetz, G-ZG*) (Bundesministerium für Gesundheit (Austria), 2013). This also includes a commitment to investing 3.6% annually into the health care system until 2016. At its core is the creation of so-called “Target Control Commissions” at the federal and state level, which set targets for care provision and financing to ensure the joint planning and oversight of health care delivery. One of the main aims of the reform is to achieve better coordination between the inpatient and the outpatient sectors, and as part of this aim, the federal Target Control Commission recently agreed on a new concept of primary care involving a multiprofessional and interdisciplinary approach (Bundesministerium für Gesundheit (Austria), 2014).

In parallel, the Austrian government also sought to strengthen health promotion, with the 1998 Health Promotion Act becoming the first federal law to make

explicit commitments in this regard. It established the *Fonds Gesundes Österreich* (‘Healthy Austria Fund’; FGÖ), responsible for supporting activities aimed at increasing awareness and knowledge, and for promoting projects and developing structures that promote health. The fund is financed by a proportion of the revenue from value-added tax (Hofmarcher & Rack, 2006). In 2006, the FGÖ became a division of the newly created *Gesundheit Österreich GmbH* (‘Austria Health Corporation’, GÖG) (see below).

### Current legal, regulatory and policy frameworks

During the 2000s, as indicated above, Austria introduced various legal and regulatory measures to strengthen cooperation between the different sectors of the health system although it has yet to develop an overarching integrated national strategy that spans the continuum from health promotion and disease prevention to the management of complex chronic conditions. The reform agenda has seen the introduction of several new structures aimed at supporting the integrated planning and control of the health care system. These include GÖG, established in 2006 as the new national research and planning institute for health care. It integrates the Austrian Federal Institute for Health (*Österreichisches Bundesinstitut für Gesundheitswesen, ÖBIG*), created in 1973, which carries out research and planning activities for the Austrian federal government, and the FGÖ described above. In 2007, GÖG was extended further to also include the newly established Federal Institute for Quality in Health Care (*Bundesinstitut für Qualität im Gesundheitswesen, BIQG*). The expectation was that this arrangement would facilitate improved coordination between structural planning, health promotion and quality assurance activities (Gesundheit Österreich GmbH, 2013).

The 2005 health reform also modified the overall approach to health care planning, leading to the development of the national health care plan (*Österreichischer Strukturplan Gesundheit, ÖSG*), first published in 2006, which replaced the previous Austrian Hospitals and Major Equipment Plan (*ÖKAP/GGP*) (Fazekas et al., 2010). The ÖSG forms the basis for integrated planning in the Austrian health care system (*Österreichisches Bundesinstitut für Gesundheitswesen, 2008*). It defines the basic parameters for detailed plans at the regional level for services offered in acute inpatient care, along with a description of the current structure

of care provision in the non-acute inpatient sector, in the outpatient sector and in the rehabilitation sector, as well as at the interface with long-term care (Hofmarcher & Rack, 2006). Binding structural quality criteria constitute an integral part of the planning statements within the framework of service provision planning.

In 2006, the Federation of Austrian Social Security Institutions established the Competence Centre for Integrated Care (*Competence Center integrierte Versorgung, CCIV*) at the Vienna regional SHI fund (*Wiener Gebietskrankenkasse*) as the focal point and centre for coordination between the insured (particularly patients with chronic diseases), statutory health insurance and contract partners (Wiener Gebietskrankenkasse, 2014). In routine operation since 2008, the CCIV has been involved in the development of structured approaches to disease management, including the nationwide roll-out of the DMP for type 2 diabetes (see below). More recent efforts included the stepwise implementation of a disease management programme for post myocardial infarction from 2010, the development of interdisciplinary guidelines for treatment of chronic diseases and the advancement of integrated care for dementia (Gleichweit & Rossa, 2009).

## 2.2 Approaches to chronic disease management

In Austria, the fragmentation of services across sectors has been viewed as a main barrier towards continuity of care, against a background of population ageing and the rising burden of chronic disease. Thus, structural changes to promote more integrated approaches to care have been a major objective of recent reforms. We here describe five examples of approaches to chronic disease management that have been introduced over the past decade in Austria.

### Disease management programme Therapie Aktiv

The Disease management programme (DMP) for type 2 diabetes *Therapie Aktiv* (active therapy), established in 2006, was devised by the Styrian regional SHI fund. Its development was supported by the Styrian state health platform, SHI and the regional medical association. The DMP represents an adaptation of the DMP for type 2 diabetes developed in Germany. It aims to improve the quality of life and prolong life for people with chronic disease, to place the patient at the centre

of care, to make efficient use of health care resources and reduce hospitalizations (Therapie Aktiv Diabetes im Griff, 2014a). It was implemented in six out of the nine Austrian states: Lower Austria, Upper Austria, Salzburg, Styria, Vienna and Vorarlberg. Three states currently do not provide the programme (Burgenland, Carinthia, Tyrol) although they offer diabetes education (Therapie Aktiv Diabetes im Griff, 2014b). All diabetes DMPs have evolved from reform pool projects established in 2006 and 2007 (Czypionka & Röhrling, 2009).

Participation in *Therapie Aktiv* is voluntary for patients and providers; participation is possible for SHI members with a chronic disease and providers who meet the requirements set out by the programme (Therapie Aktiv Diabetes im Griff, 2014a). Patients wishing to take part have to choose a physician who participates in the programme and who acts as the coordinating physician. The main strategies of the diabetes DMP involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves patient education in the form of group instruction courses. Patients receive support to develop strategies for managing their disease in everyday life, receiving theoretical information about diabetes and practical instructions for carrying out self-monitoring and foot-exercise. Training can be provided by the coordinating physician, a diabetes adviser, diabetes specialists or diabetic training centres within hospitals. Patients are also actively involved in the setting of therapeutic goals (for example, weight loss, exercise, diet, smoking cessation) and timelines, with agreed targets signed jointly. Patients are followed up at regular intervals, usually every three months.
- *Delivery system design* includes the management of the patient through the coordinating physician with conditions for referral between levels of care stipulated by the programme. The coordinating physician is responsible for regular medical supervision including medicines management for co-morbidities (for example, ocular complications, cardiovascular diseases and neuropathy) in line with current practice guidelines, and regular follow-up of the patient.
- *Decision support* involves the use of care pathways developed by the Austrian Diabetes Association (ÖDG). Physicians must participate in mandatory provider training programmes in order to be

accredited as DMP-physicians. In addition, there are annual advanced training sessions and quality circles.

- *Clinical information systems* include the standardized documentation of clinical and diagnostic measures and treatment; nationwide monitoring is planned but regular feedback reports to participating physicians have not yet been established.

The DMP *Therapie Aktiv* and its variants are principally offered and administered by the regional SHI fund. As envisaged by reform pool projects the implementation of the programme has been supported by SHI funds and the states (Czypionka & Röhrling, 2009). As noted, participation is voluntary for physicians and patients. Participating physicians (GPs or specialists in internal medicine) receive reimbursement for structured treatment and adequate documentation at a level negotiated and agreed by the states' medical association and the SHI funds. The level of reimbursement varies among states, although differences are small. There are no specific incentives for patients participating in the programme except that they are given access to education courses and a patient handbook on type 2 diabetes (Therapie Aktiv Diabetes im Griff, 2014c).

As described earlier, the DMP *Therapie Aktiv*, and its variants, have been implemented in most of Austria's states. The number of participating GPs varies by state, ranging, in 2014, from 76 in Vorarlberg to around over 320 in Upper Austria; the total number of participating GPs was just over 1000 (Therapie Aktiv Diabetes im Griff, 2014b). Overall estimates suggests that approximately 39 500 people in Austria are currently enrolled in the DMP *Therapie Aktiv*, representing around 18% of people with type 2 diabetes (Therapie Aktiv Diabetes im Griff, 2014b). Coverage varies by state however; for example, the proportion of diabetes patients enrolled with a diabetes DMP in Lower Austria in 2014 was estimated at 11% compared to almost one-quarter in Upper Austria and Styria.

### Evaluation

In Austria, DMPs have been evaluated in several federal states, using different approaches to evaluation. In Salzburg, the phasing-in of the diabetes DMP *Therapie Aktiv* was evaluated using a cluster-randomized controlled intervention trial (Sönnichsen et al., 2008). It found a decline in HbA1c levels in the intervention group although the improvement was not statistically significant when adjusted for baseline value and cluster

effects (Sönnichsen et al., 2010). There were, however, significant reductions in body mass index (BMI) and cholesterol levels, as well as improvements in a number of process measures such as participation in education and periodic examinations (for example, HbA1c check-up, eye and foot examinations). Improved process measures such as regular testing and examination were also observed for the diabetes DMPs implemented in Lower Austria. Using a before–after design with an external control group, this initiative also demonstrated a reduction in hospital utilization among those enrolled in a DMP (Ruh et al., 2009). A national, long-term evaluation of the DMP for diabetes is under consideration.

### Integrierte Versorgung Schlaganfall Oberösterreich

The concept for *Integrierte Versorgung Schlaganfall in Oberösterreich* ('integrated stroke care Upper Austria', IVS-OÖ) was developed in 2005, by the Austria-based GeniaConsult company, with input from patient representatives, for the state and the regional social health insurance fund of upper Austria. The principal aim was to improve care for patients with stroke, both in relation to acute care and at the interface to rehabilitation (OÖ GKK Forum Gesundheit, 2014). The approach was implemented as a reform pool project, with funding from the Upper Austria health fund until the end of 2010. Similar projects were implemented in Styria and Vienna in 2007 (Czypionka & Röhrling, 2009).

Integrated stroke care, as implemented in Upper Austria (IVS-OÖ), involves a range of caregivers, including GPs, emergency services, acute hospital care and rehabilitation, who form a network to provide integrated treatment and care for stroke patients along the continuum of care. The main focus of the IVS-OÖ is on the managed discharge of patients with stroke; the main strategies involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* is mainly limited to information provided to patients, through stroke awareness campaigns involving mass media such as newspapers and radio, specifically designed brochures distributed to patients in GP practices and hospitals, and a dedicated password-protected website. Awareness is also raised through a series of lectures in communities and at organizations of

retired people, who act as potential multipliers of relevant information.

- *Delivery system design* includes the development of integrated care pathways for stroke patients. Hospitals act as key partners with regard to discharge-management and after-care; however, the overall coordination of the various partners responsible for transport, diagnosis, therapy, after care, rehabilitation and follow-up is carried out by GPs (Forum Gesundheit, 2014).
- *Decision support* involves the use of practice guidelines such as a stroke checklist for GPs, as developed by GP working groups. The development of integrated care pathways was based on evidence-based guidelines.
- *Clinical information systems* include the implementation of a common ‘data warehouse’ which compiles information on stroke patients collected by organizations participating in IVS-OÖ (emergency services, hospitals, rehabilitation centres, SHI), using a standardized documentation form. Pseudo-anonymized data are compiled and analysed by the regional SHI fund Upper Austria. Data are fed back to providers as a means to monitor and improve processes and outcomes.

Until the end of 2010, the IVS-OÖ received equal funding from the Upper Austria health fund and the regional SHI fund; it has since been transferred into routine care. It brings together all 16 hospitals providing acute stroke care in Upper Austria, medical emergency services provided by the Red Cross and Samaritans across the region, three rehabilitation centres and the ambulatory rehabilitation services of the regional SHI fund, as well as the regional physicians’ chamber (OÖ GKK Forum Gesundheit, 2014).

There are no published data on the number of stroke patients who have benefited from the programme so far.

### Evaluation

The reform pool project to integrate stroke care in Upper Austria has been formally evaluated by the University of Linz. The evaluation comprised an outcome evaluation and also assessed process quality. The outcome evaluation was based on hospital discharge data including inpatient mortality and admission to stroke units. Initial findings pointed to a non-significant fall in in-hospital mortality among stroke patients (a reduction from 11.8% in 2007

to 11.7% in 2009) (Rechnungshof, 2012), an increase in admissions to stroke units and an improvement in the quality of data-coding as relates to admissions. However, there was no discernible evidence of a change in the average length of hospital stay. Age and multimorbidity were shown to be important determinants for treatment success. Main influencing parameters in the in-hospital setting were the accomplishment of thrombolysis and the number of complications.

Process evaluation was carried out through interviews with providers relating to training, interface management, and changes since project implementation. The project was perceived as an opportunity to improve interdisciplinary teamwork. The final results of the evaluation have not been made available publicly.

An assessment by the Austrian Court of Audit, which considered the period 2008–2010, concluded that the IVS-OÖ had achieved notable improvements in stroke services; it had made it possible to provide an overview of the entire stroke pathway and data collection and reporting based in the data led to an improvement in the quality of care (Rechnungshof, 2012). The total costs of the project were estimated at €2.1 million for the period 2005–2010, of which half were staff costs while approximately €500 000 were spent on information technology (IT).

### Care coordination/Interface management, Styria

Projects on care coordination (*Versorgungskoordination*) as implemented in the Austrian context generally refer to the management of the interface between different sectors (*Nahtstellenmanagement* or *Schnittstellenmanagement*), and most frequently to the managed discharge of patients from hospital to their own homes, community care or nursing home (*Entlassungsmanagement*) (Ninaus-Meznik, 2009). In Styria, in the early 2000s, the regional SHI fund (*Steiermärkische Gebietskrankenkasse*, StGKK) implemented the Hartberg district pilot project designed to improve the continuity of care following discharge from hospital through the use of a care coordinator (Gspurning, 2005). This approach was subsequently extended across Styria (*Steiermärkische Gebietskrankenkasse*, 2004), with the city of Graz implementing interface management using care coordinators (*Nahtstellenmanagement im Großraum Graz*) as a reform pool project in 2009 (Gesundheitsfonds Steiermark, 2010).

The key feature of care coordination as developed by the Styria regional SHI fund was the use of a dedicated care coordinator who visits patients (and if necessary also their carers) in the hospital and offers support relating to discharge. This approach involved key elements of self-management support and delivery system design.

- *Self-management support* involved the active engagement of patients and their carers, in collaboration with the care manager, in planning the discharge and subsequent care arrangements including rehabilitation. The support included information and practical assistance with devices and services such as wheelchairs and meals on wheels.
- *Delivery system design* included the coordinated management of the discharge of patients from hospital to their homes, community services or nursing homes via the care coordinator, who acted as key contact for patients, hospital and the patient's GP. This element involved regular meetings between the coordinator and providers outside hospital.
- *Decision support* involved the use of a checklist to identify patients requiring support by a care manager. In Graz, risk identification was performed using the Blaylock Risk Assessment Screen (BRASS) index (Ninaus-Meznik, 2009; Gesundheitsfonds Steiermark, 2010).

The programme did not involve use of a dedicated clinical information system.

In Styria, care coordinators were based at the regional SHI fund that provided financial support for the overall programme. There were six care coordinators who provided support services to 22 hospitals. The interface management programme in Graz was discontinued as a reform pool project in 2009 with plans to transfer the approach into usual care in due course (Gesundheitsfonds Steiermark, 2010). Patients identified as being in need of a care coordinator for discharge support can use this service free of charge; uptake of the service was voluntary and not conditional on the type of SHI affiliation. There are no published data on the number of patients covered by the programme.

### Evaluation

The care coordination programme in Styria has not been formally evaluated. However, in 2008, the regional SHI

fund undertook a retrospective survey of participating providers (GPs, nurses and physicians working in hospitals) to identify gaps in interface management (Steiermärkische Gebietskrankenkasse, 2009a; Steiermärkische Gebietskrankenkasse 2009b). Awareness of the programme was found to be high among providers (ranging from 77% among GPs to 97% among nurses), as was the interest in cross-sectoral networking meetings (around 80%). The main shortcomings were perceived by respondents to include the delay in receiving medical information following discharge (GPs), waiting times for post-discharge services such as rehabilitation and unplanned short-term discharge (hospital physicians, nurses), and the reluctance of patients' carers or nurses to take on responsibilities.

### Ambulatory after-care of stroke patients in Salzburg

The Salzburg programme of ambulatory after-care for stroke patients (*Ambulante Nachbehandlung von Schlaganfallpatienten*) was initiated in 1989 by the government of the Land Salzburg. The approach was newly developed as a means to facilitate access to specialized ambulatory care for stroke patients, enabling timely rehabilitation and reducing hospital costs through early discharge (AVOS Prävention und Gesundheitsförderung, 2014a).

The key feature of the programme is the coordinated provision of outpatient rehabilitation services (physio-, occupational and speech therapy) to patients with stroke in the districts of Land Salzburg. It includes elements of self-management support, delivery system design and decision support (AVOS Prävention und Gesundheitsförderung, 2014a).

- *Self-management support* involves access to a team of occupational therapists, speech therapists and physiotherapists in one-to-one and group settings with the latter incorporating activities such as trips to a museum and handicraft workshops to engage stroke sufferers in social activities. Patients are also provided with additional information through educational events such as lectures on living with stroke.
- *Delivery system design* includes a team of therapists (*Neurorehabilitationsteam*, 'neuro-rehabilitation' team) with a senior therapist and a physician in each district acting as programme lead. The physician's

involvement is on a voluntary basis. Regular team meetings and meetings of project leaders are aimed at coordinating the work of participating health care professionals.

- *Decision support* involves continuing education and the training of therapists. Therapists also have access to monthly group supervision meetings as a means to support their work.

The programme does not involve the use of a dedicated clinical information system.

The Salzburg programme of ambulatory after-care for stroke patients is largely funded by Salzburg Health Fund (*Salzburger Gesundheitsfonds, SAGES*), which provides about 95% of the total budget (€750 000 in 2013) (AVOS Prävention und Gesundheitsförderung, 2014a). Patients can access services only upon referral by a physician, hospital or rehabilitation centre and for a period of three months initially. The services provided within the programme are free of charge and can be accessed in dedicated premises or as home visits. In the latter case, patients are asked to contribute a deductible of €10 for each visit unless they are exempted from prescription fees or receive social assistance. In 2013, the neuro-rehabilitation team comprised 17 therapists providing physical (29%), occupational (28%) and speech therapy (21%) plus 20% group therapy sessions to nearly 430 patients, with approximately 60% of sessions delivered as home visits (AVOS Prävention und Gesundheitsförderung, 2014a).

Services are available across Salzburg and are accessible to patients with stroke in all six districts in Salzburg.

### Evaluation

The Salzburg programme of ambulatory after-care for stroke patients has not been evaluated formally. However, Salzburg Health Fund, as the main funder of the programme, receives regular reports on provider and patient statistics along with a financial report.

### KardioMobil Home care for chronic heart failure patients in Salzburg

The *KardioMobil – Heimbetreuung für Herzinsuffizienz-PatientInnen* ('home care for patients with chronic heart failure') was implemented in 2004, initially as a pilot project in the districts of Salzburg city and Flachgau. In 2008, it was extended to cover all of Land Salzburg

(Kardiomobil, 2007). *KardioMobil* was developed on initiative of a cardiologist at the Salzburg university hospital (*Salzburger Landeskliniken*), in collaboration with the working group preventive medicine Salzburg (AVOS). Its main objective is to support patients with chronic heart failure by enhancing disease self-management, reducing complications and hospital readmissions and improving the quality of life.

*KardioMobil* as implemented in Salzburg brings together a range of providers, including hospitals (departments of internal medicine/cardiology; chronic heart failure outpatient services), home care services provided by the Red Cross and office-based physicians. The key feature of the programme is the use of specialist nurses who provide self-management support for chronic heart failure patients in their homes; the programme further includes elements of delivery system design and decision support (AVOS Prävention und Gesundheitsförderung, 2014b).

- *Self-management support* as the key programme component involves access to a specialist nurse who provides education about the disease and instruction in self-monitoring (blood pressure, heart rate, weight) and on handling emergency situations. It also includes a follow-up assessment of patient self-management competences and needs.
- *Delivery system design* includes supporting patients with chronic heart failure in accordance with a defined protocol of three home visits by a trained nurse involving patient education and training. The nurse acts as the key point of contact for patients and coordinates care in collaboration with the patient's GP and the specialist outpatient clinic.
- *Decision support* involves continuing education for *KardioMobil* nurses on aspects of medication, including quality assurance, communication with clinicians and IT.
- *Clinical information systems* are not yet an integral part of the programme; however, there are plans to implement an electronic information system that allows the sharing of patient data within the programme.

Nurses participating in the programme receive specialist training, involving a foundation training course funded by the Red Cross Salzburg and annual refresher courses provided by the Salzburg university hospital or chronic heart failure outpatient service.

Since 2007, *KardioMobil* has been co-funded by the Land Salzburg (64% in 2013) and the regional SHI fund (36% in 2013) (the total budget in 2013 was €84 000) (AVOS Prävention und Gesundheitsförderung, 2014b). The *KardioMobil* programme comprises four Red Cross specialist nurses providing services in four districts across Land Salzburg. They are supervised by a lead nurse based at the Salzburg University hospital who looks after chronic heart failure patients in the city of Salzburg and surrounding area. Patients access the service upon referral by participating hospitals; recruitment into the programme is mostly through outpatient departments for chronic heart failure patients. Subsequent care within *KardioMobil* is coordinated by AVOS.

The services provided within the programme are free of charge and accessible to all residents in the Land Salzburg although dependent on referral by a cooperating hospital as noted above. In 2013 the service cared for 186 heart failure patients (AVOS Prävention und Gesundheitsförderung, 2014b).

### Evaluation

The Salzburg *KardioMobil* has not yet been evaluated formally although an evaluation is planned; the observational design is likely to focus on quality of care provided, efficiency and patient adherence. The Salzburg Health Fund receives regular reports on provider and patient statistics along with a financial report.

## 2.3 A patient journey

This section describes the journey of two hypothetical typical patients with co-morbid chronic disease and their likelihood of participating in structured programmes in the Austrian health care system.

*(A) A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is slightly overweight (BMI of 27). She has been unemployed for three years and receives social assistance benefits; she lives on her own.*

The patient consults her GP because of her leg ulcer; during the course of the medical examination (physical status and laboratory tests), her diabetes will be diagnosed and the line of treatment and medication determined. Prescription medicines require a co-payment of €5.40 per prescribed drug (Österreichische Apothekerkammer, 2014). The leg ulcer is treated by a dermatological

outpatient department or by the GP. Treatment at home with regular visits by mobile nurses is also available. She will be referred to an ophthalmologist because of early signs of retinopathy, with follow-up appointments provided, in line with the guidelines issued by the Austrian Diabetes Association.

The patient's smoking history and history of dyspnoea will prompt chest X-rays and spirometry testing. Based on the suspected diagnosis of chronic obstructive lung disease she is referred to a pulmonologist. All consultations and diagnostic tests are covered by her health insurance. If the patient lived in a city or was of higher economic status, she would probably have consulted a specialist directly. If her GP participates in the *Therapie Aktiv DMP*, she is likely to be invited to enrol into the programme.

*(B) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure. He lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing block and are increasingly housebound due to their illness. They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.*

The diagnosis of chronic heart failure is likely to have been established during an episode of inpatient care at a department for internal medicine (or cardiology) following referral by the family's GP in response to the first episode of acute left-heart failure based on hypertensive cardiomyopathy. The patient would be prescribed antihypertensive medication. Blood pressure will be controlled by the GP during home visits. To enable self-monitoring of blood pressure, the GP will further prescribe a blood pressure measurement device, which the patient may be asked to help pay for unless he is exempted from prescription charges. If the patient resides in Land Salzburg, the outpatient department that diagnosed his chronic heart failure might refer him to the *KardioMobil* programme.

Although the couple is being supported by their grandson, they are likely to qualify for further formal support because the wife's arthritis limits her ability to care for her husband. Depending on the level of care required they will receive cash benefits in line with the federal long-term care act. In 2014, payments ranged from €154.20 (per month) for Grade 1 support, defined as the need for more than 60 hours care per month, to €1655.80 for Grade 7, if the patient is immobile and requires 24/7 care

(Bundeskanzleramt Österreich, 2014). Depending on the grade, the GP will arrange for home visits. Home care varies between states, and is not generally coordinated.

## 2.4 Summary and conclusion

In Austria, while the health care system in place tends to continue to emphasize curative, episodic care, there have been a number of policy initiatives and reform activities in recent years to better address the challenge of chronic disease. The most important move has perhaps been the 2005 health reform, which aimed at improving coordination of planning, control and financing of the entire health care system, with the 2008–2013 governmental programme reiterating the need to develop the structure for case management and for outpatient and inpatient rehabilitation. One of the main targets of the most recent health care reform of 2013 is to strengthen the coordination between the inpatient and outpatient sectors, with primary care to be placed at the core, supported by multiprofessional and interdisciplinary cooperation.

Many of the ongoing activities were facilitated through the reform pool mechanism at the federal state level,

with the majority of current approaches to chronic care such as structured disease management having evolved from reform pool projects. Yet, evidence of the impact of overall reform pool activities has been mixed. Importantly, related projects have been slow to take off mainly because of a lack of financial incentives for physicians to participate in such projects. Limited federal oversight of the reform pool funds and projects might have led to duplication of effort, with uneven implementation across regions. For example, by the late 2000s, of all funds available, only 16% had been put to use, but this did vary greatly by region with over 30% used in Styria and only 1.5% in Tyrol (Czypionka & Röhrling, 2009).

A recent assessment of the Austrian health system concluded that although concerted efforts have been made to shift care away from hospital into the ambulatory care sector, progress has been slow and care coordination across providers requires further strengthening (Hofmarcher, 2013). There is an identified need to re-focus efforts on strengthening primary care (Stigler et al., 2013), which has been recognized and taken up in the most recent health reform of 2013.

# 3 Denmark

*Anne Frølich, Ramune Jacobsen, Cécile Knai*

## 3.1 The health care system

Denmark is a small country with fairly autonomous local governments, consisting of 5 regions and 98 municipalities. The Danish health care sector is financed through taxation, accounting for 85.5% (2012) of health expenditure, complemented by OOP payments (12.6%) and a small contribution of VHI (1.8%) (WHO, 2014). In 2012, the national health expenditure was 11.2% of GDP. More than 80% of the health budget is financed by the state through a combination of block grants and activity-based funding (Olejaz et al., 2012). The municipalities are financed through centrally collected, locally set income taxes and block grants from the state; the regions receive funding from the state and the municipalities, which co-finance regional hospital services for their respective populations.

The Danish health system is governed by a combination of national institutions, regions and municipalities. The Ministry of Health (*Ministeriet for Sundhed og Forebyggelse*, MIH) provides the overall regulatory framework for the health sector as it relates to organizing and financing health care. The Danish Health and Medicines Authority (*Sundhedsstyrelsen*; established in 2012 as a merger between the National Board of Health and the Danish Medicines Agency) is responsible for the licensing and monitoring of medicines, the general supervision of health personnel, and health service planning (Danish Health and Medicines Authority, 2013a); it also undertakes important tasks in developing quality management (Vrangbæk, 2013).

A major structural reform implemented in 2007 changed the administrative landscape of Denmark through the creation of larger municipalities and regions, with the 2005 Health Act defining the division of responsibilities between regions and municipalities (Olejaz et al., 2012). The five regions own and operate hospitals, and they finance self-employed GPs and other health professionals in independent practice, mainly on a fee-for-service basis (Vrangbæk, 2013). Reimbursement levels for private practitioners and salaries for employed health professionals are agreed through negotiations between the Danish Regions, which represents the regions at national level, and the different professional associations. The regions are also, in collaboration with the municipalities, responsible for the development of overall strategies for the preventions and treatment of chronic conditions, including disease management programmes (DMPs).

The municipalities are responsible for disease prevention and health promotion, rehabilitation, social psychiatry and other types of care not directly related to hospital inpatient care. Social services delivered by the municipalities include the care of older, disabled or chronically ill people, as well as support for mentally ill people, either in their homes or in community mental health care centres. Municipalities are represented at the national level by the National Association of Local Authorities.

The 2005 Health Act also established a system of mandatory health care agreements between regional and municipal councils. These health care agreements must adhere to centrally defined requirements and joint service goals, reviewed and accepted by the Danish Health and Medicines Authority (Vrangbæk, 2013). They cover a range of procedures including the discharge of vulnerable and older patients, social services for people with mental disorders, and prevention and rehabilitation initiatives.

Primary health care is provided by GPs in private practice. Patients register with a GP in their local area and access is free at the point of use. GPs act as the gatekeepers to secondary care, provided by specialists in hospital or private settings. Patients may access specialist services without referral, but they must then make a co-payment. Co-payments are also required for pharmaceuticals, and for dental and some other services, such as physiotherapy (Olejaz et al., 2012). Regions fund public hospitals through a combination of global budgets and activity-based funding using DRGs (Ettelt & Nolte, 2010). Private hospitals receive public funding from the

regions for providing services under the extended choice programme. This funding is usually based on fee-for-services, with the fees agreed through negotiations between private hospitals and the regions (with some earlier agreements also using a fixed percentage of the payment per DRG).

### Health care reforms of relevance to chronic disease

The 2007 structural reform of the Danish administrative system and associated changes formulated in the 2005 Health Act mentioned above have had an important impact on how health care is provided in Denmark. Improving care coordination and quality of care was an important driver behind this reform (Olejaz et al., 2012). The reform envisioned an emphasis on chronic conditions as a ‘new focus’ area for the Danish health care system. This was to some extent supported by several comparative studies undertaken during 2007–2011 between the Danish health care system and Kaiser Permanente in the United States of America (Frølich et al. 2008; Frølich, et al., 2010a; Strandberg-Larsen et al., 2010). It involved the reallocation of responsibilities in the health care sector to five newly established regions (replacing the previous 14 county councils) and 98 municipalities (created from the former 275) (Olejaz et al., 2012). As noted above, 80% of regional health care activities are financed by the state through a combination of block grants and activity-based funding. The remaining public financing for regional health care activities comes from municipal contributions, which are paid as a combination of per capita contributions and activity-based payments related to the use of services by residents of the municipality. The idea behind municipal co-financing was to encourage municipalities to increase preventative services so as to reduce hospitalization (Vrangbæk & Sorensen, 2013).

The reform further introduced mandatory health care agreements between municipalities and regions to promote coordination across municipal care services, primary care and hospital care (Vrangbæk, 2013). As noted above, agreements include a number of mandatory topics related to admission and discharge from hospitals, rehabilitation, prevention, psychiatric care and IT support systems; they are formalized at least once in each four-year election term for municipal and regional councils, and must be approved by the Danish Health and Medicines Authority. The performance of regions and municipalities in reaching the targets as outlined in

the agreements is measured by national indicators, which are made available to the public through the website 'e-health' (*Esundhed*), which is operated by the Danish State Serum Institute (*Esundhed*, 2014).

Also in 2007, the government and the Danish Regions agreed on the implementation of mandatory integrated cancer pathways, which were passed as part of the 2008 budget agreements (see below) (Olejaz et al., 2012). In 2009, the Danish Healthcare Quality Programme (*Danske Kvalitetsmodel*, DDKM) was established. It is developed, planned, and managed by the Danish Institute for Quality and Accreditation in Healthcare (*Institut for Kvalitet og Akkreditering i Sundhedsvæsenet*, IKAS). DDKM is based on the principle of accreditation and standards (organizational standards, standards related to care coordination, and disease-specific standards, such as treatment guidelines); it further includes monitoring of quality of care in primary and secondary care (Olejaz et al., 2012).

### Current legal, regulatory and policy frameworks

A range of policies and strategies are specifically aimed at organizing approaches to chronic disease management in Denmark (Frølich et al., 2008; Schiøtz, Frølich & Krasnik, 2008). The 2002 government-endorsed national strategy *Healthy throughout life – the targets and strategies for public health policy of the Government of Denmark 2002–2010* placed a special focus on efforts to reduce the major preventable diseases and disorders, in particular type 2 diabetes, preventable cancer, cardiovascular diseases, osteoporosis, musculoskeletal disorders, hypersensitivity disorders (asthma and allergy), mental disorders and COPD (Danish Ministry of the Interior and Health 2003). As part of the *Healthy throughout life* policy, the National Board of Health (Danish Health and Medicines Authority from 2012) subsequently initiated a project on major preventable diseases and disorders, which aimed to develop and strengthen systematic efforts to prevent the eight diseases and disease groups, while systematically integrating disease prevention and health promotion within Denmark's health care system (Danish National Board of Health, 2004). It identified nine sub-projects covering activities along the continuum of care, ranging from prevention and early detection to management of risk factors and rehabilitation, targeting a variety of chronic conditions, as well as promoting patient education and intersectoral efforts involving the health care system (Schiøtz, Frølich

& Krasnik, 2008). The National Board of Health was responsible for facilitating, initiating, coordinating and providing documentation through this programme (Danish National Board of Health, 2004). These efforts were followed, in 2005, by *Chronic conditions – patients, health care and community* which set out options for improving care for those with chronic conditions (Frølich, Strandberg-Larsen & Schiøtz, 2008). The 2007 report *Chronic disease management – a national strategy. disease management programmes and self-management support* built on this work and proposed recommendations to develop and implement DMPs (Danish National Board of Health, 2007). The five regions accepted the recommendations and established working groups with health care professionals and administrators to develop and implement the programmes described below. Moreover, in accordance with the 2009 budget agreement, the government allocated DKK 585 million over the period 2010–2012 for the development and implementation of regional DMPs and patient education and self-management programmes (Danish Health and Medicines Authority, 2014a).

## 3.2 Approaches to chronic disease management

The following section describes selected national, regional and local initiatives which illustrate the directions taken in Denmark in response to the rising burden of chronic disease.

### The SIKS project

The SIKS or 'Integrated effort for people living with chronic diseases' project was initially run from April 2005 to September 2007 in the Østerbro health care centre and Bispebjerg Hospital in Copenhagen, and was funded by the Ministry of Interior and Health (Frølich et al., 2010b). It focused on the implementation of rehabilitation programmes for chronic conditions requiring close collaboration between the health care centre, local hospital and GPs to support the local population. Patients taking part in the project had to have one or more chronic conditions, including cardiovascular diseases (chronic heart failure and ischaemic heart disease), COPD, type 2 diabetes, and balance problems in elderly people following falls.

The main strategies of the SIKS project involved elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involved active patient involvement in developing their own individualized treatment plans and setting rehabilitation goals. Needs were assessed by a health professional at entering the project to plan and prepare the rehabilitation process in cooperation with the patient. Services could include physical training interventions, on an individual basis or as group sessions. At completion, goal achievement was reviewed and new maintenance goals set; patients were also informed about opportunities available through relevant networks, organizations and centres. Patients who participated in education sessions run by nurses also received oral and written information to support their decision-making.
- *Delivery system design* included a multidisciplinary team to support the delivery of rehabilitation, comprising a specialist nurse with competences in patient education, medical specialists (for hospital based rehabilitation), physiotherapists and dieticians. The location for the rehabilitation depended on the severity of the disease, as defined through agreed risk stratification criteria. The health care centre and the hospital rehabilitation units were designed to offer various non-pharmacological services to people with chronic conditions. Standard packages of rehabilitation included disease specific education and patient self-management sessions, a physical training session, nutritional consultation sessions and smoking cessation programmes. The programmes lasted 7–12 weeks depending on the specific disease. Patients were followed up upon completion of the programme.
- *Decision support* involved clinical guidelines on physical training, patient education, smoking cessation, dietary modification and the follow-up programme, based on evidence-based national and international guidelines and reviewed by managers and clinicians (specialists and GPs) for acceptability in the local context. It further included monthly teaching programmes for health care staff and developed by the same working groups; these included educational courses on personal, professional, pedagogical and care-specific (for example, physiotherapy, nursing, nutrition counselling) competences. Intra-organizational

knowledge-sharing meetings for health care staff from the hospital and health care centre were held three times a year.

- *Clinical information systems* included the monitoring of practice team performance defined and assessed in terms of process and outcomes indicators. Data on individual patient diagnoses, utilization (for example, attended sessions, referrals, professionals involved in this course), physical function, laboratory test results and quality of life assessments were collected at the beginning and upon completion of the programme. The IT system for the municipality (the City of Copenhagen), was the *Sundhedsportalen* or e-health portal. Bispebjerg Hospital operated its own database.

Services provided within the SIKS project involved three principal providers: hospitals, health care centres and general practices. Access to the programme was through referral by a GP or specialist, with the relevant rehabilitation programme delivered within the community health care centre or the hospital. Throughout the duration of the SIKS project (2005–2007), 90% of the 57 GPs practising in Østerbro referred patients to the hospital or to the health care centre for rehabilitation. The project involved 700 patients with chronic conditions. The local area covers a population of 64 000 adult residents.

Although the project ended, the approaches and the methods used in SIKS and developed through a collaboration of working groups that included representatives from Bispebjerg Hospital, the Østerbro health care centre and local GPs were implemented in Bispebjerg Hospital and Østerbro health care centre (Østerbro area of the City of Copenhagen) as rehabilitation programmes for the range of chronic conditions described above. Key elements and approaches tested in SIKS have been taken up by the City of Copenhagen and its hospitals (Vadstrup et al., 2009; Vadstrup et al., 2011). For instance, Nørrebro health care centre implemented this approach in 2007 in the Nørrebro area of the City of Copenhagen. Gradually, the rehabilitation programmes introduced by the SIKS became a part of DMPs for COPD, type 2 diabetes and cardiovascular diseases in the Capital Region of Denmark (see below).

Following the 2007 reform, rehabilitation programmes for the chronically ill were financed from usual resources.

The SIKS project received further support through additional grants from the Ministry of Health.

### Evaluation

An evaluation of the initial SIKS project was carried out in 2007–2008 by project staff and externally by the National Institute of Public Health. Approximately DKK 300 000 was allocated to finance the external evaluation. The focus of the evaluation was on patient and provider satisfaction, including clinical outcomes as well as some economic aspects for all four chronic conditions. Data were collected on demographic characteristics, including age, sex, medical diagnosis; general clinical measures, such as blood pressure, BMI, waistline; disease-specific measures, such as HbA1c and lipid levels, physical functioning; quality of life measures and disease specific life quality questionnaires; and measures of resources use, such as inpatient care, specialist consultation, prescription drugs, time off work. Data were collected at baseline and at the end of the programme, and the findings were reported in peer-reviewed publications (Borg et al., 2008; Frølich et al., 2010a). The project was also evaluated within the framework of a randomized controlled study, which assessed the impact of the diabetes programme on patients receiving rehabilitation in hospital as compared with those receiving an intervention in the health care centre (Vadstrup et al., 2011).

### Regional disease management programmes

The five regions of Denmark developed disease management programmes (DMPs), working from an initial programme template developed by a working group at the National Board of Health in 2008. Each region in Denmark is responsible for the development of its own DMP in the expectation that regional DMPs will operate with each other in addressing most common chronic conditions, so that all patients with a chronic condition are covered by a specific DMP and receive the health services and provisions described in the programme.

The main strategies of the DMPs involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* refers to patient education and self-management training including information about the disease, medical management and

recognition of signs and symptoms of complications; as well as practical instruction in disease management techniques, nutrition and diet, and exercise. Patients should be offered individual or group educational sessions and written material, and should be directed to Internet-based information. It is recommended that patients be involved in developing in their treatment plans and setting goals in collaboration with health professionals. This process should include the consideration of cognitive, behavioural and emotional targets, expectations, motivations and resources, with an agreed timeline and methods for evaluation of the above mentioned targets. Patient needs should be regularly assessed, with a follow-up system customized to patient needs.

- *Delivery system design* defines the roles and tasks of providers, including GPs, and hospital and health professionals in the municipalities. Patients are to be stratified according to disease severity. Individualized integrated care plans, which describe the collaboration between general practice, hospital and community services, are developed. The plan identifies the principal care coordinator, usually the patient's GP, who oversees coordination of the providers involved in care delivery, and is responsible for follow-up and regularly assessing the patient's needs. For patients with advanced disease, the coordination function can be shared between the GP and the specialist physician, while complex cases should be offered extended support through a dedicated disease management coordinator. The role of a coordinator is new in Danish health care and has yet to be defined.
- *Decision support* refers to clinical guidelines developed by a working group, comprising clinicians representing different sectors (municipality, hospital, general practice) and professionals (specialists, nurses, physiotherapists, dieticians) supervised by the region. The guidelines are based on national and international clinical guidelines. DMPs also require health care staff to be trained in relevant disciplines of chronic disease, importance of lifestyle intervention, self-management support tools, and competences such as pedagogical skills, theories about learning and change processes, and motivation techniques.
- *Clinical information systems* are considered key in the care of patients with chronic disease; the DMPs expect data-sharing between organizations,

requiring compatibility of information systems, internally within as well as between organizations. There is a need to establish registers to record diagnoses, clinical parameters, co-morbidities, and disease stratification. DMPs also recommend the use of automatic reminders for patients and health professionals. The Capital region is establishing a cross-sectoral database recording performance measures associated with rehabilitation programmes (process measures, quality of life, baseline clinical data) in the municipalities, the hospitals and from GPs that refer patients to the programmes.

DMPs describe how the performance of practice teams concerned with patient care in the hospital sector should be monitored, principally using the Danish Quality Model (DDKM), which introduced standards for hospital accreditation from 2009 and reporting to the National Indicator Project (NIP). Fully implemented DMPs will be required to meet disease specific standards. Accreditation standards for municipal health care and for general practice are set and are being implemented (Vrangbæk, 2013).

The Ministry of Health allocated a pool of DKK 585 million over the period 2010–2012 for the development and implementation of regional DMPs (DKK 438 million) and for patient education and self-management programmes (DKK 128 million) (Danish Health and Medicines Authority, 2014a). The plan was to distribute two-thirds of these funds to a region and one-third to municipalities, allocated in proportion to the population. Each region applied for its share of the funding with specific project descriptions and budgets that support the overall goals of the ministry. The Danish Health and Medicines Authority oversaw the approval of projects in each of the regions and the results of the programmes are published on its website (Danish Health and Medicines Authority 2014b).

The development of DMPs in each region follows the generic model proposed by the National Board of Health for working groups under regional supervision. The actual content of regional DMPs is likely to differ, but the differences are not essential. Progress has varied, with for example, the Capital Region of Denmark having developed and approved DMPs for diabetes and COPD, dementia and cardiovascular diseases and for musculoskeletal disorders. DMPs for COPD and type 2 diabetes were implemented in 2010. So far, the programmes cover only a part of the Capital

Region population but are expected to cover all the targeted patients. The Central Denmark Region has developed and approved DMPs for diabetes, COPD and cardiovascular diseases, for depression and low back pain; while the Region of Southern Denmark developed and started implementing DMPs for diabetes, COPD, cardiovascular diseases, musculoskeletal disorders and cancer. The Sealand Region developed DMPs for diabetes, COPD, cardiovascular diseases, musculoskeletal disorders and schizophrenia.

### *Evaluation*

DMPs will be evaluated in terms of the performance of the delivered health care, utilization, and clinical outcomes of care. The purpose of evaluation will be to determine whether the programmes are producing the intended results on how well the treatment process functions. Results will not be generalized to other chronic diseases beyond for those for which DMPs were designed. The evaluation will be aimed at patients, health care professionals, hospital and the municipalities that own and operate the health care centres, as well as the regional consultative committees comprising representatives from the regions, municipalities and private practices and the leadership of the regions.

Assessment will be conducted by health professionals involved in DMP implementation and performance. Routine data will be used for general purpose, while specific data will be collected for specialized areas, such as rehabilitation programmes.

Routine data includes general information assessed and reported to the National Indicator Project and data from the *Landspatientregisteret*. Specific measures assessing outcomes of rehabilitation programmes will include results of physical functioning tests; specific clinical measures such as spirometric measures for COPD patients, HbA1c, lipid profile, eye test and foot inspection performed; and quality of life. The Capital region has developed an assessment and monitoring model for their DMP. The model evaluates and monitors changes in the total population of people with chronic conditions, and changes in each condition on forth-yearly basis. Health care delivered by hospitals, municipalities and general practice will be assessed to ascertain the quality of health care, patient satisfaction and quality of life, as well as utilization patterns.

### Integrated clinical pathways

In 2007, the Danish government, regions, and municipalities committed to developing integrated clinical pathways for heart disease and cancer patients, based on relevant clinical guidelines. This was partly driven by problems in quality of care and long waiting lists for patients with these conditions. The process included an 'Agreement regarding treatment objectives, sending a clear message to cancer patients', signed in October 2007 by the government and Danish Regions, and which involved the setting up of a task force for cancer patients. In December 2008, the Task Force for Cancer was extended to cover aspects of heart disease and changed its name to the Task Force for Cancer and Heart Patients. The task force, comprised of clinical working groups with representatives from the Danish Health and Medicines Authority, health professionals at the regional level, relevant medical clinical associations, GPs and specialists, and, by the end of 2008, had developed integrated clinical pathways for 34 types of cancer and four heart diseases (Vrangbæk, 2013). The overall aim of the pathways is to ensure fast track through all stages of care.

The main strategies of the integrated clinical pathways for cancer and heart diseases include components of delivery system design and decision support.

- *Delivery system design* involves a clear definition of the roles of medical specialties and their responsibilities. A multidisciplinary team, usually comprising the GP and a range of specialists, develop an individualized care plan supported by a care coordinator, who ensures effective communication and coordination between the different units involved and regularly assesses the patient's needs and problems. The region must determine the organization of regular coordination of care. Follow-up depends on the disease but is generally carried out by GPs within the ambulatory part of the programme.
- *Decision support* includes the use of national clinical guidelines to inform the development of integrated clinical pathways.
- *Decision support* also refers to the national clinical guidelines that inform the development of individual care plans.

Integrated clinical pathways for heart disease are expected to cover approximately 40 000 patients per year with

cardiovascular diseases; of those approximately 2500 patients have chronic heart failure and 20 000 ischaemic heart disease. The integrated clinical pathways for cancer aim to cover all cancer patients. The implementation of clinical pathways for specific cancer started in October 2008 and those for heart diseases in January 2010.

The Danish Health and Medicines Authority monitors the pathways and the speed by which patients are diagnosed and treated; it is also gradually developing such guidelines for all major disease types (Danish Health and Medicines Authority, 2013b). The DDKM's standards enforce the use of pathway programmes and national clinical guidelines, where available (Vrangbæk, 2013).

### Evaluation

Process evaluations of integrated clinical pathways are conducted internally, by the Danish Regions, and aim to establish monitoring points to follow up a process. Regarding the latter, the State Serum Institute (SSI) has taken on the role of a coordinator for national administrative registers from the Danish Health and Medicines Authority from 2012, and it has established specific codes for the registration of relevant monitoring points in the integrated clinical pathways for cancer. Submission of these codes to the SSI by the Danish hospitals is mandatory from October 2012. Relevant codes were also established for integrated clinical pathways for heart diseases, and submission of these became mandatory from July 2013.

A pilot project was also conducted at the Århus Hospital colon, rectum and anal cancer surgery department; this project constituted a randomized controlled trial evaluating the role of the case manager in optimizing integrated clinical pathways (Wulff, 2010).

### 3.3 A patient journey

This section describes the journey of two hypothetical typical patients with co-morbid chronic disease and their likelihood of participating in structured programmes in the Danish health care system.

*(A) A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is slightly overweight (BMI of 27). She has been unemployed for three years and receives social assistance benefits; she lives on her own.*

In the Danish health care system, patients are not screened for diabetes and therefore the patient may go undiagnosed for a long time. The patient will typically be diagnosed by her GP. According to new guidelines for COPD, smokers and ex-smokers above 35 years of age who have one or more pulmonary symptoms should be examined by their GPs. This means that the patient will probably be diagnosed with COPD before being diagnosed with diabetes. After diagnosis of COPD, the severity of the disease will be assessed and follow-up carried out regularly by her GP. The aim of this regular follow-up is to support the patient in lifestyle changes and prevent the progression of the disease. Once type 2 diabetes is diagnosed, the GP will evaluate the patient's complications, risk factors and lifestyle, knowledge, attitude and resources. Based on disease severity and the resources of the patient, the GP will decide whether to take on the patient's case or to refer her to a diabetes outpatient clinic, health care centre (although there are only a few available in Denmark) and/or educational sessions. The GP will also refer the patient to an ophthalmologist and to a privately practising dermatologist if the leg ulcer is severe or does not heal. Several regions in Denmark have shared care agreement between general practice and diabetes outpatient clinics. After the initial treatment phase, there will again be follow-up for the patient in the general practice or at the diabetes outpatient clinic (or both) every third month. Based on an overall assessment of her activity level and disease severity, the patient will be offered a personalized rehabilitation programme. This might include a smoking cessation course, prescribed exercise at a fitness centre, diet counselling, patient education for COPD and psychosocial support. The family network will be assessed to strengthen the patient's social network and the patient will probably be referred to a social worker. The social worker can help the patient obtain necessary equipment and assess her employment opportunities. Since the patient is unemployed and receives social assistance, her medication costs will be partially refunded by the municipality.

*(B) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure. He lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing block and are increasingly housebound due to their illness. They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.*

The patient will typically be diagnosed either by his GP (acute episode) or in the course of acute hospitalization. After having his conditions diagnosed he may be regularly checked by his GP or, if his conditions become worse or more difficult for the GP to manage, referred to the hospital outpatient clinic. The patient's heart problem may prompt a referral for rehabilitation that includes a disease-specific teaching programme, a physical exercise programme, smoking cessation if needed and a dietician's advice where appropriate. The GP will typically provide the patient with a prescription for his medicine, and will monitor its effectiveness to ensure a good regulation of the patient's chronic conditions. The GP may also ask the patient and his wife to contact their municipality to receive home assistance; this could include home nurse to ensure that they receive their daily medicine.

### 3.4 Summary and conclusion

The aim of Danish policy on chronic care, building from the Chronic Care Model (CCM) (Frølich et al., 2008), is to improve care for people living with chronic conditions in a cost-efficient way. The National Board of Health (Danish Health and Medicines Authority from 2012), supported by the Ministry of Health, has taken the leadership in bringing the policy ideas forward, principally supported by the regional authorities who hold the main responsibility for implementation.

The emphasis is on the core elements of the CCM (Wagner, 1998), including patient self-management support; delivery system design; use of decision support tools such as guidelines and DMPs, community participation; and expanded use of health information technology. Primary care is to be developed as the basis for the provision of continuum of services, with regional coordinators, use of non-financial and financial incentives, interdisciplinary health care teams and GPs in a coordinating role as the key elements. Other components include case management for those with complex needs; risk stratification, registration and monitoring; structured disease management; and community participation involving local authorities, patient associations and voluntary organizations to support chronic care and self-management.

It is difficult to predict whether the implementation of a policy direction informed by the CCM will become successful in the Danish health care system. Political commitment as evidenced by the government's financial

support to municipalities and regions to develop and implement DMPs at the regional level may give cause for cautious optimism to that end. At the same time, scepticism as to the success of the future direction is a

frequent occurrence, most often expressed by individual GPs and other providers (Schjøtz, Frølich & Krasnik, 2008).

# 4 England

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## 4.1 The health care system

Health care in England<sup>1</sup> is primarily organized and delivered through the National Health Service (NHS), which was founded in 1948 (Boyle, 2011). Services provided through the NHS are funded through general taxation (2012: 82.5% in the United Kingdom), complemented by OOP payments (12.6%) and VHI (1.8%) (WHO, 2014). In 2012, national health expenditure in the United Kingdom as a whole was 9.4% of GDP. The NHS covers all residents, and health services are free at the point of use (with some exceptions such as prescription drugs and dental care for certain groups of the population) (Boyle, 2011).

The Department of Health is the central government body principally responsible for setting policy for the health and social care system in England. Following the 2012 Health and Social Care Act, the specific roles and responsibilities of the Department have changed, away from direct responsibility for the delivery of the NHS to one that provides strategic direction and acts as steward for the health and care system, develops national policies and provides leadership (Department of Health, 2013a). Responsibility for the delivery of the NHS and care services has shifted to a newly established organization, NHS England (known as 'NHS Commissioning Board' until March 2013) (Department of Health, 2012a). NHS England is an executive non-departmental body; it has a wide range of statutory duties and is accountable to the secretary of state and the public (NHS England, 2014a).

<sup>1</sup> This responsibility for health care in the United Kingdom is devolved to England, Scotland, Northern Ireland and Wales. This chapter focuses on the health care system in England.

Most of the NHS commissioning budget is managed by 211 clinical commissioning groups (CCGs), that is, groups of general practices, which come together in each area to commission health care services for their communities (Checkland et al. 2013). Services commissioned by CCGs include urgent and emergency care, elective hospital care, community health services, mental health services, maternity, newborn babies' and children's health care services, among others (NHS Commissioning Board, 2012). The commissioning of some specialized services, primary care, offender health care and some services for the armed forces is the responsibility of NHS England (NHS England, 2014a). Public health services are commissioned by the newly established Public Health England (PHE) and local authorities, while NHS England commissions, on behalf of PHE, many of the public health services delivered by the NHS.

The provision of NHS care is mainly through GPs, who are the first contact point for primary care, and by salaried doctors and nurses in public hospitals (NHS trusts and NHS foundation trusts) providing secondary and tertiary care (Boyle, 2011). GPs act as gatekeepers for secondary and specialist care services. Some publicly financed care is also provided by private and voluntary providers. In the hospital sector, the creation of foundation trusts has led to greater financial and managerial autonomy of selected NHS hospitals. There is an expectation that all NHS trusts will become foundation trusts within the forthcoming three to five years (NHS Providers, 2014).

Governance of the health and care system in England is supported by a range of arm's-length bodies, in addition to NHS England and PHE, and which have assumed a range of key regulatory and quality assurance functions. Among these are the Care Quality Commission (CQC), which is the independent regulator of health and adult social care providers in England (Care Quality Commission, 2013); the National Institute for Health and Care Excellence (NICE), which produces evidence-based guidance and advice for providers and commissioners, develops quality standards and performance metrics, and provides information services across the spectrum of health and social care (NICE, 2014); and Monitor, the sector regulator for health care, which oversees NHS foundation trusts, and, from 2014, independent (i.e. private) health care providers (Monitor, 2014).

### Health care reforms of relevance to chronic disease

Health care reforms over the past 20 years have focused on the creation of a market within the NHS, starting with the introduction of an 'internal' market in 1991, which separated the purchasing function from the provision of care. The reform introduced, among other things, GP fundholding, enabling GP practices to purchase elective care on behalf of their patients (Mays, Mulligan & Goodwin, 2000). GP fundholding was abolished under the 1999 Health Act, although the principle of a purchaser-provider split was maintained by introducing into the English NHS primary care trusts (PCTs), which assumed payer responsibilities. This was accompanied by substantial investments under the 2000 NHS Plan, along with the introduction of national standards and targets and the strengthening of inspection and regulation, and which was to be supported by newly created national bodies such as the aforementioned National Institute for Health and Clinical Excellence (National Institute for Health and Care Excellence (NICE) from 2012) and the Commission for Health Improvement (Care Quality Commission (CQC) from 2009) (Department of Health, 2000).

Further reforms saw the introduction of patient choice of hospital, provider incentives through payment reform and the admission of private providers into the NHS (Department of Health, 2002; Stevens, 2004). These provisions were strengthened by the 2004 NHS Improvement Plan, which introduced GP-practice based commissioning (Department of Health, 2004a). The 2004 plan also explicitly placed the care for those with chronic conditions at the centre of (successive) government reform, by committing to invest in services closer to home provided by specialist nurses and GPs with special expertise and requiring all PCTs to implement case management by 2008. The 2009 Health Act introduced the NHS Constitution, which set out rights and responsibilities for NHS patients and providers (for example, access, privacy, dignity, choice). It also introduced provisions to enable the piloting of direct payments for health care, within a broader personal health budget pilot scheme for those with long-term needs including the chronically ill.

The aforementioned 2012 Health and Social Care Act constitutes the latest set of reforms, which introduced considerable changes to the NHS while expanding further on existing features, such as the further

integration between health and social care services and extending patient choice. It abolished PCTs and transferred responsibility of most health care purchasing to clinical commissioning groups while public health responsibility was transferred to local authorities, supported by PHE. Other changes included the strengthening of patient and public involvement through the creation of Healthwatch England at the national level (set up as a statutory committee of the CQC) alongside local Healthwatch organizations, which are funded by and accountable to the public through local authorities (Healthwatch, 2014). Newly established health and well-being boards bring together local authorities, clinical commissioning groups, local Healthwatch, public health, social care and children's services leaders to assess the health and care services needs of the local population to ensure collaboration of services and seamless care for the community (Department of Health, 2012b).

### Current legal, regulatory and policy frameworks

The need to better address chronic diseases has been recognized from the late 1990s, with various policies implemented since. For example, from 1999, the government began introducing National Service Frameworks (NSFs), which provide national guidelines for service delivery by setting quality standards and specifying services that should be made available for a given condition or patient group across the NHS (McKee & Nolte, 2004). Initially, implementation was not legally required; however, standards set by NSFs were gradually made binding on NHS organizations and formed part of the standards set by successive annual operating frameworks. NSFs have been developed for a range of chronic conditions and service areas including diabetes, coronary heart disease, cancer care, mental health services and, in 2005, long-term conditions, which focuses on independent living; care planning and access to services; and joint working across all agencies and disciplines involved in care (Department of Health, 2005a).

Subsequent developments built on the NSFs, including the 2004 NHS Improvement Plan mentioned earlier and the 2005 NHS and Social Care model which set out a comprehensive strategy for improving the care of those with chronic conditions (Department of Health, 2005b). It integrated the population management (or pyramid of care) model applied by Kaiser Permanente in the United States and the CCM developed by Ed Wagner as well as

ongoing policy initiatives in England (de Silva & Fahey, 2008). Updated in 2009, the model was to form the basis of all subsequent chronic care strategies and related policy.

Also in 2004, the national GP contract introduced a new voluntary payment programme that linked up to 25% of practice income to performance. This pay-for-performance scheme, better known as the Quality and Outcomes Framework (QOF), has been viewed as an important component of efforts to improve the care for people with chronic conditions in England and the United Kingdom more widely as it applies across the United Kingdom (see also below) (House of Commons Committee of Public Accounts, 2008).

Alongside these developments, the 2006 White Paper 'Our health, our care, our say' presented a vision for more responsive care, committing, among other things, the then PCTs and local authorities to have in place joint teams to care for those complex needs by 2008 and for each person with chronic conditions to have a care plan by 2010 (Department of Health, 2006a), a commitment reiterated in the 2008 NHS Next Stage Review (Department of Health, 2008). The White Paper also pledged to investing further in structured self-management support through the Expert Patients Programme, committing to treble investment into the programme from a capacity of 12 000 course places a year to over 100 000 by 2012 (Department of Health, 2006a). In 2008, the government launched the Whole Systems Demonstrators programme, a randomized control trial of telehealth and telecare across three sites in England to support people to self-manage their condition (Department of Health, 2011). Early trial findings informed the '3 million lives' initiative (subsequently: Technology Enabled Care Services (TECS) programme), which seeks to accelerate the use of assistive technologies in the NHS (NHS England, 2014b).

Recent developments include the formation of a 'National Collaboration for Integrated Care and Support', which brought together 13 national stakeholders, including the Department of Health, NHS England, PHE, CQC, NICE, the Local Government Association, and Monitor, among others, who signed up to a series of commitments on how they will support local areas in delivering integrated care and support as set out in 'Integrated Care and Support: Our Shared Commitment', published in 2013 (National Collaboration for Integrated Care and Support, 2013). Part of that commitment includes supporting a programme of 'integrated care

pioneers', which involved the appointment, in 2013, of 14 local areas that were expected 'to act as exemplars', demonstrating innovative approaches to the delivery of person-centred and coordinated care across the local health, public health and care and support system (Department of Health, 2012c). To support integrated care further, the government subsequently also announced the introduction of a 'Better Care Fund' from 2015, with an allocated pooled budget of £3.8 billion for health and social care services, to be shared between the NHS and local authorities (NHS England, 2013).

In parallel, the government also sought to strengthen health promotion and disease prevention to address the wider causes of ill health, including risk factors for chronic disease such as smoking, diet and physical exercise, outlined the 1999 and 2004 public health White Papers (Department of Health, 1999; Department of Health, 2004b). More recently, the 'Living Well For Longer' strategy (2014) set out the actions taken across national and local level to reduce premature avoidable mortality across the pathway from primary prevention through to treatment (Department of Health, 2014).

## 4.2 Approaches to chronic disease management

The preceding section illustrated the range of initiatives initiated in England to better address the needs of those with chronic health problems. Many of these developments have occurred within a wider framework of improving the overall quality of care delivered to patients (Doran & Roland, 2010). Furthermore, as highlighted above, the NHS has undergone considerable change since 2012. We here illustrate a small number of approaches that have been implemented over the past decade or so, while acknowledging that several have not continued, or are being taken forward in a different format because of the ongoing NHS transformation.

### Nurse-led case management ('community matron')

Nurse-led care approaches in primary care have a comparatively long tradition in the United Kingdom's health care system, dating back to the early 1990s when, under the General Medical Services contract, GPs were beginning to be reimbursed for providing chronic disease clinics and other services such as immunizations, triggering a rapid expansion in the

number of practice nurses to become involved in some form of chronic disease management (Sibbald, 2008). Informed by these experiences and by models developed elsewhere, in particular the Evercare case management model developed in the United States for people at high risk of deterioration in their health, the 2004 NHS Improvement Plan sought to strengthen the role of nurses in the management of patients with complex needs by introducing the role of the 'community matron' (Department of Health, 2004a). This was conceived as a specialized, senior nursing role undertaking intensive, home-based case management for older people at risk of hospitalization and other high-intensity service users, and which was expected to lead to fewer (emergency) admissions and, ultimately, reduced health care costs. The approach was initially piloted in nine PCTs in England from April 2003 ('Evercare pilot programme') (UnitedHealth Europe, 2005), but the community matron policy was rolled out before the conclusion of the pilot programme, with a target set to reduce emergency bed days by 5% by 2008 (Department of Health, 2004a).

The key feature of the community matron role is case management led by a senior or advanced practice nurse of persons with complex needs. The main strategies of this approach involve elements of self-management support and delivery system design (de Silva & Fahey, 2008).

- *Self-management support* involves patient education and active patient involvement in developing care plans and goal setting. It further includes regular assessment and documentation of self-management needs and activities.
- *Delivery system design* includes clearly defined roles in the form of the community matron (or equivalent case manager role), which includes care and case management through liaising with the patient's GP and other providers. It usually also involves case finding and risk stratification through the use of standardized risk assessment tools.
- *Decision support* includes the use of care pathways and clinical guidelines as well as training of nurses within national competence frameworks and guidance.
- *Clinical information systems* may involve use of risk stratification tools to identify patients at risk of re-hospitalization.

The 2004 NHS Improvement plan foresaw the employment of over 3000 community matrons by 2008 (Department of Health, 2004a). Community matrons were most often employed directly by PCTs and, as their use was endorsed by the then government, all NHS patients in need of case management support should have had access to these services. However, according to the workforce census, a total of 1654 community matrons were in place by September 2009, and by 2013, this number had fallen to 1454 (Health and Social Care Information Centre, 2013a). It has been argued that this figure might present an underestimate as the community matron role is likely being recorded within other occupational groups and taking into account the number of case managers not formally designated as community matron, in 2007, their total number was estimated to be in excess of 3000 posts (House of Commons, 2008). Indeed, evaluations have pointed to some confusion about the designation assigned to those who case manage people with complex and long-term health needs, with the notion of 'community matron' frequently used interchangeably with case manager (Lillyman, Saxon & Treml, 2009).

It is difficult to assess the role community matrons play in the NHS following the 2012 NHS reform. As noted earlier, the 2012 reform abolished PCTs, which had been the primary employer of community matrons. Currently, community matrons are typically employed by community provider services (NHS Careers, 2014), and a recently announced government 'new vision and service model for district nursing' foresees for district nurses to work with community specialist nurses including community matrons to deliver specialist care including palliative and end-of-life care (Department of Health, 2012d, 2013b).

### *Evaluation*

To date there has not been a formal national evaluation of community matron services as such. An independent evaluation of the Evercare pilots, which preceded the community matron policy, found that the case management of frail elderly people introduced an additional range of services into primary care, thereby increasing access to and quality of care (Boaden et al., 2006). However, it also demonstrated that there was no significant impact of the intervention on rates of emergency admissions for those at high risk for hospitalization (Gravelle et al., 2007).

### **Case management in primary care**

It is worth noting that case management has resumed renewed attention in the context of the GP contract. The 2013/14 GP contract introduced a new enhanced service 'risk profiling and care management', which promotes the use of risk stratification tools for identifying and managing patients who are chronically ill or who are at high risk of emergency hospital admission (NHS Commissioning Board, 2013). This was subsequently replaced by a new 'unplanned admissions' enhanced service as part of the 2014/15 GP contract, which, in a move to reduce unnecessary emergency admissions to secondary care, also includes the proactive case management of at-risk patients. It requires that at least 2% of the patient population of the practice aged 18 years and older will be covered by this scheme ('case management register') (BMA, 2014). The agreement stipulates that practices:

- provide identified vulnerable patients who have urgent queries with same-day telephone consultations or with follow-up arrangements;
- provide timely access to accident and emergency (A&E) clinicians, ambulance staff and care and nursing homes to support decisions relating to hospital admissions and transfer to hospital;
- produce personalized care plans (with a named accountable GP) for patients on the case management register following a national template and to review care plans regularly as clinically necessary. The care plan should also identify a care co-coordinator (if different to the named accountable GP) as the main point of contact for the patient and who will be responsible for ensuring that the agreed care plan is being delivered, and to inform the patient or their carer of any changes;
- ensure that patients identified as vulnerable are contacted by an appropriate person following discharge from hospital. Practices are also required to review emergency admissions and A&E attendances of their patients from care and nursing homes; and
- undertake regular reviews of all unplanned admissions and readmissions for vulnerable patients to identify factors which could have avoided the admission.

The enhanced service is funded through reallocation of points within the QOF (see below).

## The Quality and Outcomes Framework

The Quality and Outcomes Framework (QOF) was implemented with the 2004 national GP contract. It introduced a new voluntary payment programme that linked up to 25% of GP practice income to performance (Doran & Roland, 2010), which is considered the most ambitious pay-for-performance scheme in the world. The scheme was part of a wider government programme of initiatives to increase the quality of care delivered by the NHS, and the new contract specifically aimed to make the GP profession more attractive, to reduce the wide variation in payments to practices, to fairly link reward to workload and to help reduce health inequalities.

The contract constitutes an agreement with the general practice rather than the individual physician. It involves the 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; this proportion is typically between 40% and 90% (National Audit Office, 2008). Primarily a financing scheme that ties payment to performance, it features a set of key strategies, including delivery system design, decision support and clinical information systems.

- *Delivery system design* will vary at practice level but may include regular staff meetings, patient follow-up (usually by phone or post), and medicines management.
- *Decision support* includes the use of clinical guidelines as well as training of practice nurses on the basis of individual learning plans.
- *Clinical information systems* include an automated mechanism for the collection of data for the clinical quality indicators from GP electronic medical records, including disease registration and performance monitoring, through a national IT system, the Quality Management Analysis System (QMAS). Data extracts are accessible to the Health and Social Care Information Centre to support the publication of QOF information (Health and Social Care Information Centre, 2013b).

There have been several updates to the QOF since the original 2004 contract, successively including or redefining a wider range of indicators. For example, in 2009/10, there were over 130 quality indicators in four domains: clinical, organizational, patient experience and additional services (BMA & NHS Employers, 2009).

The 2012/13 QOF measured achievement against 148 indicators in the same four principal domains (Health and Social Care Information Centre, 2013b). The 2013/2014 QOF modified the domains into clinical, patient experience, public health (including an ‘additional services’ sub-domain), and a ‘quality and productivity’ domain (Box 4.1). The most recent 2014/15 framework has sought to reduce QOF by retiring and amending a substantial number of indicators, and the ‘quality and productivity’ domain was removed and instead to be used to fund the ‘unplanned admissions’ enhanced service as described above (BMA, 2014).

The payment scheme is voluntary for GP practices and patients join it by virtue of being registered with a given practice participating in the scheme. When introduced in 2004, the scheme applied to across the United Kingdom and most practices had joined. From April 2013, for the first time since its introduction in 2004, the QOF was different between England and the devolved administrations (NHS Employers, BMA General Practitioners Committee & NHS England, 2014). The scheme currently covers over 8000 GP practices with over 54 million registered patients in England (Health and Social Care Information Centre, 2013b).

### Box 4.1: Domains in the 2013/2014 QOF

The 2013/2014 QOF for England comprised a clinical domain, a public health domain, a quality and productivity domain and a patient experience domain (NHS Employers, 2013). The clinical domain included over 90 indicators across 20 clinical areas: atrial fibrillation, secondary prevention of coronary heart disease, heart failure, hypertension, peripheral arterial disease, stroke and transient ischaemic attacks, diabetes mellitus, hypothyroidism, asthma, COPD, dementia, depression, mental health, cancer, chronic kidney disease, epilepsy, learning disabilities, osteoporosis, rheumatoid arthritis and palliative care. Each area is typically covered by two to three indicators, with a larger number for diabetes (16) and mental health (10). The public health domain comprised 18 indicators across eight areas, including primary prevention of coronary heart disease, blood pressure, obesity, smoking, cervical screening, child health surveillance, maternity services and contraception. The newly introduced quality and productivity domain included nine indicators, such as review of specialist referrals, the number of emergency admissions, the implementation of care pathways, among others. The fourth patient experience domain included one indicator, which seeks to ensure a minimum patient consultation time with the doctor. The ‘organizational domain’ of earlier versions of the QOF was discontinued.

### Evaluation

There has been a large and continuously evolving number of academic evaluations of the QOF involving multiple (observational) designs, including longitudinal time series (Campbell et al., 2007, 2009), analyses of routine data sets (Doran et al., 2008), qualitative designs based on interviews with GPs (Roland et al., 2006) and ethnographic studies (McDonald et al., 2007; Grant et al., 2009). There have been no evaluations using an experimental design (Steel & Willems, 2010). The implementation of the QOF across the United Kingdom has meant that there is no natural control population with which to compare achievements (Gillam & Steel, 2013).

Some of the key observations included that the QOF scheme led to rapid and universal adoption of electronic records by GPs, since payments were dependent on data extracted from electronic records. Practices employed more staff, especially nurses and administrative staff, and proactive care for major chronic diseases such as diabetes and asthma were increasingly provided by nurses working in disease-focused clinics within their GP practices. The scheme led to an increase in the rate of quality improvement of clinical care for major chronic diseases; however, this occurred against a background of care that was already improving rapidly and within two years of the introduction of the scheme, the rate of improvement had reached a plateau (Campbell et al., 2009). There has been criticism in the United Kingdom that the indicators were set at too 'easy' a level, while at the same time the scheme has also had an effect in reducing inequalities in the delivery of primary care (Doran et al., 2008). One recent systematic review of existing research on the QOF noted that while there was evidence of modest improvements in the quality of care for chronic diseases covered by the framework, its impacts on costs, professional behaviour and patient experience had remained uncertain (Gillam, Siriwardena & Steel, 2012). A further review also noted that the QOF has had limited impact on improving health outcomes, which the authors attributed to the framework's focus on process-based indicators and the indicators' ceiling thresholds (Langdown & Peckham, 2014). In a summary assessment, Gillam and Steel (2013) further highlighted the QOF's emphasis on single diseases, and although it is possible within the framework to account for 'simple co-morbidity', it was considered to be less suitable to manage the needs of people with multiple conditions (Gillam & Steel, 2013).

### Partnerships for Older People Projects

The Department of Health's Social Care, Local Government and Care Partnerships Directorate led the 'Partnerships for Older People Projects' (POPP) from 2005 to 2010 as a means to encourage provision of person-centred and integrated services for older people, to encourage investment in care approaches that promote health, well-being and independence and to prevent or delay the need for higher intensity or institutional care (Department of Health, 2006b). POPP comprised 29 local authority-run pilot sites throughout England, with the first round of 19 sites starting in May 2006. POPP were intended to test ways of shifting resources and culture away from the focus on intensive and institutionalized care towards preventative and locally focused care approaches, integrating the health and social care sectors (Windle et al., 2009).

Projects varied in their use of elements of self-management support, delivery system design and clinical information systems.

- *Self-management support* included the involvement of older people in the development, running and evaluation of each of the projects and so better meet the needs of the target populations. Some project strategies involved peer support, including the promotion of the Expert Patients Programme but also broader health and well-being advice from other older people. Others used staff and volunteers acting as 'navigators' to help older people through the health, social care and other statutory agency network, as well as monitoring current services (Department of Health, 2006b).
- *Delivery system design* involved the development of community-based multi-agency teams, including rapid response services to reduce use of emergency services. One site (Leeds) developed a psychiatry liaison service, which consisted of a multidisciplinary team of psychiatrists, psychiatric nurses, an occupational therapist and health support workers, with administrative support. Multiple projects made use of designated roles, such as community matrons and case workers.
- *Clinical information systems* involved the introduction of integrated IT systems between primary and secondary care, and in some cases between primary and social or community care. Some other projects made use of telehealth technology and case finding software.

POPP was supported by a major grant by the Department of Health of a total of £60 million over the period 2006–2008. This was specifically targeted at local authority-led partnerships to develop pilot projects for older people. Participation was further incentivized by means of becoming a designated POPP pilot site and the opportunity to enter into partnerships with local independent sector organizations. Following completion of the pilot period, 85% of POPP projects secured funding to continue in some form, in many cases funded through the local PCT (Windle et al., 2009).

Altogether, 522 organizations were involved with projects across the POPP programme, including NHS organizations, such as PCTs, hospitals and ambulance trusts as well as organizations outside the NHS such as the fire service, police and housing associations; national and local voluntary organizations; and private sector organizations. The programme covered around 264 000 older people over the three years, with particularly heavy use in the third year. A number of projects within POPP were sustained beyond completion of the pilot phase.

### Evaluation

There have been multiple independent, academic evaluations of various local POPP; a national evaluation was carried out by a partnership of the Personal Social Services Research Unit (PSSRU) (Windle et al. 2009). The evaluation focused on analysing process and outcome measures such as health service utilization, cost–effectiveness and quality of life, along with project implementation aspects. It found that POPP pilot sites had a demonstrable effect on reducing hospital emergency bed-day use when compared with usual care. It also found tentative evidence of cost-effectiveness for sites where data was available (11 out of 29). Users of POPP services generally reported improvements in overall quality of life, and health-related quality of life was reported to have improved in several domains including mobility, activities of daily living, pain and anxiety. The evaluation findings further pointed to an association between POPP programmes and a wider culture of change within their localities.

### Integrated care pilots

In recognition of rising concern of health and social care needs created by an ageing population, the Department of Health, in 2008, made further funding available to support health care organizations, on a pilot basis, to

implement innovative approaches to providing better integrated care (Department of Health, 2009). This led to the establishment of 16 integrated care pilots, operating from 2009 over a period of two years. The set aims for pilots included to improve the quality of care and outcomes for their target populations, to enhance partnerships in care provision and to make more efficient use of scarce resources, among others.

As one of the overarching aims of the programme was to test different models of integration, pilot sites varied widely in their approaches, ranging from condition-specific strategies focusing on diabetes, cardiovascular risk, COPD or dementia, to more generalist approaches, which aimed to provide improved support for people at risk of admission to hospital. However, all pilots involved elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involved patient education and the provision of self-management tools by senior nurses (community matrons, advanced practice nurses) and training in the self-management of medicines.
- *Delivery system design* included the development of care pathways, managed discharge and case management, led by senior or specialist nurses. It could also include the use of integrated community teams providing a single point of access for patients.
- *Decision support* involved some form of health or social care professional training, particularly regarding generic skills that enabled them to better work in multidisciplinary teams or in a rapid-response capacity, but this was not a major focus of most of the pilots.
- *Clinical information systems* included the use of case finding and risk stratification software across some sites; a few sites aimed to establish a single integrated IT system for primary and community care, while others made use of telecare services and remote health monitoring.

The total number of participating service users varied by site. In some sites, patients were not designated as participating but were automatically tracked as part of the activity or intervention if they met certain criteria and were registered with a GP. Most of the pilots began operating in autumn of 2009 and operated at least until March 2011, when the formal pilot period and funding

ended. Some were built on existing or pre-planned initiatives.

### *Evaluation*

A national evaluation of the integrated care pilot programme was conducted from 2009 to 2012 (Ling et al., 2010; RAND Europe & Ernst & Young LLP, 2013). A real-time, embedded, multi-method evaluation that ran concurrently with pilot implementation identified a range of barriers to integration as well as facilitators considered to be common to major organizational change, such as leadership, organizational culture, IT, physician involvement and availability of resources (Ling et al., 2012). Aspects identified as particularly important for delivering integrated care were personal relationships between leaders in different organizations, the scale of planned activities, governance and finance arrangements, support for staff in new roles, and organizational and staff stability.

A focus on a subgroup of six pilots that had used risk profiling tools to identify older people at risk of emergency hospital admission, and that had combined this with intensive case management for people at risk found that most staff involved in the pilots thought that care for their patients had improved. In contrast, participating patients reported to have found it significantly more difficult to see a doctor or nurse of their choice and that they felt less involved in decisions about their care (Roland et al., 2012). That analysis further showed that case management interventions were associated with a 9% increase in emergency admissions. Although there were some methodological challenges, the findings did suggest that it was very unlikely that the pilots had achieved their goal of reducing emergency admissions. At the same time, analyses showed significant reductions of some 20% in elective admissions and outpatient attendance in the six months following an intervention, while overall inpatient and outpatient costs were significantly reduced by 9% during the same period. Overall the evaluation of the six pilot sites suggested that case management might have resulted in improvements in some aspects of care and that it had the potential to reduce costs of specialist care. At the same time it highlighted that to improve patient experience, case management approaches would need to be introduced in a way which respects patients' wishes.

### 4.3 A patient journey

This section describes the journey of two hypothetical typical patients with co-morbid chronic disease participating in structured programmes in the English health care system.

*(A) A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is slightly overweight (BMI of 27). She has been unemployed for three years and receives social assistance benefits; she lives on her own.*

While services and protocols may vary in different parts of the country, the patient's COPD would typically be diagnosed by her GP when she presents with relevant symptoms (for example, increasing breathlessness and coughing) or a respiratory infection and/or history of moderate to heavy smoking. Alternatively, she may present to the local hospital A&E department. The GP or hospital clinician would diagnose COPD based on history, examination and some basic investigations such as a chest X-ray and pulmonary function tests. If she is first diagnosed in primary care, her GP would be likely to manage her disease rather than to immediately refer her to secondary care. She would probably be referred to a practice nurse for smoking cessation advice, given a prescription for an inhaler or nicotine patches or referred for pulmonary rehabilitation. In cases of uncertainty or difficulty managing symptoms, her GP would refer her to hospital for specialist care. If she initially presented to the hospital A&E department, she would commonly be referred to a hospital respiratory physician for initial management.

Type 2 diabetes is typically asymptomatic in its early stages. Her diabetes would probably have been picked up opportunistically as part of a routine glucose screening test offered to those who are overweight. GPs and practice nurses are increasingly likely to manage diabetes themselves but sometimes may seek an initial assessment in secondary care (for example, endocrinologist or diabetologist). The clinician will confirm the diagnosis and look for evidence of complications of the disease, in addition to giving advice on management. She would likely be referred to a dietician (to help with weight loss and optimize nutrition), a chiropodist (if ulcers were present) and an ophthalmologist or some other diabetic retinopathy screening or monitoring service. If needed, initiation of insulin might take place during a hospital outpatient appointment, provided by a specialist nurse, although insulin treatment is increasingly initiated and

managed in primary care. Her care for her diabetes and her COPD would largely be seen as separate care pathways, although initiatives in some areas support a more integrated approach.

*(B) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure. He lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing block and are increasingly housebound due to their illnesses. They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.*

The patient's heart failure will likely have been diagnosed by his primary care physician, on the basis of presented symptoms (for example, swelling in legs, shortness of breath), physical examination, and basic investigation including an echocardiogram. Most often, the diagnosis of asthma is suspected on the basis of the patient's history. Blood pressure is routinely checked for most NHS patients, and hypertension would also be diagnosed by the GP or practice nurse. His treatment would likely include medications (for example, ACE inhibitors, diuretics), and counselling by GP or practice nurse on cardiovascular risk factors (for example, diet and sodium intake, physical activity, smoking cessation). Access to self-management education for heart failure varies by geographic location, but he may be referred to a community group. He may also be assigned a case manager or community matron to visit him in his home, again depending on local service provision. There are fewer services in England to support carers, and the couple would be very lucky if the GP had contacts with a local voluntary organization that could provide some support for his wife. The GP or social worker may refer him to an occupational therapist, who would visit the flat and make requests for tools and equipment that may help the couple lead easier lives. These might include a stairlift or walker, or railings for the bathroom.

#### 4.4 Summary and conclusion

There have been numerous initiatives in England over the past 15 years that aimed at improving the quality of care for those with chronic conditions in particular. Policy initiatives have involved, at the national level, the setting of standards and guidelines; the increasing systematic use of nonmedical professions in chronic disease and case management; and a national pay-for-performance scheme to incentivize high quality chronic care in particular. These were accompanied by a wide range of local initiatives, although initiated from the centre, including, for example, the establishment of pilot projects to promote and enhance care coordination and integration between primary and secondary care and across health and social care.

This change programme is ongoing, as described in earlier sections of this chapter, including the formation of a 'National Collaboration for Integrated Care and Support' in 2013, to support local areas in delivering integrated care (National Collaboration for Integrated Care and Support, 2013); the appointment, in 2013, of 14 local areas as 'integrated care pioneers' to demonstrate innovative approaches to the delivery of person-centred and coordinated care across sectors (Department of Health, 2012c); and the introduction of the Better Care Fund as a financial instrument to further incentivise collaboration across health and social care services locally (NHS England, 2013). Further change is to be expected following the change in the leadership of NHS England from April 2014. This involved the development of a 'Forward View' in October 2014, which set out the NHS strategy for the five years from 2015 (NHS England, 2014c), shaping thinking on the NHS for the foreseeable future (Ham, 2014).

# 5 Estonia

*Taavi Lai, Cécile Knai*

## 5.1 The health care system

The Estonian health care system is governed by the Ministry of Social Affairs. It involves several actors, including the Health Board, formed in 2010, and the Estonian Health Insurance Fund (EHIF). Health care funding is principally through SHI, which covers approximately 95% of the population. Contributions are related to employment, with non-contributing individuals (such as children and pensioners) representing almost half of the insured population. SHI accounted for 69.1% of total health expenditure in 2012, complemented by taxation (10.8%) and OOP payments (18.4%) (WHO, 2014). In 2012, health expenditure was 5.9% of GDP. OOP payments are mainly for pharmaceuticals and dental care.

The EHIF is the main purchaser of health care services. The Ministry of Social Affairs is responsible for financing emergency care for uninsured people, ambulance services and public health programmes, funded from the state budget. The role of municipalities in health financing is small (Couffinhal & Habicht, 2005; Habicht, 2008; Habicht & Habicht, 2008). EHIF funds are collected centrally to balance regional disparities in income. Most health care funds are allocated to four regional EHIF departments; pharmaceutical and temporary sick leave benefits are administered centrally, as is a small fraction for selected expensive or infrequent procedures such as bone marrow transplants, peritoneal dialysis and some oncology and haematological treatments.

The EHIF contracts with licensed providers in primary care, specialist outpatient and inpatient care. These are

typically public sector providers although contracting with licensed private providers is possible. General conditions are negotiated with provider associations such as the Society of Family Physicians and the Hospital Association, for a period of five years. Individual provider contracts determine service volumes and total costs by specialty.

Citizens have free choice of GP, with whom they register. GPs principally have a gatekeeping function, with direct access to specialists granted for a small number of specialties and follow-up consultation for a chronic disease.

GPs are paid through a combination of basic allowance, capitation fee, and fee-for-service, with an additional compensation for those practising in more remote areas.

Hospitals are owned by the state, local government and other public organizations; they provide outpatient and inpatient services (Government of the Republic of Estonia, 2002). Payment is on the basis of DRGs, implemented from 2004 and complementing fee-for-service payments.

### Health care reforms of relevance to chronic disease

Following independence, Estonia introduced, in 1992, a social security system to ensure a sound revenue base for the health care system (Jesse et al., 2004; Koppel et al., 2008; Lai et al., 2013). In parallel, Estonia began to implement a primary care system based on the principles of general practice, replacing the previous system which comprised of polyclinics and ambulatory care, owned by the municipalities and by a few private providers. The 1997 primary care reform plan set out to expand primary care to cover the whole population with family physician services by 2003. In 1998, some primary care planning functions were recentralized from the municipality to the county level. Increasing access to primary care formed an important precondition for downsizing the hospital network and centralizing specialist care. The framework for family medicine is now a distinct part of the 2001 Health Service Organization Act (Government of the Republic of Estonia, 2002).

The 1990s also saw a reform of the pharmaceutical sector, involving, among other things, the introduction of an essential drug list, a system for drug reimbursement, based on disease severity, medication efficacy, and ability

to pay, and the privatization of pharmaceutical services (for example, pharmacies).

The early 1990s further saw a restructuring of the hospital sector, with the introduction of quality standards and a licensing system. The Hospital Master Plan 2015, issued in 2000, projected a reduction by two-thirds of the number of hospitals (from 68 to 15), a reduction by two-thirds in the number of acute care inpatient beds and the concentration of acute inpatient care in 15 large hospitals by 2015 (Habicht, Aaviksoo & Koppel, 2006). Complementing the reduction in the number of acute care beds, a system for rehabilitation and long-term care was to be developed. The process of reforming the hospital system is ongoing, with small hospitals being turned into nursing homes or primary care centres for outpatient care (Government of the Republic of Estonia, 2011; Ministry of Social Affairs, 2004).

### Current legal, regulatory and policy frameworks

While the management of chronic diseases as a concept is not explicitly addressed in health policy documents, the overall set-up and structure of health care does support chronic disease management. One of the stated goals of health care system restructuring was the need to provide for chronic disease management, with the GP acting as principal coordinator in primary care.

In 2005, the EHIF introduced a bonus payment system for GPs as an incentive to support disease prevention and the management of selected chronic conditions (see below). In 2009, a new framework for assessing the performance of GP practices was adopted by the Estonian Family Medicine Association, including guidelines for evaluation processes, types and indicators.

The overall approach is supported by a system of evidence-based clinical guidelines, driven by medical associations in cooperation with the EHIF (Ravijuhend, 2014). There are widely accepted treatment guidelines for diabetes, chronic heart disease, multiple sclerosis and others (59 for 21 specialties).

Strategic plans have been developed to support primary care nursing, home care nursing and GPs on questions of chronic disease management including ways to improve and coordinate patient access to all levels of health care, rehabilitation and social care (Eesti Õdede Liit, Eesti Haigekassa & Eesti Gerontoloogia ja Geriaatria Assotsiatsioon, 2004; Eesti Õdede Liit, 2008). These

development plans provide a long-term strategic vision for the specialty and are thus distinct from activity guidelines that provide guidance for day-to-day work.

More recently, in 2008, the Estonian government adopted the National Health Plan (NHP) 2009–2020 (Ministry of Social Affairs, 2008). Its main objective was to increase life expectancy for men and women respectively to 75 and 84 years by 2020. The NHP sets out five strategic areas with specific objectives, sub-objectives and measurable target indicators for each, including social cohesion and equal opportunities; safe and healthy development for children and youth; a living, working and learning environment to support health; healthy lifestyle; and the development of a high-quality and accessible health care system. It further specifies health care targets, such as the development of a patient-centred health care system through better patient information and coordination between the different levels of health care; the availability of high-quality health care services through the development of primary medical services, optimization of the active care hospital network and the development of nursing/welfare care; and the long-term sustainability of health care funding that protects patients from financial risk. Chronic disease management is not specifically addressed by the NHP although it addresses prerequisites and general principles for structured approaches.

## 5.2 Approaches to chronic disease management

As noted above, a key component of the Estonian health care system is the central role of GPs in overall patient management and care coordination. This is accompanied by well-developed information systems with the GP as principal holder of patient data on all medical services, including hospital care. Overall, there are three main forms of chronic disease management in Estonia: quality management in primary health care; chronic disease management at the interface between primary and secondary care; and other activities within primary care (for all other diseases).

### Quality management in primary health care

The central disease management role of GPs is supported by a bonus payment system to encourage the prevention and management of chronic conditions. This payment

system was established, in 2006, for type 2 diabetes and cardiovascular diseases.

### Type 2 diabetes

The system covers all diagnosed diabetes cases in GP practices. The quality of diabetes care is continuously monitored by the EHIF and GP practices according to the GP diabetes care quality management and practice evaluation frameworks. The framework sets specific rules on the number of consultations, the nature, volume and frequency of tests required by various age–gender–disease severity groups of type 2 diabetes. A financial incentive is provided to GP practices in the quality management framework for diabetes care. Disease management in primary care is also linked to specialist diabetes centres that provide additional support for more severe disease cases. These specialist care units combine out- and inpatient care with nurse-led ‘foot clinics’ and collaborate closely with dieticians and social care workers.

### Chronic cardiovascular diseases

The bonus system covers all diagnosed cardiovascular diseases cases in Estonia. The main setting is the GP practice but it also includes specialist care, community (patient groups) and the social care system. The quality of cardiovascular diseases care is continuously monitored by EHIF and GP practices according to the GP cardiovascular diseases care quality management and practice evaluation frameworks. It is actively encouraged by EHIF, which provides additional financial incentives in line with a care quality management framework, which sets specific rules for the number of nurse consultations, the nature, volume and frequency of tests required by various age–gender–disease severity groups of cardiovascular diseases.

The impact of the diabetes and cardiovascular diseases quality management system on the overall performance of the health care system has not been assessed so far. The system is voluntary for GPs and in 2012 about 97% of GP practices had joined. The proportion of GPs achieving set targets continues to increase, pointing to improved disease management and more systematic referral patterns among GPs while the target thresholds and number of indicators are continuously increased and adapted.

## Chronic disease management at the primary/secondary care interface

### Multiple sclerosis

Three regional care centres form the focal points for the structured management of patients with multiple sclerosis; it covers all diagnosed cases with the disease in Estonia. The system is funded within the regular system but there is no specific funder-driven encouragement for the structured management of multiple sclerosis. Social care services are financed separately by the Estonian Social Insurance Board.

### Parkinson's disease

The development of the structured management of patients with Parkinson's disease began simultaneously in the community and health care sectors, as a bottom-up initiative. The Estonian Parkinson's Association was created, bringing together Parkinson's patients, family members, doctors and representatives of Parkinson's related specialties.

### Schizophrenia

The development of the structured management of patients with schizophrenia was on professional initiative with support from patient organizations. It covers all patients diagnosed with schizophrenia in Estonia and all GP practices. The quality of schizophrenia treatment/care is in line with international guidelines and is continuously monitored by service providers.

### COPD

The structured management of COPD was developed as a professional initiative. It covers all patients diagnosed with COPD in GP practices. The approach is funded within the framework that governs all other health care providers in Estonia.

The main setting for the structured management of these conditions is the care centre or the hospital where the majority of activities are performed in the outpatient setting. The system also spans primary care, social care and community patient groups.

The main strategies employed are very similar regardless of the disease. They involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* refers to patient education provided in primary care settings by any member of the primary care team (generally a GP or family

nurse) but can also be provided in a specialist care setting in more severe disease cases. Patients are involved in developing their individualized care plans, which cover consultations by other specialists for improved management of co-morbidities according to patient condition and needs. For some conditions, the wider community may be involved in supporting patients, such as the Parkinson's Association for patients diagnosed with this condition, including the provision of information materials, lectures, practical training as well as mentoring and practical everyday support. All patients have regular assessments based on their health status. Additionally, all patients have direct access to a GP for unscheduled visits in case of disease relapses.

- *Delivery system design* includes case finding with referral to specialist care. There is an important role for teamwork and integrated care for providing (personalized) rehabilitation for conditions such as Parkinson's disease. Teams comprise of psychiatrists, social workers, and rehabilitation and other specialists. Regular assessments and follow-up are part of the treatment process which commences following confirmed diagnosis.
- *Decision support* entails the use of evidence-based guidelines and specialist expertise provided within international networks. For example, the multiple sclerosis centres work within the framework of international multiple sclerosis associations that provide expertise and second opinion if needed. Provider education is part of the continuous professional development of GPs. In case of type 2 diabetes and cardiovascular diseases, a quality management system for follow-up and GP practice evaluation is in place.
- *Clinical information systems* are employed to support disease management. For example, the information system used in the multiple sclerosis centre is part of a larger system that includes electronic booking and information systems for the acute care hospital, its outpatient care, rehabilitation and long-term care units. The electronic system is connected to the patient and treatment information system that covers all health care providers in Estonia. From September 2009, the system has been supplemented by an electronic patient record system that links all service provider-based patient records into one network and thus enables electronic access to all

patient data (including laboratory tests and imaging) regardless of the place where the data were generated.

### *Evaluation*

Evaluation of structured disease management activities in Estonia is not consistent and systematic, owing to staff shortages, lack of funding, resistance from policy-makers, health professionals and funders, and the limited availability of valid and reliable data. Lack of awareness of the need for programme evaluation among policy-makers (and also health professionals) is probably the foremost barrier to implementation of programmes evaluations. This is at least partially caused by the fact that there is no overall chronic disease development policy in Estonia which also highlights low level of stewardship in this area provided by the Ministry of Social Affairs.

However, EHIF has provided incentives for regular quality assessments within primary care. The main indicators of effect are improved patient outcomes, survival and satisfaction. Process measures relating to referral rates and clinical measures are regularly monitored, as are the costs of existing care centres. Additional external evaluations can be performed by the EHIF as part of the cardiovascular care quality management framework and is currently performed annually on a random sample of GP practices.

Since 2010, evaluations of GP practices have been performed by the Estonian Society of Family Doctors and a list of the 20 highest ranking practices is also published (Estonian Health Insurance Fund, 2010).

## **5.3 A patient journey**

This section describes the journey of two hypothetical typical patients with co-morbid chronic disease in the Estonian health care system.

*(A) A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is slightly overweight (BMI of 27). She has been unemployed for three years and receives social assistance benefits; she lives on her own.*

The patient is covered by social insurance and has direct and free access to a GP. She also has free access to specialist care but needs a GP referral for that.

Thus, the first diagnosis of both diabetes and COPD generally comes from the patient's GP, according to national diagnosis and treatment guidelines. Both diagnosed diseases can be managed solely by the GP, but given the evident disease severity and co-morbidities, it is likely that the patient will be referred to an endocrinologist and pulmonologist. The specialist appointment is generally made by the patient, but for the patient in this case study, it is more likely made by the GP or a nurse in the practice.

Depending on the disease severity assessment by the specialist, the patient can be referred for hospitalization, scheduled for routine treatment in ambulatory specialist care or referred back to GP for treatment with a verified diagnosis and specialist input. Regardless of the next steps for treatment, all consultation results are channelled back to the GP.

The patient described in this case study is most likely to remain under the care of both the GP and an endocrinologist. The GP coordinates the patient's overall treatment and the primary management of diabetes, and oversees to some degree the follow-up of specialist care, for example, by providing reminders of specialist consultations. The GP also refers the patient to nurse-led 'foot clinics' while the specialist schedules follow-up visits for specialist care if needed. The specialist may also refer the patient to any other specialist although this is generally performed by the GP and the information is shared among providers.

The social assistance benefit in this case is most likely a form of disability benefit requested for the patient by the GP. Both GP and specialist may contact social care workers to ask that the patient be considered for social care services, although this is most likely made by the GP. The same also applies to referrals for rehabilitation services. A daily lifestyle consultation is provided by the GP or primary care nurse and is supported by disease-specific lifestyle advice from an endocrinologist and pulmonologist (and other specialists if need be).

Overall, the allocation of treatment responsibilities between GP and specialist is largely dependent on specific aspects of the disease and patient preferences.

*(B) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure. He lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing*

*block and are increasingly housebound due to their illness. They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.*

Both husband and wife are covered by health insurance due to their age and have free access to the health care system.

The first diagnoses are generally made by the GP who manages their day-to-day treatment. Diagnosis and treatment are coordinated according to respective guidelines, with diagnosis verified during a specialist consultation which is also used to fine-tune the treatment, incorporating specialist expertise and additional testing in specialist care. The patient may be admitted to hospital for further testing and treatment ‘calibration’. Selection of a specific ward depends on which disease is currently affecting patient’s health the most. During hospitalization, treatments provided by cardiologists or pulmonologists will be coordinated by the main treating doctor. Follow-up visits after hospitalization are scheduled before discharge. All relevant data from specialist consultations are channelled back to the GP, indicating whether nursing or social care may be needed by the patient.

Patient management on the primary care level could include regular visits by a primary care nurse and GP, if the patient is not able to visit the GP practice in person and their health situation calls for home visits. The couple’s grandson could receive financial support from the social care system for the care he provides to his grandparents, in addition to support from a trained social worker or home nurse.

#### **5.4 Summary and conclusion**

There is currently no explicit strategy in Estonia that fully encompasses the systematic management of chronic diseases. However, elements of such a vision are emerging, involving four main components: a central role of GPs; the development of treatment guidelines by medical specialties; the strategic development of plans

for specialties; and the development of care centres for selected conditions.

Thus, one of the most important reforms in the Estonian health system has been the establishment of the GP system as the cornerstone for health care delivery, with GPs acting as gatekeepers to specialist care and the coordinator of care for their patients, supported by a well-developed information system and elements of pay-for-performance for the management of hypertension and type 2 diabetes.

Second, treatment guidelines as developed by medical associations (specialties) in cooperation with EHIF form widely accepted guides for conditions such as diabetes, chronic heart disease, multiple sclerosis and others. These also include so-called ‘specialty specific activity guidelines’, such as activity guidelines for home care nurses and primary health care nurses, both of which addressing the management of chronic diseases through for example stipulating the need for proactive patient follow-up, primary health care teams and coordination of activities with social care and other medical specialties.

Third, there are strategic development plans for specialties, for example, for primary health care nursing, home care nursing and GPs of relevance for the management of chronic disease such as improving and coordinating patient access to primary, secondary and tertiary health care, rehabilitation and social care.

Finally, care centres for conditions such as multiple sclerosis and type 2 diabetes build around acute hospital care units in central hospitals by adding chronic disease management and rehabilitation options and providing links with patient organizations and social care.

Overall, these four components can be seen to form a strong basis for the further development of chronic disease management in Estonia; however there remains considerable room for the further advancement of coordination and targeted action to uncover its full potential.

# 6 France

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## 6.1 The health care system

The French health system is based on SHI and provides all legal residents with health coverage, as per the 1999 Universal Health Coverage Act (CMU Act) (Allonnie, Dourgnon & Rochereau, 2006; Chevreul et al., 2010). In 2008, SHI accounted for 73.8% of health expenditure, complemented by OOP payments (6.8%), taxation (5.1%) and VHI (13.5%) (WHO, 2014). In the same year, national health expenditure was 11.1% of GDP.

Although the Ministry of Health oversees overall health sector planning and guidance on health policies, regions have an increasingly important role in health care provision through the regional health agencies (*Agences Régionales de Santé*, ARS). These agencies were created in 2010, following the 2009 Hospital, Patients, Health and Territories Act, thereby merging seven regional institutions in charge of the hospital sector, the private self-employed sector, health and social care for elderly and disabled, and public health. The ARS have responsibility for ensuring that health care provision meets the needs of the population by improving coordination between ambulatory and hospital care and health and social care services, while respecting national health expenditure objectives (Chevreul et al., 2010).

The ARS develop regional strategic health plans (*plan stratégique régional de santé*, PSRS), which set out the development goals for regional provision over a five-year period, in accordance with national or regional priorities. The main aim of the PSRS is to coordinate ambulatory

and hospital care and health and social care for the elderly and disabled in response to population needs.

Health services are delivered by public and private providers in ambulatory care and in hospital. GPs mainly work in private practice as self-employed professionals, with around 75% working in health centres or hospitals in addition to their private practice. GPs and specialists are paid on a fee-for-services basis, with covered SHI fees set nationally, based on agreements between professional organizations and SHI. Extra-billing in addition to these fees concerns about half of patients seeking health care. Doctors employed in a public hospital receive a salary.

### Health care reforms of relevance to chronic disease

A concern for lack of coordination and continuity of care within the health sector has prompted a series of health care reforms from the 1990s. Since 1996, the expected national ceiling for SHI expenditure is defined annually by law (Social Security Financing Act, SSFA). Its decision is based on reports of the General Accounting Office (*Cour des comptes*) and the National Health Conference, which represents all stakeholders (Durand-Zaleski & Obrecht, 2008; Chevreur et al., 2010). The 1996 reform also introduced mechanisms to stimulate pilot projects using provider networks at the local level to support coordination and continuity of care. These provider networks (*réseaux de santé*) were formalized under the 2002 Patients' Rights and Quality of Care Act (Président de la République Française, 2002), with the aim to strengthen the coordination, continuity and interdisciplinarity of health care provision, with a focus on selected population groups, disorders or activities. Concomitantly, the SSFA for 2002 introduced specific budgets dedicated to provider networks.

The 2004 Health Insurance Act, which has renewed the organization and the management responsibility of SHI, has set out measures to improve the long-term disease (*affections de longue durée*, ALD) scheme (see below). The law also introduced a form of gatekeeping through the preferred doctor scheme (*médecin traitant*) in the ambulatory care sector with higher co-payments for patients accessing care outside this coordinated care pathway. It further created the National Authority for Health (*Haute Autorité de Santé*, HAS), which, among other things, was made responsible for the development of guidelines for the treatment of chronic diseases and the definition of eligibility criteria for inclusion in the ALD system (Durand-Zaleski & Obrecht, 2008).

In the same year, the 2004 Public Health Act defined five major health plans and 100 public health priorities with individual target indicators for the period 2005–2009. Targets were organized into 22 categories, of which 11 concerned chronic conditions or diseases (Durand-Zaleski & Obrecht, 2008). The law also foresaw the development of a national public health plan for those with chronic illness, which was eventually published in 2007 (Président de la République Française, 2004; Ministère de la Santé et des Solidarités, 2007b). The Public Health Act created the National Cancer Institute (INCa) under joint supervision of the Ministers of Health and of Research. This move followed a history of concerted actions against cancer, including the five-year Gillot-Kouchner Cancer Plan introduced in 2001, with further extension (2003–2007), which added a focus on prevention, screening, quality of care and patient-centred care.

The 2009 Hospital, Patients, Health and Territories Act set out a series of measures with importance for chronic disease care (Chevreur et al., 2010). First, the transfer of tasks between professionals was made legal beyond the mere scope of experiments, and contractual agreements of care protocols between professionals were to be developed. Second, regulations pertaining to multidisciplinary and multiprofessional care centres were streamlined, which clarified their financial and legal status. Finally, it introduced the concept of patient education in the public health code, defined the content of patient education programmes and the necessary competences of providers delivering them. Patient education, prevention and treatment information for the chronically ill have also played a major role in the 2006–2009 triennial contract that SHI signs with the Ministry of Health, defining the objectives, the management and the governance of SHI (*Convention d'objectifs et de gestion*, COG).

### Current legal, regulatory and policy frameworks

In many ways the aforementioned 2007 national public health plan for those with chronic illness (*Plan pour l'amélioration de la qualité de vie des personnes atteintes de maladies chroniques (2007–2011)*) can be seen as the overarching strategy in the French system to address the care for those with chronic disease, with a major focus on improving the daily quality of life of people living with chronic conditions. An example of its implementation is the 2008 *Circulaire d'organisation des soins palliatifs* which set out a policy for palliative care and its development, and provided guidelines for the organization of palliative

care, including the role of volunteers and their action to support patients and their relatives (Direction de l'hospitalisation et de l'organisation des soins, 2011).

Already in 2002, the SSFA introduced a financing mechanism for provider networks, the fund for the quality improvement of ambulatory care (*Fonds D'Amélioration De La Qualité Des Soins De Ville*, FAQSV) and the national and regional fund for the development of provider networks (*Dotation Régionale/Nationale de Développement des Réseaux*, DRDR/DNDR) (Durand-Zaleski & Obrecht, 2008). Both funds could be used to finance networks (infrastructure and operating costs), while the DNDR could also finance new services as outlined above. These budgets were replaced, in 2008, by the quality and coordination of care funds (*Fond d'Intervention pour la Qualité et la Coordination des Soins*, FIQCS) following the 2007 SSFA (Président de la République Française, 2006; Chevreul et al., 2010). The FIQCS budget was hence not exclusively dedicated to provider networks, but also funds initiatives such as health IT projects and multidisciplinary and multiprofessional care centres. Similarly, in 2012, the FIQCS was merged into a regional intervention fund (*Fonds d'Intervention Régional*, FIR), accommodating among other things the budgets for the hospital modernization and the continuity of care system (*permanence des soins*). In consequence, funding of provider networks has become less secure. Funds are allocated at the regional level on an annual basis at a total of €163 million for provider networks in 2009, upon a yearly call for proposals. All provider networks that have benefited from public funds must submit to an evaluation procedure, the framework of which is jointly defined by SHI and the Ministry of Health (Direction de l'hospitalisation et de l'organisation des soins, 2009). It provides networks with assessment criteria (based on structure and process but not on outcomes) and targets for each criterion. Depending on the level of target achievement for each criterion, networks are given a mark (A–E). This final mark determines, together with more subjective criteria, the continuation of funding.

On top of these targeted chronic disease management policies and frameworks, a number of 'supportive' policies with some impact on chronic disease can be identified. As noted above, the 2004 health insurance reform introduced a gatekeeping primary care system plus a referral system for access to specialist care as a means to improve care coordination (Chevreul et al., 2010). It also foresaw the introduction of an electronic

personal medical record support for care management to be in place by 2007; however, it is currently still under development with local pilot runs launched in 2010. In 2009, the Hospital, Patients, Health and Territories Act regulated the delegation of tasks, the modalities for multidisciplinary and multiprofessional care centres, and the framework for patient education programmes. The 2009 SSFA introduced the *Contrats d'Amélioration des Pratiques Individuelles* or CAPI scheme, thereby reforming the provider payment system. It aimed at improving the quality and efficiency of care and to complement the prevailing fee-for-service remuneration by introducing pay-for-performance (Chevreul et al., 2010). CAPI consisted of voluntary individual contracts between GPs and the statutory health insurance, whereby the GP agreed to meet specific goals including the management of chronic diseases, preventive health care, and agreed levels of prescribing generic drugs and defined categories of drugs. In 2011, this pay-for-performance scheme (renamed *rémunération sur les objectifs de santé publique*; ROSP) was incorporated into the physicians' collective bargaining agreement with an expanded list of objectives and extended to additional specialties, taking effect in 2012. Participation in the ROSP system is on a voluntary basis, for a three-year period, and the physician may leave the contract at any time. Specific objectives of the ROSP contracts for patients with chronic conditions are to improve the proportion of diabetic patients treated in line with current recommendations (for example, 65% of the diabetic patient population receive an eye examination) and to control blood pressure for 50% of patients with high blood pressure over a period of three years. GPs participating in ROSP receive additional remuneration on top of their normal fee-for-service income, which takes into account the size of the population treated by the doctor and 29 quality indicators with intermediate and final targets. Overall, the amount earned can exceed €7000 per year for a doctor achieving over 85% of the targets and treating more than 1200 patients. There is no penalty for the GPs who do not achieve the targets. In 2012, more than 75 000 physicians participated in the programme, receiving an average annual remuneration of €3746.

## 6.2 Approaches to chronic disease management

As noted above, a key concern in the French system remains the fragmentation of the system and here we describe a range of approaches that have been introduced

over the past decade towards chronic disease management in France.

### Provider networks

Provider networks are considered the main approach to providing coordinated care for those with complex needs (Durand-Zaleski & Obrecht, 2008), with an estimated 1000 plus networks operating across France. They include disease-specific networks and provider networks for particular population groups, for example focusing on older people. The total amount of public funds spent on provider networks in 2009 was estimated to be €163 million (Département de la coordination et de l'efficience des soins & Caisse nationale de l'assurance maladie des travailleurs salariés, 2009).

The origins of the provider networks date to the late 1980s, as a new organizational approach to better meet the specific needs of those diagnosed with HIV/AIDS. The same principles apply to the majority of contemporary provider networks. This approach has been complemented and formalized by the establishment of a legal framework for SHI funding, which provides a financial incentive to set up or consolidate a network. Provider networks are principally funded through FIQCS as described above.

### Diabetes networks

Diabetes networks are particularly well established, and include, for example, the REVESDIAB network (*Réseau de santé Val de Marne Essonne Seine et Marne pour les diabétiques de type 2*) (REVESDIAB, 2009). They are coordinated at national level by the National Association for the Coordination of Diabetes Networks (*Association nationale de coordination des réseaux diabète*, ANCREDE). For 2007, ANCREDE reported on 72 funded networks covering 50 000 patients and 14 000 health professionals (Ciutan & Gouzien, 2007).

Diabetes networks employ strategies that include elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves active support of patient empowerment and self-management (REVESDIAB, 2009). Support for patient self-management is generally delivered in the form of information and training sessions, for example on foot care, insulin injections, diet and

exercise. Patients formally agree with the network professionals on a care plan setting out therapeutic goals. Goals may include the attainment of adequate HbA1c levels, weight reduction and smoking cessation.

- *Delivery system design* includes an annual assessment of patient needs, focused in particular on cardiovascular risk factors. It also includes use of multidisciplinary health care teams comprising GPs, hospital physicians, dieticians, nurses, podiatrist and pharmacists operating on the basis of a protocol on common care (Durand-Zaleski & Obrecht, 2008). For those with additional needs (for example, obesity and/or substance abuse), the diabetes network liaises with other specialized networks and provides ready access to those services (REVESDIAB, 2009).
- *Decision support* involves the use of evidence-based guidelines and provider training on the application of care protocols.
- *Clinical information systems* includes the use of a shared information system, involving a database of routine indicators (HbA1c, weight, blood pressure, etc.) collected during yearly check-ups and used for evaluation and quality control; reminder systems are not common however, and GPs do not have systematic access to centralized patient information. The shared information system generally includes a care folder that stays with the patient, containing main objectives and results (for example, HbA1c tests) to inform all staff involved in the care of the patient.

Patients can join a network through their physician (usually the GP) or directly (5%). Participation is free of charge; in addition, patients may access services they would otherwise have to pay for such as educational sessions, dietary counselling, supervised weight loss and exercise programmes, in partnership with other networks (for example, networks on weight control such as the *Réseau d'Obésité Multidisciplinaire d'Essonne et Seine-et-Marne*, ROMDES) (Romdes, 2014) or on substance abuse (for example, *Réseau Addictions Val de Marne Ouest*, RAVMO) (Réseau Addictions Val de Marne Ouest 2014). For patients who cannot access provider networks because they do not exist in their locality, another option is the *maisons du diabète* ('diabetes homes'), located in twenty cities throughout France (Union des Maisons du Diabète, 2014). These homes are non-profit-making institutions providing diabetic patients free access to

nurses and dieticians for educational sessions, as well as information on diet and other lifestyle issues. Both networks and diabetes homes cover approximately 5% of the diabetic patients in France.

### *Evaluation*

As noted above, there is a legal obligation for provider networks to be evaluated. The Ministry of Health previously required for evaluations to follow a quasi-experimental design, but such designs have rarely been used. All provider networks that have benefited from public funds must submit to an evaluation procedure, prepared jointly by the insurance fund and the Ministry of Health, requiring reporting on a total of 34 mostly quantitative indicators on an annual basis (Direction de l'hospitalisation et de l'organisation des soins, 2009). A 2007 ministerial document associated the sustainability of network funding to the production of an external evaluation to demonstrate the added value of the provider network compared to usual services (Ministère de la Santé et des Solidarités, 2007a). It stipulated that at the end of each financing period (ranging from 18 months to three years), an external assessment should be carried out. External evaluators are invited to bid and are selected at the regional level by the ARS. The evaluation focuses on provider network working and organization, the participation and integration of key actors, patient care and consequences on professional practices, and economic analysis.

Although, typically, an evaluation is based on a before–after design without control, it does include an element of benchmarking, ranking the network in relation to the best-performing network of the relevant medical domain (for example, diabetes). For example, the best performing network in terms of patient satisfaction will obtain ten points, the worst 0 points. Evaluated domains for patients include impact on the territory (number of patients and percent of the estimated target population), care pathways, coordination, efficiency (number of hospital admissions or hospital days) and satisfaction. For professionals, evaluated domains are: impact on the territory (type of professionals and percent of the estimated target population by category), number of professionals in the territory that belong to at least one network, care pathways, coordination and safety (adverse events). The evaluation also includes a cost domain, namely total expenditure, expenditure per patient and operating costs.

### **Coordination of Professional Care for the Elderly (COPA)**

Gerontological provider networks are becoming increasingly established and represented by national or regional umbrella groups such as the FREGIF (*Les Réseaux de Santé Gérontologiques d'Ile-de-France*), the association of gerontological provider networks in the capital region. An example of such a network is the Coordination of Professional Care for the Elderly (COPA) network. Set up in an area of Paris in 2006, it is a locally adapted blend of approaches that have been inspired by programmes such as PACE in the United States (Bodenheimer, 1999) and the Canadian programme on care integration, PRISMA (PRISMA, 2014).

The COPA model's key features include a strengthening of the role of the primary care physician, the use of a case manager, the integration of health professionals into a multidisciplinary primary care team and of primary and specialized care through introducing geriatricians into the community to see patients in their homes and organize hospitalizations while the primary care physician retains principal responsibility for medical decisions (Vedel et al., 2009a, 2009b). The main strategies employed by COPA thus include elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support:* The patient is involved in setting goals and designing a treatment pathway.
- *Delivery system design:* Case management is the centrepiece of the intervention. The case manager is a specially trained nurse, responsible for geriatric assessment and the development of an individualized care plan that includes nonmedical care. The case manager works closely with the GP, with specialists and others acting as 'support team' involving geriatricians, psychologist and social worker. Occasional multidisciplinary meetings (GP, geriatrician, carers) can be organized by the case manager.
- *Decision support:* Providers receive training based on the InterRAI assessment instrument and algorithms to provide guidance for the individualized care plan. The InterRAI tool CHIP (Community Hospital Intake Profile, a 9-item score) is used to assess whether the patient is eligible for entry in the intervention.

- *Clinical information systems:* The intervention uses a database which is not yet integrated into the clinical routine, but is required for evaluation and documentation.

Patients join the network through their GP. The network was established in one district of Paris but is being implemented in other parts of Paris also; in 2007, it involved 79 out of 200 primary care physicians working in that area. By the end of 2007, some 250 older people had been referred to COPA (Vedel et al., 2009a).

#### *Evaluation*

COPA is internally evaluated on an annual basis, and externally every three years, to ensure that public money provides added value to both patients and professionals as stipulated by regulation described above. It is currently being evaluated in terms of its impact on quality of care, service utilization and professional practice (de Stampa et al., 2008).

### Specific programmes

#### **Sophia diabetes care programme**

The Sophia diabetes care programme was established as a pilot in 2008 in 10 departments across the country. Offered by the health insurers, the overarching aim for the programme is to act as an intermediary between the patient and his/her GP, with a nurse-led intervention at its core (Caisse Nationale de l'Assurance Maladie, 2010).

The main strategies of the Sophia programme involve elements of self-management support, delivery system design and decision support.

- *Self-management support* involves advice and information to support patient self-management of their condition and health behaviour provided by a trained nurse or a health counsellor. It also includes a patient information website.
- *Delivery system design* involves a regular individualized, need-based telephone intervention provided by a trained nurse (on average every 6 weeks). It uses a risk-stratification approach to determine the frequency of the intervention. Although the intervention is nurse-led, the GP remains the main coordinator.
- *Decision support* comprises evidence-based guidelines on diabetes care; these inform the content of the

telephone intervention. Risk stratification software is used to also inform the intervention.

The Sophia programme is voluntary. Its present focus is on patients covered by the ALD scheme. Patients are invited by their health insurer to join; participation is free of charge. GPs are invited directly by the health insurer to follow up with the patient and oversee objectives and functioning of the programme. Participating GPs receive €66 per patient per year.

The Sophia programme initially aimed at covering 136 000 patients with type 1 and type 2 diabetes (6% of all patients) in 10 departments, subsequently extended to an additional nine regions to reach a total of 400 000 patients with diabetes (and under the care of 17 500 GPs). By November 2010, 62 000 patients had signed up to the programme (Caisse Nationale de l'Assurance Maladie, 2010), and it was rolled out nationwide in 2013.

Based on the model of the Sophia diabetes care programme, SHI launched its asthma care programme in early 2014. It is currently being implemented in pilot sites in 19 departments and is expected to contain the same key components as the Sophia diabetes programme.

#### *Evaluation*

Sophia is under the auspices of the SHI, which has commissioned an external evaluation of process, outcome and economic indicators. The evaluation suggests a moderate improvement in process (for example, percentage of ophthalmological check-ups and Hb1Ac controls) and minor improvements in intermediate outcomes (Hb1Ac) in patients with poor glycaemic control (Caisse Nationale de l'Assurance Maladie, 2013).

#### **Health Action by Teams of Self-employed Health Professionals (ASALEE)**

The Health Action by Teams of Self-employed Health Professionals (ASALEE) in the Deux-Sèvres region was set up as an experiment in 2004; it linked 41 GPs and eight nurses for primary care provided in private practices, in order to improve the quality of health care, especially for patients with chronic diseases.

The main strategies employed by ASALEE include elements of self-management support, delivery system design and clinical information systems.

- *Self-management support* mainly consists of disease-centred education sessions operated by nurses.
- *Delivery system design*: There are clearly defined roles for involved staff. Nurses are responsible for providing education about diabetes and high blood pressure, as well as screening for cognitive problems and cardiovascular risk factors in individuals over 75 years old. These nurses also assist doctors in collective screening campaigns, especially those targeting breast cancer and colorectal cancer.
- *Clinical information systems* consist of reminder systems on patient notes and monitoring systems: if missing laboratory tests are manually detected by the nurse, an electronic reminder is inserted into the electronic patient record.
- *Delivery system design*: Follow-up consultations are organized and coordinated by a dedicated discharge manager (employed by SHI), including two consultations with the GP and one with the cardiologist in addition to the nurse visits.
- *Decision support*: Care algorithms are provided for participating health professionals, based on recommendations by HAS and the French Society of Cardiology.
- *Clinical information systems*: A paper-based log-book is provided for the patient, containing biological information, which is updated at each visit and to be shared among all participating health professionals.

### Evaluation

ASALEE was considered an experimental project. It has been subject to a once-only evaluation using HbA1c as a progress and outcome indicator and including an economic evaluation. Data from the French observatory on general practice have been used to generate a control group. The evaluation undertaken by the research institute IRDES (*Institut de recherche et documentation en économie de la santé*) showed that, at the same cost, glycaemic control in the intervention group was better than for controls (Bourgueil et al., 2008). The HAS has assessed whether experiences can be transferred and expanded, and has decided in 2012 that 'ASALEE cooperation protocols' can be put in place locally after agreement by the ARSs.

### Hospital discharge programme for patients with heart failure (PRADO)

SHI launched in 2013 the PRADO programme for patients hospitalized for heart failure in five departments, aiming to reach 60 000 patients per year. The main aim is to achieve a better coordination of care after discharge, to allow the patient to leave the hospital as soon as possible and to avoid further hospitalizations.

The main strategies of the PRADO programme involve elements of self-management support, delivery system design, decision support and, to a limited extent, clinical information systems.

- *Self-management support*: A specifically trained nurse performs weekly home visits during 2 months to deliver patient education, and there are support brochures for patients.

The PRADO programme is voluntary for patients and providers. Patient eligibility and hospital discharge date are determined by hospital medical staff. GPs receive a financial incentive for their coordination efforts since they are authorized to bill a 'long consultation' (i.e. the tariff of two standard consultations) for the first patient contact.

An evaluation of the PRADO programme is forthcoming.

### Affectations de Longue Durée

The Affectations de Longue Durée (ALD) scheme was introduced into the French health system with the establishment of the statutory insurance system in 1945 as a means to protect those with long-term conditions from financial hardship associated with treatment (Box 6.1). Designed as a financing mechanism, through exempting from co-payments those with long-term conditions, the scheme as such does not constitute a disease management intervention. However, following the 2004 health insurance reform, the scheme was developed further to incorporate a more structured approach to the care of those with recognized ALD (Durand-Zaleski & Obrecht, 2008). This involves the requirement for GPs to develop a care protocol for each patient requiring ALD exemption, setting out the patient's clinical pathway, the health professionals involved, the treatments prescribed, and the planned follow-up. Protocols are defined for each condition within the ALD system by the HAS, and the GP must obtain signed consent from the patient regarding the care protocol. The patient must present the protocol to every specialist visited in order to qualify for full reimbursement and is otherwise required to make the usual co-payment (Chevreul et al., 2010). To support this approach, the HAS provides guidance documents

for patients and physicians. For patients, these include information booklets on the treatment pathway in understandable language. For physicians, basic guidance exists for all diseases under the ALD scheme. Very exhaustive patient pathway guidance has been published for COPD, chronic renal failure, Parkinson's disease and heart failure, and others are to follow (Haute Autorité de Santé, 2012).

**Box 6.1:** *The ALD system in France*

The ALD scheme is based on a list of 30 (mostly chronic) diseases or disease groups. All expenses related to the treatment of one of the ALD-diseases are fully covered by SHI up to the statutory fees. Eligibility for exemption for a patient with any of these conditions is determined by the patient's health insurance on request from the GP. Patients with multiple conditions or with a (costly) single condition not formally listed as ALD (for example, a rare disease) may also be eligible for full coverage if accepted by the relevant health insurance fund. The addition of new conditions to the ALD list has generally been determined by the costs associated with treatment, with conditions being added as a new (costly) treatment became available (for example, HIV, hepatitis, multiple sclerosis). While the ALD list comprises the major chronic conditions, restrictions apply; for example, depression and COPD are considered only if at advanced stage. In 2012, 9.5 million people benefited from exemptions through this scheme.

### Telemedicine in the Greater Paris region

In 2012, a 5-year plan with a total budget of €10 million was established by the Paris ARS to foster the development of telemedicine in two major directions: (1) managing chronic illness, in particular the promotion of the efficient utilization of health services in people with long-term conditions and (2) improving access to specialized care in deprived populations. Chronic illnesses targeted for telehealth programmes were: congestive heart failure, end-stage renal failure, mental disorders and obesity. Based on the results of the experiments, the Paris health authority may propose a widespread adoption.

### Cancer initiatives

Within the French health system, the field of cancer holds a prominent position and receives widespread political attention. A series of distinct initiatives have been developed that are presented below.

### Protocol for disease communication and promotion of shared decision-making (*Dispositif d'annonce*)

The *dispositif d'annonce* was introduced within the 2003–2007 Cancer Plan ('measure 40'). It is an organizational approach aimed at improving the ways in which the diagnosis of cancer is communicated to a patient, to better organize the process and competences needed for discussions of a diagnosis of cancer, and to promote shared decision-making between professionals, patients and their relatives (Haute Autorité de Santé, 2008).

A related strategy proposed by the Cancer Plan was the *dispositif d'accès aux soins de support*, the organization of access to supportive care ('measure 42') (Ministère des Solidarités, de la Santé et de la Famille, 2005). It aims at supporting patients through measures of more effective pain relief, addressing the problem of fatigue, providing psychological and social support by multidisciplinary teams, including those working outside health care structures (for example, patient discussion groups or physical activity) and offering access to auxiliary care (nutrition, beauty treatments) (Tivoli et al., 2005; Baize et al., 2008).

The main strategies employed by the *dispositif d'annonce* include elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves shared decision-making and teaching patients coping strategies. Upon learning of the illness and feeling distressed, each patient should receive the best possible information and support. This includes time set aside to explain the disease and treatment options, the possibility for the patient to be included, if desired, in determining treatment choices, and psychological and social support if needed (Moumjid et al., 2003a; Moumjid et al., 2003b; Moumjid, Brémond & Carrère et al., 2003).
- *Delivery system design* includes the development of individualized care plans and personalized follow-up.
- *Decision support* includes the use of national recommendations on patient communication developed by the HAS/INCa.
- *Clinical information systems* are being implemented by regions to enable sharing of cancer patient records (*Dossier communiquant de cancérologie*, DCC) and to support decisions by the multidisciplinary team

(*Réunion de concertation pluridisciplinaire* (RCP); see below).

In 2007, over 92 000 patients were supported through a dedicated *dispositif d'annonce*, representing 30% of new patients diagnosed with cancer. Also, nearly 23 000 patients had received a personalized care programme, representing 7% of newly diagnosed patients. The initiative is funded from regional budgets within the MIGAC envelope (*Missions d'intérêt général et d'aide à la contractualisation*), a specific budget to finance activities of 'public utility' as part of usual care (hospital reimbursement) within SHI.

### Evaluation

INCa and the national cancer patient association evaluated the *dispositif d'annonce* in order to ascertain the number of patients concerned and their level of satisfaction with the system. In 2010, the French national association of supportive care in cancer (*L'Association francophone pour les soins oncologiques de support*, AFSOS) launched a national evaluation of access to supportive care *baromètre AFSOS*; results will be published during 2011 (Scotté et al., 2011).

### Multidisciplinary team meeting (*Réunion de concertation pluridisciplinaire*, RCP)

Measure 31 of the 2003–2007 Cancer Plan proposed the implementation of multidisciplinary team support (RCP) for each patient newly diagnosed with cancer to discuss the case, elaborate a treatment plan and communicate it clearly to the patient (Ray-Coquard et al., 2004). Multidisciplinary team meetings are viewed as a key opportunity to identify cancer networks and care establishment, arranging referral and identify a patient representative at the hospital.

The main strategies employed by the RCP include elements of delivery system design, decision support and clinical information systems.

- *Delivery system design* includes the development of individualized care plans and personalized follow-up via the multidisciplinary team meeting. The team comprises at minimum a surgeon in the specialty concerned (for example, a thoracic surgeon for lung cancer), a radiologist and a medical oncologist. In practice there is a forum of specialties to discuss a patient's case and care 'calendar'. In each territory (department or city) there are several

multidisciplinary meetings, one for each cancer specialty every two weeks to assess or discuss treatment decisions concerning cancer patients.

- *Decision support* is informed by regional guidelines (recommendations of practice in cancer). HAS/INCa provide national recommendations for practice in oncology and the network implements them through regional professional cancer guidelines (Ray-Coquard et al., 2005).
- *Clinical information systems* are being implemented by regions to enable sharing of DCC and to support decisions by the multidisciplinary team.

In 2007, nearly 500 000 RCPs were recorded, representing approximately 45% of patients, up from 28% in 2006. Similar to the *dispositif d'annonce*, RCPs are funded from regional budgets within the MIGAC envelope, a specific budget to finance activities of 'public utility' as part of usual care (hospital reimbursement) within statutory health insurance.

### Cancer networks

Networks in the field of oncology have been established in France since the 1990s and have informed the organization and mission of current cancer networks (Farsi et al. 2002; Bey, 2006). The 2003–2007 Cancer Plan strengthened the role of cancer networks at the regional and local level.

### Regional networks

At the regional level, networks have been developed to coordinate all relevant actors and levels of care in the management of cancer and to guarantee the quality and equity of care across all regions. The network must ensure multidisciplinary management (RCP) and continuity of care, from diagnosis to return-to-home care. Every patient, whether treated in a clinic, hospital or cancer care centre (*les centres de lutte contre le cancer*), should receive support in the network with all clinics, hospitals and cancer care centres in a given territory being either directly part of a regional network or organizing a network of cancer care in their own territory. The regional network is intended to bring together existing local networks (see below) and organize the tools common to all participants.

The main strategies employed by regional cancer networks include elements of self-management support,

delivery system design, decision support and clinical information systems.

- *Self-management support* involves shared decision-making and training patients in developing coping strategies upon being diagnosed with cancer. The *dispositif d'annonce* forms a core component of self-management support.
- *Delivery system design* includes the development of individualized care plans as implemented within RCP and personalized follow-up. It also involves regular (monthly, six-monthly) meetings of providers in the form of workshops for each group of specialties of regional importance, such as variation in clinical practice or regional guidelines.
- *Decision support* includes the use of regional cancer guidelines as implemented within RCPs, with networks translating national guidelines developed by the HAS/INCa. Regional networks develop supportive care guidelines for managing stress, pain, anaemia, and other side-effects of cancer.
- *Clinical information systems* are being implemented by regions to enable sharing of DCC. The DCC is implemented with the goal of integrating the national electronic health record programme (*dossier médical personnel*, DMP).

Similar to the general approach to financing provider networks in France, the majority of regional cancer networks are financed by the FIQCS with some receiving funding through MIGAC.

### Local or multipathology networks

The 2003–2007 Cancer Plan set out provisions to facilitate the local management and monitoring of cancer patients through the better integration of GPs into networks of cancer care. Local or multipathology networks were not structured solely around cancer however (Ellien et al., 2009).

The main strategies employed by local cancer networks include elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves shared decision-making and training patients in developing coping strategies upon being diagnosed with cancer. The

*dispositif d'annonce* forms a core component of self-management support.

- *Delivery system design* includes the participation of GPs in the multidisciplinary consultation. The GP develops a monitoring plan, covering episodes in different hospitals and treatment at home and monitoring after care including the development of an individualized care plan and personalized follow-up.
- *Decision support* includes the use of regional cancer guidelines as implemented within RCPs, with an element of provider education at local level (GPs, home care nurses) as a means to implement regional guidelines. It further involves access to specialist expertise in hospital.
- *Clinical information systems* include network GP's access to the medical records of participating patients.

The funding of cancer networks is the same as that of provider networks, namely through the FIQCS, by a joint decision of the ARS. This source of funding also goes towards the continued training of health professionals and improved coordination among actors.

### Evaluation

The regional networks are evaluated on an annual basis to assess structure, process and evolution of the network, as well as the number of patients covered. This evaluation is part of a process introduced in 2010 (*procédure de reconnaissance*) (Institut National du Cancer, 2013). Also in 2010, the newly established National Cancer Council (*Conseil national de cancérologie*), which brought together all cancer professional representatives, was commissioned by the HAS and INCa to develop the best approach to evaluation in the field of cancer care (Société Nationale du Cancer, 2010).

## 6.3 A patient journey

This section describes the journey of two hypothetical typical patients with co-morbid chronic disease in the French health care system.

(A) 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is slightly overweight (BMI of 27). She has been unemployed

*for three years and receives social assistance benefits; she lives on her own.*

Patients with chronic conditions are typically diagnosed by a GP, who will support the patient to apply for the ALD procedure for diabetes and complete a care protocol form, which will then be submitted to the local health insurance fund. As the ALD considers diabetes without restrictions, the patient will be accepted under the ALD scheme.

Once in the ALD system, the patient will have at her disposal a full range of paid services including specialist visits, medication, self-management support tools, and hospitalization, if necessary. Full coverage of costs is granted only for expenses related to the ALD condition; any other service or device (for example, dental prostheses) will require co-payment.

As there is no structured individualized disease management, it is the responsibility of the patient and her GP (and specialist) to ensure her care pathway. The quality of care and coordination of multiple interventions depend on her relationship with the GP and the specialists. Since 2005, the patient has a financial incentive to opt for a gatekeeping scheme with the *médecin traitant* ('preferred doctor') and she would consult her GP first who will, if necessary, refer the patient to a pneumologist, ophthalmologist or dermatologist. The patient is likely to receive basic diet counselling by the GP without further action at this point.

If available locally, the GP may refer the patient to a provider network for diabetes or COPD. In this case, the patient would benefit from an annual structured general check-up and a range of free services, depending on the indication, including diet counselling, ophthalmology, foot care, and patient education workshops aiming to improve self-management skills. In addition, the patient may be proposed by SHI to participate in the Sophia diabetes care programme, in which case she would receive phone calls (the frequency of which are determined by disease severity) aiming to inform the patient about diabetes and to achieve better self-management.

*(B) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure. He lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing block and are increasingly housebound due to their illness.*

*They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.*

By and large, the patient journey of this 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure resembles the example of the diabetes patient described above. The diagnosis is usually established by the GP. As the patient exhibits three conditions all of which qualify for the ALD scheme (heart failure and high blood pressure, depending on severity), he will benefit from ALD services. The coordination of general and specialist care then depends on the degree to which the patient and GP consider coordinated care necessary. There is a financial incentive for patients to see their GP first to obtain a referral; however, the system does not oblige them to do so. Neither is there a systematic structure that links GPs to specialists and/or hospitals; the degree of 'connectivity' entirely depends on personal and local factors.

The patient may be encouraged to enter a provider network (or may take the initiative and suggest it to his physician). Again, this is not systematic, but depends on the presence of a local network. In Paris, the patient would have a choice of networks for chronic heart failure or chronic pulmonary disease, depending on the dominating illness. In either network, the patient can benefit from an enhanced and structured coordination of care, self-management support and free access to otherwise fee-based services such as a dietician. This pathway is only typical when networks are locally available as in the densely populated Paris region.

As he and his wife are both experiencing increasing mobility issues, the patient's GP may recommend an evaluation to determine whether he can benefit from home care arrangements, as he wishes to stay independent. Additionally, if locally available, the entry into a network for frail older people (such as COPA, although there are very few of these) could be an option. In that event, a case manager would propose an individual intervention plan, aiming at integrating and coordinating medical and social services.

## 6.4 Summary and conclusion

In France, a major concern about lack of coordination and continuity of care within the health sector has prompted a series of initiatives starting from the mid-1990s, with important components including the

formation and subsequent formalization of provider networks and the development of a national public health plan for people with chronic disease. Overall, recurring themes can be identified in the current strategy to address chronic disease: (1) reinforcing prevention and patient education; (2) the transfer of tasks (that is, the redefinition of task sharing between physicians and nurses); and (3) the development and implementation of novel delivery and remuneration concepts.

Personalized prevention, patient education and treatment information for the chronically ill have played a major role in the mid-2000s. The educational approach, which led to the establishment of the nationwide Sophia programme for people with diabetes, has been a key concern of the SHI. The 2009 Hospital, Patients, Health and Territories Act has also set the framework for the delegation of medical tasks to nonmedical professions, considered as a necessary step to improve interprofessional cooperation as well as experimentation with novel care structures against the background of budget constraints and workforce shortages. Finally, the establishment of dedicated funds (FAQSV, DNDR, FIQCS) has created a financing mechanism, which facilitates the development of novel and integrative delivery systems. This has been complemented by structural measures such as a preferred doctor scheme introducing a coordinated care pathway, and the increasing use of pay-for-performance instruments within the individual GP contract CAPI

scheme in 2009; this initiative is increasingly accepted by doctors and grew to include specialists under the ROSP scheme in 2012.

The notion of disease management as a means to address chronic diseases has only recently received attention. A 2006 report of the Inspector of Health and Social Affairs compared international approaches to disease management and recommended that France launch a pilot for a national programme (Bras, Duhamel & Grass, 2006). This recommendation was respected by the 2007 National Public Health Plan on Quality of Life for the Chronically Ill, which foresaw the implementation of the Sophia programme and also identified care coordinators as a means to improve the care of patients with multiple morbidities. DMPs as such are not explicitly named in this plan, which is not fully implemented yet. More recent developments have identified case managers as a possible option in the care for frail older people (Premier Ministre & Centre d'analyse stratégique, 2009).

Overall, however, it remains to be seen to what extent these novel approaches will find sufficient ground within the French health care system given the continued strong cultural and professional reluctance to delegate tasks (particularly in a system based on fee-for-service payment) and to implement novel methods of monitoring health and delivering care.

# 7 Germany

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## 7.1 The health care system

In the German federal system, regulation of health care is shared between the federal and 16 state governments (*Länder*). The German health system is financed mainly from SHI (67.6% in 2012), complemented by OOP payments (12.1%), taxation (8.7%) and VHI (9.5%) (WHO, 2014). In 2012, national health expenditure was 11.3% of GDP. About 90% of the population are covered by SHI, with the remainder covered by substitutive private health insurance (Bundesministerium für Gesundheit (Germany), 2013).

Since 2009, all residents have been required to take out health insurance. SHI contributions are dependent on income (14.6% of gross income from 2015) and are shared between employer and employee, at 7.3%, although the employee will have to contribute a small additional premium, set by individual SHI funds (Bundesministerium für Gesundheit (Germany), 2014a). Dependants are covered free of charge while those receiving social assistance or unemployment benefits are covered by the state. Individuals further contribute to the cost of health care through co-payments for inpatient care and prescriptions of up to a maximum of 2% (1% for patients with a chronic illness) of annual gross income.

In the SHI system, the Joint Federal Committee (*Gemeinsamer Bundesausschuss*, G-BA) is the highest decision-making body. It is composed of the National Association of Statutory Health Insurance Funds and the federal associations of health care providers (physicians, dentists and hospitals); patient representatives are involved in an advisory role (*Gemeinsamer*

Bundesausschuss, 2013). Regulation of the health care system is embedded in legislation, set out in Social Code Book V (*Sozialgesetzbuch*, SGB). Many tasks have been delegated to corporatist actors at various levels of administration, with for example responsibility for overseeing ambulatory care in the SHI system delegated to the federal and regional SHI physician associations, while the regulation of hospitals falls under the remit of the *Länder*.

There are different types of SHI funds<sup>1</sup> and historically, residents were automatically allocated to a fund based on their profession or type of employment. However, since 1993 (effective from 1996), individuals may choose any SHI fund (with a few restrictions), with a risk-compensation mechanism (*Risikostrukturausgleich*, RSA) introduced in 1994 to compensate for differences in populations insured by different funds. Initially adjusted for age, sex and incapacity to work only, since 2009, SHI funds receive centrally allocated risk-adjusted contributions based on morbidity (Bundesministerium für Gesundheit (Germany), 2014b).

Health care services are provided through a mix of public and private providers. Ambulatory care is mainly delivered by office-based primary and specialist care physicians who have been granted a monopoly to provide care outside hospital. Office-based physicians are principally reimbursed on a fee-for-service basis, using a national relative value scale (*Einheitlicher Bewertungsmaßstab*, EBM), which is negotiated nationally between the national associations of SHI funds and of SHI physicians.

Patients have the freedom to choose any provider in the ambulatory care sector and some choice of hospital upon referral although voluntary gatekeeping using so-called GP-centred care plans (GP contracts) has been in place since 2004. Hospitals are owned and operated by a variety of public, charitable or religious and private profit-making organizations. Since 2004, the reimbursement for inpatient care has been through activity-based funding using DRGs (German DRGs, G-DRGs).

### Health care reforms of relevance to chronic disease

In Germany, a key concern in the health care system, and the social insurance system as a whole, has been

the fragmentation of care, in particular between the ambulatory and hospital sector. As a consequence, health care reform efforts over the past two decades have promoted the better integration of care, targeting different actors in the health care system (Hilfer, Riesberg & Egger, 2007). Already in 1993, the Health Care Structure Act (*Gesundheitsstrukturgesetz*, GSG) introduced provisions to support more integrated models of care, further expanded with the 1997 SHI Reform Act (*Zweites GKV-Neuordnungsgesetz*), which introduced a legal basis for experimental and pilot projects. However, although these provisions stimulated the development of more coordinated care approaches through, for example, the creation of practice networks and related formations, newly established models tended to remain at the level of time-limited pilot projects (Busse & Riesberg, 2004).

The 2000s saw a series of regulatory changes that built, in part, on the (limited) experience of the 1990s, including, in 2000, the introduction of provisions for the development of integrated care structures between the ambulatory care and hospital sectors through the 2000 Health Care Reform Act (*GKV-Gesundheitsreformgesetz*). The law also required SHI funds to set aside a defined amount per member for primary prevention or health promotion activities, with the explicit aim of reducing health inequalities (Busse & Riesberg, 2004). At the same time, it became increasingly clear that the risk compensation scheme introduced in 1994, as described above, needed to take account of morbidity to sufficiently compensate for differences in the risk structure among SHI funds (Breyer & Kifmann, 2001; Lauterbach & Wille 2001; Jacobs et al., 2002); also it disincentivized funders from investing in care for chronic disease. To (partly) address these shortcomings and until a fully-fledged morbidity-adjusted risk compensation scheme could be developed, the 2001 Risk Structure Compensation Reform Act (*Gesetz zur Reform des Risikostrukturausgleich*) introduced, from 2002, structured care programmes for those with chronic disease (disease management programmes, DMPs) into the German health care system (see below). The introduction of DMPs can be seen in the context of a critical analysis of the health care system published by the Advisory Council on the Assessment of Developments in the Health Care System in 2001 (Siering, 2008).

Subsequent changes included a further strengthening of integrated care with the 2004 SHI Modernization Act (*Gesundheitssystemmodernisierungsgesetz*, GMG) which

<sup>2</sup> These include general regional funds, company-based funds, guild funds, substitute funds, and funds for farmers, seamen and miners.

involved the removal of certain legal and financial obstacles and so effectively established integrated care as a distinct sector (Busse & Riesberg, 2004). The 2004 reform also strengthened GP-centred care (*Hausarztzentrierte Versorgung*, HZV, or GP contracts) through requiring SHI funds to offer their members such models, and introduced medical care centres (*Medizinische Versorgungszentren*, MVZ), which provide care across several health care specialties within the ambulatory care sector, an approach with similarities to the ‘polyclinic’ model of care characteristic of the former German Democratic Republic (Ettelt et al., 2006). These provisions were further enhanced through the 2007 Act to strengthen competition within SHI (*GKV-Wettbewerbsstärkungsgesetz*, GKV-WSG), which made health insurance mandatory for all and introduced the morbidity-adjusted risk compensation scheme (*MorbiRSA*), both with effect from 2009.

Further developments included the 2008 reform of long-term care which enabled piloting the delegation of selected tasks traditionally performed by doctors, including the monitoring of patients with chronic disease, to nonmedical staff, such as nurses or physiotherapists (Deutscher Bundestag, 2008a). The 2008 law on the advancement of organizational structures in health care (Deutscher Bundestag, 2008b) and the 2012 reform (*GKV-Versorgungsstrukturgesetz*, GKV-VStG) further strengthened provisions for GP-centred care (Deutscher Bundestag, 2011). The commitment to advancing GP-centred care in the German SHI system was renewed in the 2013 agreement of the incoming coalition government, including the upholding of the legal requirement of SHI funds to offer GP contracts (Bundesregierung, 2013a). It also foresaw the strengthening of nonmedical health professionals to deliver delegated tasks in the form of pilot projects across the country, including a requirement to evaluate these projects.

### Current legal, regulatory and policy frameworks

During the 2000s, Germany introduced various legal and regulatory measures to better address chronic disease although it has yet to develop an overarching, integrated national strategy that spans the continuum from health promotion and disease prevention to the management of complex conditions and palliative care.

Currently, structured care or DMPs, as introduced by the aforementioned 2001 Risk Structure Compensation Reform Act, represent the principal regulatory and policy framework for chronic disease management in Germany. Indeed, the nationwide introduction of DMPs has been viewed as one of the most important developments with regard to the care of patients with chronic health problems in the German health care system (Ettelt et al., 2006).

As noted earlier, parallel developments included a strengthening of integrated care from 2004, which enabled SHI funds to designate financial resources, totalling 1% of income, for selective contracting with single providers or networks of providers (Busse & Riesberg, 2004). However, this start-up funding (*Anschubfinanzierung*) could only be used for integrated care contracts concluded by the end of 2008. Strengthening GP-centred care (GP contracts) aimed at enhancing coordination and continuity of care, and, ultimately, saving costs by reducing duplication of services in the ambulatory care sector. Patients sign up voluntarily with a family doctor as the first point of contact for a period of at least one year; this was tied to financial incentives for the joining doctor. Since 2007, all SHI funds have to offer GP-centred care. The promotion of medical care centres aimed at enhancing care coordination through teams that typically include at least one GP but may also involve various specialists, nurses, pharmacists, psychotherapists and other health care professionals (Ettelt et al., 2006). Also since 2007, patients with chronic disease and older patients are entitled to receive care management following discharge from hospital. Providers and SHI funds are required to organize individual and suitable follow-up care, which can be provided through integrated care contracts or through regional contracts between the various actors.

In addition, the legal framework provides opportunities to explore new approaches to care and treatment options through pilot projects (see section ‘Community nurses’) and provisions for selective contracting in areas of special ambulatory care.

The regulatory framework further stipulates that citizens have the right to early detection of chronic disease. Since January 2008, SHI funds are required to inform their members about all available preventive care measures, involving the issuing of a ‘prevention passport’ to document one counselling sessions on cancer screening (for example, cervical, breast, prostate, colorectal) when

the recommended age for screening is reached (for example, cervical: women  $\geq 20$  years; prostate: men  $\geq 45$  years in 2007).

## 7.2 Approaches to chronic disease management

The preceding section illustrates the diversity of initiatives initiated in the German health care system to better address the needs of those with chronic health problems. A key concern remains the fragmentation of the system; we here describe five main approaches that were introduced over the past decade to address chronic disease management in Germany. An overview of what has been referred to as new ‘innovative care models’ is available from the InGe project, funded by the Robert Bosch Stiftung (2013–2014) (Innovative Gesundheitsmodelle, 2013).

### Disease management programmes

German DMPs have been defined as ‘structured care approaches for people with chronic conditions that have to be approved by the Federal Insurance Office’ (Bundesversicherungsamt, 2014). DMPs involve the coordinated treatment and care across different providers and on the basis of scientific and up-to-date evidence. The overarching aim of DMPs is to improve the quality of care for people with chronic disease, in particular the prevention of long-term consequences and complications, and to ultimately reduce the costs of care.

Their introduction by law was prompted by perceived shortcomings in the German health care system as outlined earlier. Implemented in a top-down process, DMPs were strongly supported by SHI funds such as regional funds, which, because of their member profile, were disadvantaged by the risk structure compensation scheme; their national association took a leading role in the development of the programmes. In contrast, smaller SHI funds, which traditionally had many young and healthy members (such as company-based and substitute funds), were concerned about potential financial disadvantages. Physicians were initially opposed because of concerns about data confidentiality, and interference with and restrictions on clinical decision-making (Siering, 2008).

DMPs are anchored in legislation, with the Federal Joint Committee tasked with the development of their

content while the Federal Insurance Office is responsible for the accreditation and oversight of programmes. The implementation of DMPs has been limited to a selected set of common and costly conditions, that require an a coordinated approach to treatment and for which there are evidence-based guidelines, among others (Siering, 2008). Following these criteria, between 2003 and 2006 DMPs were introduced for six conditions: breast cancer; type 1 and type 2 diabetes; coronary heart disease; asthma and COPD. A special module for chronic heart failure was recently added to the DMP for coronary heart disease (Bundesversicherungsamt, 2014).

Participation in DMPs is voluntary for patients and providers; participation is possible for SHI members with a chronic disease and providers who meet the requirements set out in the regulations. Patients wishing to take part have to choose a physician (usually their family physician) who then acts as the coordinating physician. The main strategies of DMPs involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves access to an education programme approved by the Federal Insurance office (Bundesversicherungsamt, 2014), which is frequently provided through group sessions in local training centres. This is the case where the treating DMP physician is not certified to provide training or cannot provide training facilities in his or her practice. It is a legal requirement that patients be actively involved in negotiating treatment goals although there is little guidance on how this should be achieved in practice. Patients are followed up at regular intervals, with patient reminders for missed sessions. Some SHI funds offer telephone services to further support their members participating in DMPs. There is no additional self-management support beyond the obligatory patient education programme, which is usually composed of four to five 90-minute sessions (Siering, 2008).
- *Delivery system design* includes the coordination of three care levels: the coordinating physician, specialized medical care and inpatient care, with the conditions for referral between levels of care set out by regulation. An example of coordination of the three levels of care in the diabetes DMP is provided by Siering (2008). Within the diabetes DMP, the coordinating physician should be a family physician although in certain cases (for example, the doctor

has already been treating the patient) this can be a specialist, for example, a cardiologist in coronary heart disease DMPs; gynaecologists usually act as coordinating physicians in the breast cancer DMP. Patient follow-up is ensured by the requirement to document a range of indicators (see below) at regular intervals of three to six months.

- *Decision support* involves the use of evidence-based guidelines as developed by the Institute for Quality and Efficiency in Health Care (IQWiG). Participating physicians have to meet defined training standards and may have to attend further training to qualify for participation in a DMP; providers are obliged to attend further training events or quality circles on a regular basis.
- *Clinical information systems* include the standardized documentation of the course of treatment, including information on the patient's condition and test results, medication regime and agreed treatment goals. Data are submitted to the SHI funds and the DMP partners who produce quality reports. Providers receive feedback reports on a number of parameters including information on how their patient data compare with the average of all practices treating at least 10 DMP patients. Since 2008, it has been mandatory to use electronic documentation forms.

DMPs are principally offered by SHI funds, based on contracts between SHI funds and providers, usually represented by the regional SHI physician associations (KV). Direct contracting between funders and networks of physicians or hospitals is possible but rare. In January 2013 there were 134 SHI funds (GKV-Spitzenverband, 2013), each offering its own range of DMPs. As each DMP has to be accredited by the Federal Insurance Office, there are many DMPs in Germany as a whole; at the end of 2013 there were about 10 500 DMPs, between 1700 and 1800 for each of the six conditions (Bundesversicherungsamt, 2014). However, as the content and organizational structure of DMPs by condition is regulated at the national level, they are very similar.

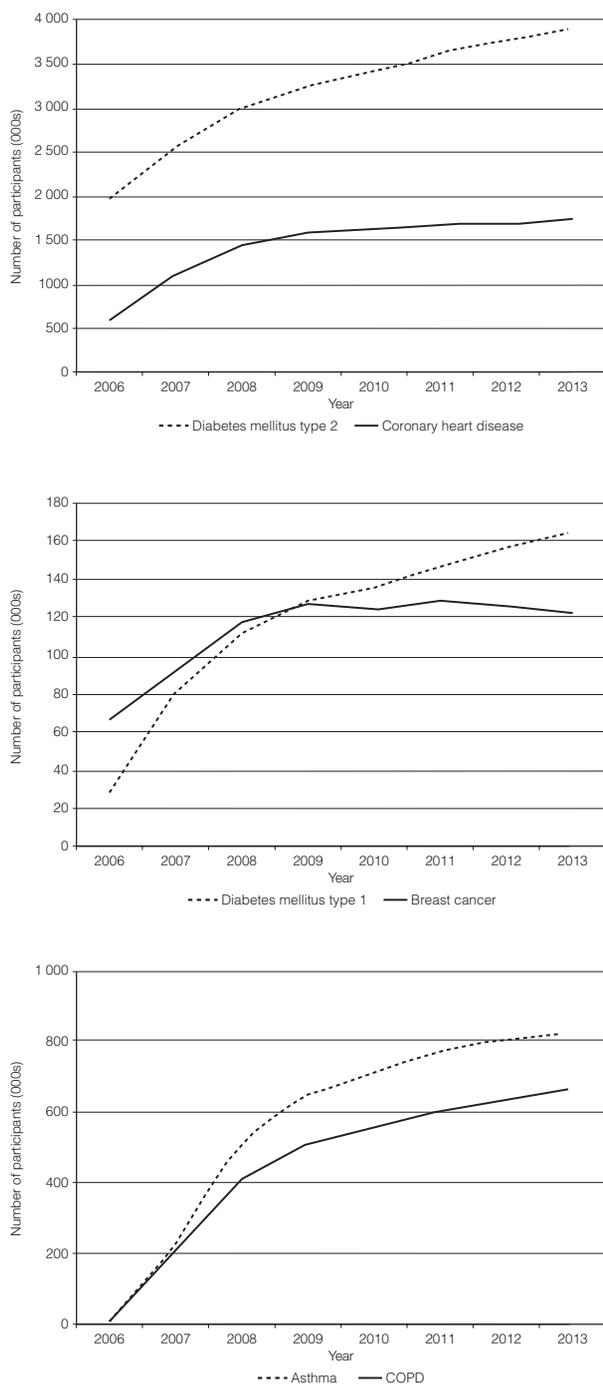
DMPs are financed through the statutory system, involving incentives for providers and funders. Participating physicians receive financial compensation for, among other things, the documentation of patient data and patient education. The precise amounts vary among regions, with around €20–25 for initial documentation and €15 for follow-up while patient

education is reimbursed at around €20 per education unit (typically 90 minutes), the number of education units to be taken varies by condition. Patient education sessions required by the DMP are free of charge.

As described earlier, the introduction of DMPs was linked to the risk compensation scheme by adding a 'DMP risk-adjuster' so that funds received additional compensation for each member joining a DMP (Busse, 2004). This provided considerable financial incentives for SHI funds to offer such programmes, facilitating their rapid nationwide implementation (Siering, 2008). However, the DMP risk-adjuster was abolished in 2009 with the introduction of the morbidity-adjusted risk compensation scheme, and compensation is now based on the morbidity profile of SHI members only. This has meant that the payment for members joining a DMP has decreased and SHI funds only receive a fixed amount (€180 in 2009 and 2010, subsequently reduced to €168 in 2011, €153.12 in 2012 and €147.84 in 2013) for each patient enrolled in a DMP, to cover programme operating costs. Whether SHI funds continue to benefit from offering DMPs now will depend, to a great extent, on whether DMP can reduce health care costs.

Following their introduction in 2002, the number of enrolled patients increased year-on-year although the rate of increase slowed from 2009 (Fig. 7.1). It is not clear as yet whether this is because the majority of eligible patients have already enrolled or whether this is due to the change in the financing mechanism (Fullerton, Nolte & Erler, 2011). By the end of 2013, a total of 6.4 million insurance members had enrolled in one or more DMP, with numbers ranging from 122 214 enrolled in the breast cancer DMP and 163 650 in the type 1 diabetes DMP, to over 1.7 million in the coronary heart disease DMP and 3.8 million in the type 2 diabetes DMP (Bundesversicherungsamt, 2014).

The number of physicians participating in DMPs varies, with an estimated 65% of family physicians acting as the coordinating physician in type 2 diabetes DMPs, 57% in coronary heart disease DMPs and about one-third in asthma and COPD DMPs. Just over 9% act as the coordinating physician for breast cancer DMPs and about 4% for type 1 diabetes DMPs, as these are mostly coordinated by gynaecologists and diabetes specialists, respectively.

**Fig. 7.1** Participation in DMPs in Germany since 2006

SOURCE: Adapted from Kassenärztliche Bundesvereinigung, 2014.

### Evaluation

The regulatory framework for DMPs in Germany stipulates that DMPs are evaluated formally to compare the quality of programmes offered by different SHI funds. An overview of the original principles of the statutory evaluation is presented in Siering (2008). In brief, the overarching aims are to verify that programme targets are reached, that criteria for assessment are adhered to and that the costs of care and patient quality of life within DMPs are assessed. The minimum requirements

for statutory evaluation are set by the Federal Insurance Office; evaluation costs are borne by SHI funds, with the most recent update of evaluation requirements published in 2012 (Bundesversicherungsamt, 2012). As this statutory evaluation generally follows an observational, non-experimental design, it does not permit comparison of the quality of care provided in DMPs to usual care. Also, although it involves a longitudinal design, as the evaluation period has to cover three years, the interpretation of observed temporal changes among participants is difficult. The evaluation is not based on individual-level data but on average data across patients without adjusting for attrition. At the time of writing, national evaluations had been published concerning the DMP for type 2 diabetes for the period 2003–2008, the DMP for coronary heart disease covering 2004–2009, as well as a progress report on the DMP for breast cancer (Bundesversicherungsamt, 2014).

To assess effectiveness, several SHI funds commissioned independent scientific evaluations, mostly of type 2 diabetes DMPs, including the ELSID (Evaluation of a large scale implementation of disease management programmes for patients with type 2 diabetes) study (Ose et al., 2009; Miksch et al., 2010). Evidence from these controlled studies point to improved outcomes such as quality of life (Ose et al., 2009) and mortality (Miksch et al., 2010; Stock et al., 2010; Drabik et al., 2012) as well as reduced costs (Stock et al., 2010). However, the extent to which improved survival can indeed be attributed to the diabetes DMP remains uncertain (Miksch et al., 2010; Schäfer et al. 2010; Fullerton et al., 2012), with other studies failing to provide evidence of improved medical outcomes (Linder et al., 2011; Fuchs et al., 2014).

Evaluations of DMPs for other indications are less frequent. Mehring et al. (2014) assessed the COPD DMP in the federal state of Bavaria. Using routinely collected data and a statistical control, their analysis points to improvements in the quality of care for those enrolled in the programme as measured by guideline adherence and self-management education, but the DMP did not lead to a reduction in the number of emergency admissions in this group. The same authors also examined the asthma DMP in the same state, using a longitudinal before–after approach (Mehring et al., 2013). This also found improvements in the quality of care for patients enrolled in the DMP, as well as a reduction in the proportion of those requiring hospitalization.

Overall, the evidence of ‘success’ of DMPs in Germany remains subject to debate. Considering the main objective for DMPs, which is to improve the quality of care for those with chronic disease, and judged on the basis of the available evidence, it appears that this objective has broadly been achieved (Fuchs et al., 2014).

### Hausarztzentrierte Versorgung (GP contracts)

The introduction of GP contracts within the 2004 health reform was aimed at improving the coordination of care and strengthening the role of primary care (*Hausarztzentrierte Versorgung*) in the German health care system overall, a notion particularly welcomed by family physicians who also saw this as a means to improve their working conditions through a new payment model.

Patients signing up for a GP contract agree to always consult their family physician first (except for consultations with ophthalmologists and gynaecologists); the family physician takes on the role of the care coordinator and refers patients to specialists or other care providers if needed. Other health care providers are not involved in the contract. Taking the example of the GP contract of the regional SHI fund AOK Baden-Württemberg, the main chronic care strategies involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves annual check-ups, advice on preventive measures and information on health promotion or disease prevention programmes and other services offered by the SHI fund. A system for the assessment of cardiovascular risk factors (‘arriba’) (Donner-Banzhoff, Popert & Altiner, 2010) supports shared decision-making on treatment options.
- *Delivery system design* includes a clear definition of roles in so far as the family physician acts as the gatekeeper to specialist care. The use of qualified practice assistants to perform case management or other tasks in the care of chronically ill patients is encouraged through financial incentives (see below).
- *Decision support* involves the use of treatment guidelines, regularly updated and made available by the association of family physicians. Also, providers have to participate in (continuous) professional training in selected DMPs (coronary heart disease, type 2 diabetes, asthma/COPD) and in at least

four quality circles per year. They are also required to commit to further training in psychosomatic medicine and rehabilitation care.

- *Clinical information systems* include the (optional) use of an electronic medical record (‘patient passport’) with full access rights to data restricted to the individual patient although she/he can grant access to the family physician. Pseudo-anonymized patient data are analysed externally with feedback reports for individual physicians. Physicians are required to implement a quality management system according to the requirements set by the regional family physicians’ association.

Since 2007, all SHI funds have been required by law to offer GP contracts, to be implemented by 30 June 2009 although the specific requirements regarding contracting partners and reimbursement have changed over time (Gerlach & Szecsenyi, 2011; Osterloh & Rieser, 2014).

GP contracts are principally financed within the statutory system and involve incentives for providers and patients. The first generation of contracts were ‘add-on’, that is, they formed part of the regular SHI reimbursement with a bonus for additional services provided within the GP contract. Subsequent (2008) regulations made it possible to negotiate more flexible reimbursement schemes, involving elements of capitation. Family physicians received a lump sum for each enrolled patient per year plus a quarterly payment for every patient contact and a bonus for chronically ill patients. There were also bonuses for rational prescribing, prevention and screening services, for the coordination of inpatient and ambulatory care, and for employing practice assistants qualified in chronic care as described below. This mode of payment provided a considerable incentive for family physicians to participate in GP contracts as it ensured a minimum income for registered patients independent from the number of consultations.

Although no additional funding had been set aside for GP contracts, SHI funds initially agreed to pay higher fees, expecting that contracts would lead to lower health care costs in the long term. This was based on limited experience from earlier projects, which suggested that a reduction in prescription costs of about 1–1.5% per annum may be possible (Wensing et al., 2009). Following the 2010 SHI Financing Act, in effect from 2011, payment of higher fees to physicians participating in GP contracts was possible only where contract partners

were able to demonstrate efficiency savings through, for example, reduced prescription costs. The efficiency requirement is however being reconsidered under the new (2013) coalition government, in recognition that the existing reimbursement modes had hindered the wider uptake of GP contracts (Osterloh and Rieser, 2014).

It is difficult to assess the number of GP contracts that have been concluded since their introduction. An assessment by the ministry of health of SHI data representing some 60% of all SHI members found that at the end of 2012 the majority of SHI members should have had access to such a contract but their availability varies across SHI funds and regions (Bundesregierung, 2013b). Precise data were however not presented. According to a 2010 survey, about 19% of those covered by SHI had signed up to a GP contract (Kassenärztliche Bundesvereinigung & Forschungsgruppe Wahlen Telefonfeld, 2010). This relatively low uptake may be explained by reluctance among patients to ‘trade in’ their choice of a specialist care provider (Lisac et al., 2010).

### Evaluation

An recent evaluation of ‘add-on’ GP contracts offered by five substitute SHI funds sought to assess the quality and efficiency of such contracts (AQUA Institut, 2013). It used routine SHI data for some 575 000 members who were enrolled in a GP contract in 2006 and 2007 and who were followed up to 2008. Applying an observational design with statistical control, the evaluation found some evidence for improved process indicators such as the proportion of specialist referrals, the proportion of patients receiving multiple medications (poly-pharmacy), and the proportion of those receiving regular check-ups compared to those receiving usual care. However, there were no clear benefits in terms of inpatient admission and costs.

The findings of an evaluation of the GP contract AOK Baden-Württemberg described above were published in 2013. Building, mainly, on routinely collected data and using statistical controls, that evaluation also pointed to improved process indicators for those enrolled in such contracts, such as a reduction in the number of unjustified specialist referrals, as well as increased participation in structured DMPs, or a reduced increase in pharmaceutical spending over the evaluation period 2008–2010 (Gerlach & Szecsenyi, 2013; Laux et al., 2013). A survey of some 2500 patients found increased satisfaction among enrolled patients, in particular as it

related to preventative measures; patients also reported that they were more likely to be presented with a written care plan (Goetz et al., 2013).

### Integrierte Versorgung

As described earlier, provisions to promote the development of more integrated forms of care (*Integrierte Versorgung*) in the German health care system were introduced in the early 1990s. This did not lead to the creation of sustainable structures however, prompting further regulatory provisions, from 2004, to encourage the development of new care structures across traditional sectoral boundaries (integrated care contracts). As has been the case with other approaches described here, the promotion of integrated care was set against the background of perceived shortcomings in the German health care system, in particular lack of coordination and communication between providers across sectors.

There is a range of integrated care contracts targeting specific chronic diseases or entire populations. We here describe two models representing the latter, *Gesundes Kinzigtal*, which coordinates and directs health care for all members of two SHI funds in the region of Kinzigtal (Hildebrandt et al., 2010) in the Black Forest area of south-western Germany, and *Prosper/proGesund*, an integrated network of providers developed by the miners’ SHI fund (*Knappschaft*) and offered in eight (former mining) regions, mostly in the Ruhr area (Knappschaft, 2014).

Participation in integrated care contracts is voluntary for patients and providers. The main strategies of *Gesundes Kinzigtal* (‘Healthy Kinzigtal’) and of *Prosper/proGesund* involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support*  
*Gesundes Kinzigtal* offers access to regular check-ups and risk assessments and patients are involved in the development of individual treatment or prevention plans and goal setting, which are regularly revisited. Patients are represented by a patient advisory board and patient ombudsman and regular surveys are aimed at monitoring patient satisfaction (Hermann et al., 2006).

*Prosper/proGesund*: Patients own a ‘health booklet’ detailing diagnoses, appointments and medications

and there is a telephone hotline for patient questions (Amelung, 2007). There is a special programme for patients older than 75 (*ProSenior*) in one region. This involves patients in the development of an individual treatment plan based on annual risk screenings, with access to additional support by a coordination office.

- *Delivery system design*

*Gesundes Kinzigtal* involves clearly defined roles with patient-identified care coordinators (physician or psychotherapist) who participate in an integrated provider network and a designated management organization responsible for coordinating providers in the network. Coordination also includes the provision of rehabilitative services following inpatient care, for example through cooperation with fitness clubs, telemonitoring service providers and others.

*Prosper/proGesund* involves clearly defined roles with regional office-based physicians forming a provider network around a regional hospital with designated staff acting as network coordinators, responsible for the implementation of ideas and the coordination of network activities (for example, organization of working groups and quality circles). To support recovery after hospital stays, *Prosper* also provides short-term care services.

- *Decision support*

*Gesundes Kinzigtal* has developed treatment guidelines for more than 15 different diseases. Providers and experts from the participating SHI funds collaborate in working groups to develop guidelines and care pathways.

*Prosper/proGesund*: Representatives of both ambulatory care and hospital sectors form a steering committee, which develops treatment guidelines, care pathways and care strategies; the SHI fund is also represented in the committee. Network partners have access to regular quality circles.

- *Clinical information systems*

*Gesundes Kinzigtal* operates a quality management system and system-wide electronic patient records. Patient data are analysed on a regular basis using predictive modelling to identify high-cost risks.

*Prosper/proGesund* operates electronic patient records, an intranet to enable communication between different service providers in the network and advanced practice software that permits instant information on available care pathways when a

patient diagnosis is entered. Patient data are also used to develop new care pathways and for evaluation purposes; patient feedback is regularly collected through a patient survey.

*Gesundes Kinzigtal* is funded by two SHI funds in the federal state of Baden-Württemberg, the AOK Baden-Württemberg and the LKK Baden-Württemberg. The overarching goal is to achieve long-term savings by investing in the prevention of chronic disease; it involves over 20 preventive and health promotion programmes for specific conditions that seek to improve patients' health outcomes and enhance their quality of life (Hildebrandt, Schulte & Stunder, 2013). The contract covers all aspects of medical care except dental care. SHI members enrolling in the programme maintain choice of provider and can leave at the end of each quarter. Start-up funding of about €4 million was used to set up management, quality control, evaluation projects and additional services; the programme also attracted additional funds for evaluation through, for example, the German Federal Ministry of Education and Research.

*Gesundes Kinzigtal* is coordinated and managed by the *Gesundes Kinzigtal GmbH* ('Healthy Kinzigtal Ltd.'). a regional integrated care management company that brings together a local physicians' network and a health care management company (OptiMedis AG) (Hildebrandt et al., 2010). Based on an integrated care contract, the reimbursement of physicians participating in *Gesundes Kinzigtal* does not require negotiation with the regional SHI physician association. Instead, the management arm of the management company acts as the 'controller'; it reimburses additional services that it considers cost-effective, including preventive measures such as regular medical check-ups, prognosis calculations, goal agreements and project group sessions. The reimbursement of physicians also involves a pay-for-performance element. Overall financial success takes into account all members of the AOK and LKK Baden-Württemberg, independent of participation in *Gesundes Kinzigtal* to ensure that any savings are not due to risk selection or the insufficient provision of care (Siegel et al., 2008). By mid-2013, over 90 providers participated in *Gesundes Kinzigtal*, including office-based physicians (about 60%), hospitals, nursing homes, and home care services. It covered just over 9300 SHI members, representing about 30% of those enrolled with the two SHI funders (*Gesundes Kinzigtal GmbH*, 2013).

*Prosper/proGesund* is funded by Knappschaft, a SHI fund initially restricted to miners. The fund traditionally operates its own medical network of office-based physicians, hospitals, rehabilitation clinics, and a medical-social service. Reimbursement schemes are negotiated between representatives of *Knappschaft* physicians and the national *Knappschaft* fund. Since all service providers are reimbursed through the fund directly, the distribution of funds is not limited by sectoral boundaries. Physicians receive a payment when participating in quality circles; there is also a bonus system that passes on cost savings achieved by the network, calculated on a quarterly basis, to providers, both office-based physicians and hospitals (Merten, 2008). Patients who enrol in *Prosper* make a commitment to seek care only from providers who are part of the network; in return, they will be exempt from selected co-payments and are also eligible to receive a premium of up to €90 (per year). In 2013, some 2000 office-based doctors participated in *Prosper/proGesund*, covering around 250 000 patients (Knappschaft, 2014).

As the two examples described here illustrate, the nature and scope of integrated care contracts varies across Germany. Many focus on the interface between acute hospital and rehabilitative care. By the end of 2008, about 6400 integrated care contracts had been concluded, covering an estimated 4 million SHI members (around 6% of all SHI members), with around 25% enrolled in contracts that cover most or all medical care in a given region (Grothaus, 2010). Coverage varies widely across regions, however, and an assessment by the Advisory Council on the Assessment of Developments in the Health Care System (SVR) in 2009 found that, in contrast to *Gesundes Kinzigtal* and *Prosper*, less than half of these contracts had incorporated elements of intersectoral care (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen, 2009). From 2008, the number of integrated care contracts has remained stagnant (Grothaus, 2010). This has been linked to the aforementioned termination of start-up funding, which became effective from 2009, with an estimated 20% of contracts terminated in 2008 and 2009 because of the discontinuation of that funding (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen, 2012).

### Evaluation

Evaluation of integrated care contracts is not mandatory. The *Gesundes Kinzigtal* is being evaluated by independent research institutions, coordinated by a newly established

agency based at Freiburg University (Evaluations-Koordinierungsstelle Integrierte Versorgung, 2014). Ongoing evaluations include an assessment of the shared decision-making approach adopted by the care model. A quasi-experimental, population-based controlled trial is aimed at evaluating service utilization and health outcomes in the intervention region compared with usual care (OUM: over-, under- and misuse of services study, carried out by Cologne University), among others (Hildebrandt, Schulte & Stunder, 2013). Preliminary findings of the latter point to improvements in the quality of care received by those enrolled in *Gesundes Kinzigtal* compared to the control group. One internal evaluation used claims data for the period 2005–2012 and applied a retrospective controlled, matched-pairs study involving some 4500 participants in each group. This suggested a small survival benefit in the intervention group, of 1.4 years: among those enrolled with *Kinzigtal*, 1.8% died, compared to 3.7% in the control group over a period of 2.5 years following enrolment (Schulte et al., 2012). There was also evidence of potential cost savings, with those participating in the care model incurring costs that were some €150 lower (per annum) than for non-members, although this effect was statistically not significant.

*Prosper* undertakes regular (biannual) member surveys to assess member satisfaction.

### Community nurses

The 2008 reform of long-term care provided a legal basis for the nationwide use of community nurses in pilot projects. It made possible the delegation of selected tasks traditionally performed by doctors to nurses or practice assistants, including the monitoring of patients with chronic disease. This presented a considerable step in the German health care system where nurses have traditionally played a very small role in primary care.

The introduction of community nurses in the provision of health care was largely prompted by local government-supported pilot projects in the eastern part of Germany, in anticipation of future shortages of family physicians in rural areas in particular. A pilot programme, *AGnES*, developed at, and subsequently evaluated by, the University of Greifswald, was implemented from 2005 to 2008 across four regions in the north-eastern part of Germany (van den Berg et al., 2009). It was supported by the German nurses association and the German council

for long-term care (*Deutscher Pflegerat*) as a means to strengthen the role of nurse practitioners in Germany. Other stakeholders, in particular family physicians and their associations, were however concerned about introducing another layer of care as well as losing control over the provision of medical care. Instead, they promoted the training of GP practice assistants, who are already employed by practices and have a long-standing relationship with patients, to perform such tasks. The main concept pursued is *VerAH* (*Versorgungsassistentin in der Hausarztpraxis*; 'care assistant in family practice'), offered as part of the AOK GP contracts.

We here describe both approaches; they involve elements of self-management support, delivery system design and clinical information systems.

- *Self-management support* mainly involves access to trained case managers in both approaches. In selected models, *AGnES* also provides access to telecare devices that enable patient self-monitoring (for example, blood glucose, blood pressure), and data transmission, from their own homes (Terschüren et al., 2007).
- *Delivery system design* includes, within the *AGnES* programme, a clear delegation of basic medical tasks to a community nurse such as blood pressure measurement and electrocardiography as well as management tasks, for example documenting medication, patient education, or case management. Community nurses have more extensive training; they work for different GPs and may perform basic medical tasks at their own discretion. Within *VerAH*, tasks can be delegated to practice assistants, but they are legally assigned and performed under the supervision of the GP.
- *Clinical information systems* within *AGnES* may involve the use of e-health technology such as data transfer recorded during home visits and transmitted to the treating physician's practice, and access to a video communication system enabling communication between nurse and physician.

A critical difference between *AGnES* and *VerAH* is the extent to which nurses or care assistants are associated with a particular physician's practice. The original *AGnES* concept foresaw that nurses could provide services to a range of practices while within *VerAH*, care assistants were already employed by a physician and they received additional training. Furthermore,

the qualification and training required by the *AGnES* programme was more complex than that within *VerAH* as was the range of tasks to be performed. Thus, the *AGnES* training programme, developed by the University of Greifswald, included 274 hours of training and a 12-week internship. Conversely, the *VerAH* programme requires practice assistants to complete eight modules of 40 hours duration in total, including case management, prevention management, health management and home visits, as well as an internship (Institut für hausärztliche Fortbildung im Deutschen Hausärzterverband (IhF) e.V., 2009). The case management module involves training in communication and motivation techniques while the health module focuses on patient education about health risks.

Since March 2009, reimbursement of medical services delegated to nonmedical professionals (using nurses or care assistants) has been regulated at the national level (Kassenärztliche Bundesvereinigung, 2009) It involves a fee of €17 for a first home visit and €12.50 for subsequent visits, although this applies to underserved regions only. Services provided can include blood pressure monitoring; the assessment of mental, physical, or psychological problems; geriatric assessments; the assessment of laboratory parameters; and coordination with other service providers. All services must be delegated by a physician. The *AGnES* nurse was redesignated as nonmedical practice assistant.

### *Evaluation*

The *AGnES* pilot programmes were principally designed to test the feasibility of introducing community nurses to provide access to primary care in rural and underserved areas. The first evaluation sought to assess the acceptability of the concept, the competences of nurses and the quality of care as perceived by participating family physicians (van den Berg et al., 2009). Using a cross-sectional design based on routine and newly collected data, the evaluation found high acceptability by patients; the majority of physicians rated the support provided by nurses positively. The use of nurses identified a hitherto unmet need for long-term care. However, the design of the evaluation did not permit assessment of improvements in the quality of care as measured by objective parameters; also, in the absence of a control group it was not possible to demonstrate how the quality of care compared with usual care.

The use of *VerAH* care assistants was assessed as part of the evaluation of the GP contract AOK Baden-Württemberg described above. Using a survey of all participating GP practices and of care assistants working in these practices, the evaluation found that care assistants did take on a number of patient-management tasks such as medicines management and case management (Mergenthal et al., 2013). This was reported to have freed up GP time, and have led to perceived improvements in the quality of care.

### 7.3 A patient journey

This section describes the journey of two hypothetical typical patients with co-morbid chronic disease in the German health care system.

*(A) A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is also slightly overweight (BMI of 27). She has been unemployed for three years and receives social assistance benefits; she lives on her own.*

Being unemployed, the patient would normally be covered by the SHI scheme. She can register voluntarily with her GP to take part in the DMP for type 2 diabetes and COPD. If the GP works in a medical care centre, she might also have fairly instant access to a pulmonologist, a diabetes specialist, and education programmes for COPD and diabetes on site. Access to these services is conditional on choosing a GP who participates in DMP.

Management within the DMP begins with a thorough briefing on the programme, where the coordinating physician and the patient jointly set treatment goals for both the diabetes and the COPD. Pharmaceuticals are prescribed according to the regulating framework that identifies the preferred treatments of type 2 diabetes and COPD. Any deviation from these procedures must be explained to the patient. The GP coordinates the patient's care. Because of her retinopathy, the GP refers her to an ophthalmologist for an eye examination. She is also referred to a foot clinic for her leg ulcer and the possible consequential damage to her legs and feet. She will be referred to a diabetes specialist in case of difficulties controlling her blood pressure or blood sugar levels, or when a switch from oral antidiabetic drugs to insulin becomes necessary. The patient is referred to a hospital (which should participate in the DMP) in the case of severe hypoglycaemia or diabetic ketoacidosis or

if infection of her foot is suspected. The COPD DMP stipulates referral to specialists when treatment results are unsatisfactory despite intensified therapy; when long-term treatment with oral steroids is required or when there are secondary disorders. Referral to a hospital is required in the case of a life-threatening exacerbation or significant deterioration of COPD in spite of initial treatment.

Following specialist treatment, the patient returns to the care of her GP. Monitoring is documented on a quarterly or half-yearly basis, at registration and at examination appointments, in both the diabetes and the COPD DMP. The patient is required to actively participate in the DMP, for example, attending recommended education programmes; she will also receive two information brochures after initial registration, on diabetes and on COPD. Failure to participate in the programme (for example, repeat missing of follow-up appointments or a prescribed education programme) may lead to her being dis-enrolled from the programme by her SHI fund. Conversely, active participation may be rewarded by additional benefits, such as a reduction in the prescription fee for pharmaceuticals. The DMP guidelines do not specifically refer to the particular social situation of the patient (in this case, unemployment). However, her circumstances are taken into consideration through the individual risk assessment required as part of the DMP and through the joint coordination of treatment goals. In addition, the coordinating physician always has the option of taking measures that apply in the usual care process.

The participation of her GP in an integrated care or GP contract would not alter the management of the patient.

*(B) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure. He lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing block and are increasingly housebound due to their illness. They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.*

As a retired engineer, the patient will be covered by SHI, while paying a reduced monthly rate for pensioners. He will also be eligible to participate in the DMP for asthma and in the new module for chronic heart failure (part of the DMP for coronary heart disease) if his GP offers these programmes and the patient remains sufficiently mobile to attend the training programmes for asthma

and hypertension. As the patient and his wife become increasingly housebound, the GP or practice assistant will visit the patient and his wife at home, monitor their chronic conditions regularly, and possibly perform a geriatric assessment in order to identify other health problems and needs. To prevent both from becoming physically inactive, the GP could prescribe a course of physiotherapy for mobilization which could also be done as home visits. The patient and his wife are entitled to receive benefits for the refitting of their apartment if this is required (a shower to replace a bathtub; or the widening of doorframes to increase accessibility for use of a wheelchair). If their pensions are small, they may apply for welfare benefits to pay for a home help to assist with tasks such as cleaning and laundry. Should they need help taking their medication, the SHI fund also pays for a nursing service on a daily or weekly basis as required to prepare their medication. The GP might also help the couple to apply for a three- to six-week course of geriatric rehabilitation which is also covered by the SHI. The patient may be referred to a specialist or hospital as specified in the DMP for asthma and heart failure. If he is not happy with his care, he can also visit a specialist directly to obtain a second opinion on his treatment. As a patient with a chronic illness, he will have to make co-payments for medication, physiotherapy, inpatient and rehabilitation care up to a maximum of 1% of his gross income per year. If his GP participates in a GP or integrated care contract that includes case management for heart failure patients, he might receive regular follow-up telephone calls by the practice assistant and be trained in self-assessment of his condition.

Should the patient or his wife require help with basic personal care, such as personal hygiene, dressing or getting up, they can apply for benefits from their statutory long-term care insurance.

## 7.4 Summary and conclusion

In Germany, there is consensus that the traditional acute, episodic model of care is no longer suitable to meet the needs caused by the changing disease burden in the population. The 2000s saw a range of regulatory initiatives, accompanied by financial incentives, to stimulate and facilitate the implementation of new models of care and SHI funds and providers have made use of these new opportunities. Despite this progress and as demonstrated by the 2009 report by the Advisory Council on the Assessment of Developments in the Health Care System (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen, 2009), the implementation of more efficient and effective care for those with chronic conditions has faced considerable barriers. The challenges were reiterated in a more recent assessment by the same group (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen, 2012).

If the goal is a population-based, intersectoral and multidisciplinary approach to health care that is of high quality and needs-oriented, there is a need for the better understanding of current and future health (and social) care needs, along with a restructuring of the care and (financial) incentive system. This requires continued evaluation and further development of newly established approaches to care, based on sound methodological approaches and valid and reliable data sources, which so far have been limited in their usefulness to inform programme advancement and evaluation. Overall, however, there is a need to provide for a continued supportive policy environment that facilitates the creation of sustainable new care models and so enables long-term planning and optimization of care suited to meet the epidemiological and demographic challenges.

# 8 Hungary

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## 8.1 The health care system

The Hungarian health system is based on the principles of SHI, introduced in 1990. Act LXV of 1990 established the Health Insurance Fund (HIF) administered by the National Health Insurance Fund Administration (NHIFA). In 2012, SHI accounted for 52.3% of total health expenditure, complemented by taxation (11.4%), OOP payments (27%) and VHI (2.7%) (WHO, 2014). National health expenditure was 7.8% of GDP.

All citizens living in Hungary have to take out health insurance; opting out is not permitted. Based on the current legal framework, the health insurance system should theoretically cover all citizens, but the health insurance status of approximately 4% of the population is unclear (Gaál et al., 2011).

The central government sets the overall regulatory framework and is responsible for policy development and, through the NHIFA, health care purchasing. HIF budget, insurance contributions and provider payments are determined centrally by the National Assembly, the government and the Ministry of Health. NHIFA contracts directly or through local governments with health care providers. Services are provided in health care facilities owned by local governments who are responsible for capital costs; private practitioners in primary care contract with local government and the NHIFA to deliver services within these premises (Gaál et al., 2011).

Primary care services are principally reimbursed through capitation while the majority of health care providers

are salaried public employees. As average salaries tend to be lower than in other sectors of the economy, it is common for patients to make informal payments to physicians at the point of service (Gaál, Evetovits & McKee, 2006). Hospital services are reimbursed on the basis of activity, using DRGs since 1993, with outpatient specialist services such as those provided in polyclinics and dispensaries reimbursed on a fee-for-service basis.

Patients are free to choose a family physician, but they can change primary care provider only once a year. Family doctors may not decline accepting patients who live in their primary care district, but they have the option of accepting applicants from other districts. Primary care physicians in Hungary are expected to act as gatekeepers for specialist care, but patients often bypass their GPs as a wide array of specialist services, including dispensaries, are accessible without referral and there are no incentives to physicians to act as gatekeeper.

#### Health care reforms of relevance to chronic disease

The 1990 reform of the Hungarian health system represented an important departure from the previous system, emphasizing decentralization of the former hierarchical model of centralized integrated health services, which was replaced with a new contract model of quasi-public arrangements for health system administration (Gaál et al., 2011). However, from 1994, reforms and structural changes focused on strict cost-containment policies, which were only relaxed from 2002, when the government began expanding the health sector for a period of four years. From the mid-2000s, reform efforts returned to cost containment, prompted by a state budget deficit of 10% of GDP; public expenditure on health has declined substantially since. Changes were characterized by extensive downsizing of acute hospitals, including a reduction in the number of hospital beds by 25% and hospital closures in the second half of the 2000s, cuts in pharmaceutical expenditure and rising levels of OOP payments from patients (Gaál et al., 2011).

With the move away from the traditional health care model that characterized the former state-socialist system, one of the key concerns for the current system in Hungary has been a lack of coordination among health care providers. Act XCI of the Social Insurance Funds' Budget of 1999 was introduced in an attempt to overcome shortcomings in the payment system

for hospitals which offered no incentives to prevent unnecessary hospitalization. This reform also saw the formal launch of a care coordination pilot, introducing financial incentives for health care providers as a means to improve integration and coordination of care in the system (see below).

More recent reform efforts led to a substantial reduction of hospital beds as described above; a proportion was transformed to increase chronic, rehabilitative and nursing care capacity by 35% to better meet the needs of patients with complex health problems (Gaál et al., 2011). However, this move was not accompanied by investments in infrastructure and human resources for rehabilitation necessary to support the actual provision of rehabilitation services on these new beds.

#### Current legal, regulatory and policy frameworks

Chronic disease management is being addressed strategically in Hungary through various national-level programmes that focus on system delivery and the integration of different levels of care. For example, the 2003 National Public Health Programme, which was introduced as a 10-year programme, defined primary and secondary prevention measures, education, information and communication technology and service delivery intervention plans (National Assembly, 2004). Among its four main priority areas, priority three focused on cardiovascular diseases and cancer and priority four addressed education, communication between providers, along with monitoring and information systems. It was accompanied by the launch of national screening programmes for breast and cervical cancer. Screening for colorectal cancer and prostate cancer was introduced on a pilot basis for people aged 50–70 years in 2006; however, the latter was terminated in 2009 (Gaál et al., 2011).

In 2006, the Ministry of Health launched the National Cancer Control Programme to address the entire spectrum of cancer care through 16 main objectives (Ministry of Health (Hungary), 2006a). Similar to the National Public Health Programme, the emphasis was on the integration of levels of care and the involvement of patient organizations in monitoring and supervising programme implementation. The 2006 National Programme for the Prevention and Treatment of Cardiovascular Diseases, issued by the Federation of the Hungarian Medical Societies, also envisaged a uniform, integrated system delivered through a network of centres

that supervise and coordinate care across levels of providers (Ministry of Health (Hungary), 2006b).

Also in 2006, the Ministry of Health launched the Healthy Society Complex Programme, supported by the EU (Ministry of Health (Hungary), 2006c). It introduced the concept of community centres (described below) to integrate primary care, outpatient specialist services and social care at the level of small regions. The 2008 Development of Regional Medical Rehabilitation Services emphasized the role of rehabilitation as an important component of chronic care (Ministry of Health (Hungary), 2008). It defined a regional rehabilitation model covering different geographical levels for primary, secondary and tertiary rehabilitation and identified the need to expand capacity, particularly in ambulatory rehabilitation with appropriate infrastructure. More recent reform papers further emphasize care coordination although ensuring the mobilization of stable and predictable flows remain the core challenge for the Hungarian health care system.

## 8.2 Approaches to chronic disease management

The preceding section illustrated the various initiatives in Hungary's health care system to better address the needs of those with chronic health problems. As noted, a main concern remains the lack of coordination among the various sectors. Against this background it is however important to recognize that, historically, a form of chronic disease management was provided for through dispensaries, which are single-specialty institutions providing outpatient specialist services to people with, for example, pulmonary disease, dermatological conditions, sexually transmitted diseases, substance abuse or psychiatric disorders. Recent approaches to chronic disease management have tended to build on this approach through integrating existing dispensaries into newly established regional oncology centres, regional pulmonary networks or national diabetic networks. We here describe a range of approaches that have been introduced over the past decade towards chronic disease management in Hungary.

### Treatment (and financing) protocols

The legal framework for treatment (and financing) protocols was introduced in 1997/1998. Implementation at the local level is ongoing, with protocols introduced

for the first time in 2005 in oncology. The main aim of treatment protocols is to control the costs of treatment, such as the use of expensive drugs in cancer care. Other conditions targeted by treatment protocols are asthma/COPD and cardiovascular diseases, including chronic heart failure, ischaemic heart disease, stroke and others.

The principal approach is the use of care pathways. Their implementation involves elements of self-management support, decision support and clinical information systems.

- *Self-management support* includes the distribution of educational material on cancer, hypertension and other cardiovascular diseases, but also more active self-management support for certain conditions, provided by patient associations (National Association of Hungarian Asthma Nurses, 2010); hospitalized patients with cancer or cardiovascular diseases are actively supported by health care staff before discharge.
- *Decision support* forms the key strategy of this approach centred on treatment protocols developed by professional associations on the basis of best available evidence, although there is variation in the quality of guidelines; in addition, provider education is available for some conditions, organized at national level and frequently supported by pharmaceutical companies.
- *Clinical information systems* are used in so far as Hungary operates an established system of disease registries for cancer, asthma/COPD and cardiovascular diseases.

The type of providers involved in the delivery of treatment and financing protocols depend on the chronic disease. For hypertension, care is GP-based whereas for cancer, COPD and asthma, care is specialist-based. Thus, the setting of treatment protocols could be within a GP practice, a hospital or a disease-specific dispensary (cancer or pulmonary dispensaries).

Treatment protocols are funded under SHI. There are no special financial rewards or penalties for protocol adherence. The extent to which physicians adhere to treatment protocols is not known; adherence is likely to depend on the professional ambition of the family doctor, further supported by the sponsorship activities of pharmaceutical companies. Although treatment protocols should in principle cover all persons with a

given diagnosis, there is a lack of information confirming that this is indeed the case. Documented regional inequalities in terms of access to care and distribution of medical capacity suggest that patient coverage by treatment protocols is likely to vary (Gaál et al., 2011).

### Evaluation

Treatment (and financing) protocols have been evaluated to determine their impact on population health status, specifically mortality reduction. The evaluation employed a total population approach without control or time series analysis on routine statistical data sources (the national disease registries and health care utilization database of the NHIFA). Routine input (basic human resource and infrastructural standards) and process (adherence to protocols) evaluation involving new data collected during site visits were also carried out, but only nominally so. The outcome evaluation is aimed at the government as funder and at providers; it is performed routinely, in an ad hoc fashion, by the relevant national institutes and professional supervisory system of the National Public Health and Medical Officer Service of Hungary, with no specific budget allocated to it.

### Care coordination pilot programme

The care coordination pilot programme (*Irányított Betegellátási Rendszer*, CCP) was developed in 1998, on the initiative of a private entrepreneur with an interest in improving the quality of life of people in the city of Veresegyház (State Audit Office of Hungary, 2005). Considered to be the most comprehensive measure in the area of health care coordination in Hungary, the programme sought to address the shortcomings of health system monitoring and the various payment systems by introducing new financial incentives (Gaál et al., 2011). Launched in 1999 it was in operation until late 2008.

The CCP (also known as care coordination system, CCS) principally built on the experience of models such as the United Kingdom's GP fundholding in the 1990s and the United States' managed care. It aimed to make health care providers responsible for the delivery of an entire spectrum of care for the enrolled population in a given geographical region, using risk-sharing under global budgets, with a view to ultimately reducing health care costs. This approach to financing was made possible through an amendment to the 1998 Act on the 1999 Budget described earlier.

The principal feature of the CCP involved the formation of a care coordinating organization (CCO) with main strategies centred on elements of self-management support, delivery system design, decision support and clinical information systems (Gaál et al., 2011).

- *Self-management support* involved the education of patients, usually by specialized nurses; active engagement of patients in developing treatment plans and setting goals; provision of self-management tools to monitor, for example, blood sugar and lung function where indicated, and regular assessment of problems and accomplishments (Bibok, 2010).
- *Delivery system design* included the creation of a CCO that takes responsibility for delivering care to an enrolled population. The CCO could be formed by GPs or groups of GPs, a polyclinic or a hospital. Additional features included regular meetings of providers, medicines management, case finding and follow-up and case management, as well as systematic screening.
- *Decision support* involved the development and use of local care pathways and evidence-based guidelines that the CCO developed in discussion with local providers, especially family doctors.
- *Clinical information systems* included access to the NHIFA database, which records provider activities and allows for the analysis of health care utilization at individual level. CCOs used the data to monitor and provide feedback on the performance of local providers (for example, about protocol adherence) as well as to create 'patient profiles' to support disease and case management.

As noted above, the principal feature of the CCP was the CCO, with responsibility for a defined population, mainly enrolled individuals with GPs acting as care coordinators. Where polyclinics and hospitals formed the CCO, these had to contract with local GPs whose registered patients then became the population covered. The participation of providers was voluntary and GPs could decline to participate (Gaál et al., 2011).

The CCP was principally funded within the statutory system, with additional sources set aside to cover administrative costs and the introduction of prevention programmes. The key difference to usual care financing was the use of global budgets based on an adjusted

capitation payment to cover all primary, secondary and tertiary care for the population enrolled with the CCO. The CCO acted as virtual fundholder in that the actual budget remained with the NHIFA. Throughout a given year, providers delivering services to the CCO's population were reimbursed as in usual care, namely within nationally defined frameworks, with the balance between the virtual budget and actual costs calculated at year-end. Any savings were transferred to the CCO, which could use these funds for remuneration and investment purposes. Initially, the allocation of savings was based on decisions made by the CCO, but became centrally regulated after 2003. Where CCOs did not accrue savings, and instead accumulated a deficit, the care coordinating function could be withdrawn and patients were to receive usual care.

The CCP was introduced gradually across Hungary, with the first wave of nine CCOs launched in 1999 (four hospitals, two polyclinics and two GP groups) covering about 160 000 residents, and expanding to 16 CCOs (six hospitals, five polyclinics and five GP groups) involving 1500 GP practices and covering 2.2 million residents in 2005. The number of CCOs varied over time, as CCOs left or joined the CCP during that period. Although the intention was to roll out the CCP across Hungary, it ended in 2008 for political reasons.

### Evaluation

There have been several ad hoc evaluations of the CCP for different audiences: decision-makers (government, National Assembly), funders (NHIFA) and the public (National Health Insurance Fund Administration, 2004). These focused mainly on structure and process measures, including the CCP's regulatory background, financial performance and distribution of savings, and were conducted by the NHIFA, Ministry of Health and the National Audit Office (State Audit Office of Hungary, 2005). Evaluations primarily used the reports of CCOs and selected qualitative methods (interviews and documentary analysis). Quantitative analysis was used only to assess the financial performance of CCOs. CCOs also conducted internal evaluations, comparing patients in terms of health care costs and utilization, for which some collected new data. However, the findings of these evaluations are not publicly available. A number of different indicators have been used to measure the CCP's effects: savings and distribution of savings among providers in the model; average cost per patient; utilization patterns; protocol adherence (for example,

percentage of recommended drugs used); the number of people screened; the number of people enrolled in primary prevention programmes; and the number of people receiving coordinated care.

### Multifunctional community centres

Multifunctional community centres were established as part of the 2006 Healthy Society Complex Programme (Ministry of Health (Hungary), 2006c). The government built on the concept of the care coordinating pilot described in the preceding section, and a desire to bring together primary, secondary outpatient and social care into one location. The aim was to improve efficiency in the health care system by providing better quality of care at lower cost.

The principal approach is the creation of a community centre. Although the framework for these centres does not prescribe the carrying out of specific functions, common features include elements of delivery system design and clinical information systems.

- *Delivery system design* involves the actual creation of the community centre with the aim of integrating primary, specialist care and social care. This also includes the development and use of integrated care pathways.
- *Clinical information systems* are to be implemented by all centres to permit information sharing; the use of an integrated information system is a requirement.

Although patient involvement is not a requirement, centres may provide self-management support in the form of patient education.

Community centres involve a range of health care providers, including family doctors, dentists, mother-and-child health nurses, night duty providers, specialists and social care workers. The construction of centres and the refurbishment of existing facilities were supported by the EU as part of the EU's European Regional Development Fund framework. Running costs are funded within the statutory system, with additional funding from local government in accordance with the services provided.

The overall programme aimed to establish 50–60 centres, covering 50–60 small regions (30–35% of small regions across Hungary). Priority was to be given to deprived areas as identified by the level of unemployment,

economic performance or health care needs (Ministry of Health (Hungary), 2006c).

### Evaluation

In principle, an evaluation of the impact on mortality, quality of life and socioeconomic status of the local population is expected at two time points: (1) the end of a multifunctional community centre project and (2) five years after completion. The evaluation would be carried out by the beneficiary local government, with a potential external evaluation carried out by the funder (EU, central government). The expected focus is on structure, process and outcome measures, including metre-squares built, equipment purchased, scope of services provided, use of telemedicine, screening programmes implemented and the number of people screened and treated, as well as utilization of services and premature mortality at the individual and population level. It is possible to assess the effects of a given project with small regions as controls, using routine statistical databases, such as that operated by the NHIFA, disease registries and data held by local organizations.

### Disease management programmes

A range of approaches that can be subsumed under the term ‘DMP’ operate in the Hungarian health care system. These tend to be embedded in the existing infrastructure of specialist outpatient units (in the case of diabetes) and dispensaries (in the case of asthma). A common feature of these approaches is that initiation or funding derives in part or entirely from the pharmaceutical or medical device industry. We here present two approaches.

#### Asthma DMP

The asthma DMP was initiated in 1994 by a pharmaceutical company (AstraZeneca). It principally builds on the concept of nurse-led care, adapted from models in place in other countries to enhance the quality of asthma care in Hungary. The principal location for the treatment of asthma is the pulmonary dispensary and the asthma DMP is located within this setting, inherited from the state-socialist system.

The programme’s key strategies involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* includes patient education about the disease and its complications, risk

factors, medication and access to lung function self-monitoring tools. Patients are actively involved in developing a treatment plan, goal-setting and decision-making. There is regular assessment of patient needs and accomplishments according to a customized follow-up system with the asthma nurse assessing patients in person or by telephone. A patient-maintained diary documents needs and activities.

- *Delivery system design* involves a specialist asthma nurse, who acts as the case manager and the patient’s first point of contact, always reachable via mobile phone, as well as regular staff meetings to discuss cases and problems. While the nurse may take certain medical functions from the physician, responsibility for all care decisions remains with the treating physician.
- *Decision support* includes the use of treatment plans based on evidence-based guidelines and the training of providers, in particular specialist asthma nurses.
- *Clinical information systems* involve the use of a national registry of asthma patients maintained by the National Institute of Pulmonology; asthma nurses are also required to keep a detailed record of each patient they manage.

The asthma DMP is principally funded within the statutory system, reimbursing the activities of providers (pulmonary dispensaries). The programme is supported by pharmaceutical companies, which fund the training of asthma nurses and also provide extra payment for the nurse. They fund equipment (a mobile phone for the asthma nurse; and a spirometer for the patient) and printed materials.

As noted above, the asthma DMP was initiated by one pharmaceutical company, with other companies following suit; it gradually evolved into a formal national network that operates as a self-supporting association of respiratory nurses involved in the care of patients with asthma. By January 2010, there were approximately 850 trained asthma nurses across Hungary. The number of pulmonary dispensaries in 2007 was approximately 160.

### Evaluation

There is no documented evidence of an evaluation of the asthma DMP.

### Diabetes care management programme

Similar to the asthma programme, the diabetes care management programme was the result of a partnership between pharmaceutical companies and professional organizations (the Hungarian Diabetes Association). It was designed to improve the care of patients with type 2 diabetes through a range of measures, with nurse-led care at its core.

The principal setting for the diabetes care management programme is the specialist diabetes outpatient unit in a hospital or university clinical department. The key programme strategies involve elements of self-management support, delivery system design and decision support.

- *Self-management support* includes patient education provided by a diabetes nurse; access to self-monitoring devices (glucometer); and regular follow-up visits to routinely assess problems and accomplishments, both in person and by telephone.
- *Delivery system design* includes a clear definition of the roles of health care staff in the diabetes dispensary, regular staff meetings to discuss problematic cases and regular follow-up of patients. It also involves the use of discharge ‘social nurses’ who manage patient discharge from inpatient care and coordinate social support, including cash and in-kind payments.
- *Decision support* includes 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.

The use of clinical information systems was planned but not implemented. Planned strategies envisaged include: reminder systems, electronic booking system and provider feedback.

The diabetes care management programme involves nurses, specialists and hospitals or university clinical departments. The programme is principally funded within the statutory system, which reimburses specialist diabetes outpatient units. It is further supported by pharmaceutical and medical devices companies, which cover extra costs such as payments to doctors and nurses, the provision of equipment and operational costs, such as mobile telephone bills. The training of diabetes specialists

(physicians and nurses) is organized by the Hungarian Diabetes Association.

The extent to which this programme has been implemented by specialist diabetes outpatient units is not well understood. In 2008, there were 176 specialist diabetes units, of which 41 were in Budapest. With one unit in Budapest covering approximately 500 patients with type 2 diabetes requiring insulin treatment, this equates to about 20 000 diabetic patients covered by such units in Budapest. However, not all units in the city offer all programme components.

### Evaluation

There is no documented evidence of an evaluation of the diabetes care management programme.

## 8.3 A patient journey

There are several possible entry points into the health care system for patients with one or more chronic illnesses:

- The family doctor (either the patient presents with a problem or is identified during annual screening);
- Night duty service or emergency ambulance service (for serious acute problems, for example, severe dyspnoea or very high blood pressure causing acute problems). The hospital is a possible entry point if the patient is taken there as a result of the acute problem; and
- An outpatient specialist surgery, dispensary or screening unit for which no referral is needed from the family doctor, such as dermatology, general surgery, ophthalmology, pulmonology or oncology; the patient may either present with a problem or is identified during screening.

As gatekeeper of the system, the family doctor should be the end-point for case management and coordination of care. Yet, it is common for a specialist seen by a patient to assume this coordinator role; some patients coordinate their own care by choosing a specialist for each problem. The family doctor may be bypassed for financial or professional reasons. Financially, the doctor has few incentives to act as a care coordinator, especially for complex cases that increase the workload, whereas specialists may take on this role when patients with financial means are able to pay them informally.

Specialists may have a greater professional incentive to coordinate care for chronically ill patients who are more interesting to them than to family doctors. Patients may also bypass family doctors due to a lack of trust.

Assuming that the family doctor is the point of entry for a chronically ill patient, the patient journey for two cases is presented below.

*(A) A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is slightly overweight (BMI of 27). She has been unemployed for three years and receives social assistance benefits; she lives on her own.*

The first step is an accurate description of the patient's present health status. Primary care surgeries only have basic diagnostics available, such as blood pressure and blood sugar measurement and electrocardiography. Complex diagnostics require a referral plan to outpatient specialist care (laboratory tests, an ophthalmologist, diabetes specialist, dermatologist, vascular surgeon (dealing with leg ulcers) or pulmonologist (COPD). For diabetes, symptoms evaluated would include leg ulcers, blood pressure, blood sugar blood profile, retinopathy and BMI. Where a diabetic patient has access to one of the diabetic dispensaries in the national network, a diabetes multidisciplinary team (specialist, nurse, and dietician) meets with the patient and follows up once in a 3-month period. The specialist prepares a drug therapy plan, on the basis of which the family doctor can prescribe oral antidiabetics and insulin, if needed. The dietician prepares a dietary and weight-loss plan. Once the therapy plan has been made, the patient is referred back to her family doctor. Some dispensaries organize diabetes clubs for patients, but their availability is ad hoc and depends on the commitment of local staff.

For the treatment of the patient's leg ulcer, the family doctor will seek an expert opinion from a dermatologist and a vascular surgeon. If surgical intervention is not required, then the patient is prescribed conservative therapy (special wet bandages) and home care based on the surgeon's written indication: 14 home care visits can be prescribed four times in a year. Should more than 14 visits be needed, a district nurse will take over. There is also an informal market for home care services which the patient or her relatives can purchase privately.

The local pulmonary dispensary is responsible for the treatment and management of the patient's COPD. The

patient would meet her family doctor only if the need arose for treatment of acute respiratory insufficiency, flu shots or end-stage oxygen therapy. Medicines for COPD can be prescribed only when the pulmonologist provides a written indication. The prescription of therapeutic exercises to manage a patient's BMI is at the discretion of the family doctor.

There is little coordination between social services and the health care sector in Hungary targeting patients requiring social assistance. The family doctor would direct the patient to the social services offered by the local government and certify need, but the patient would then be responsible for applying for cash, in-kind or institutional support (placement in a home for the elderly or assistance in the patient's own home with shopping or cleaning). Since most prescriptions require cost-sharing by patients, there is a co-payment exemption scheme for patients on social assistance with a monthly ceiling recently adopted to prevent fraud. The eligibility card issued by the local government entitles the patient to a restricted number of medicines free of charge.

In future, patients who live alone might benefit from a home-signalling system now under development.

As noted above, the family doctor would ideally act as a case manager, who would see the patient once a month for disease control (supervising drug therapy, checking key parameters and issuing routine laboratory tests), when there is no acute problem. Notably, the knowledge and personality of the family doctor are the key to ensuring patient compliance and efficient coordination in the use of necessary health services, given there is little professional supervision of the primary care system in Hungary. Although there is a formal supervisory system in place, operated by the National Public Health and Medical Officer Service, there is no nominal control by the authorities of providers in practice except in cases of serious misconduct.

*(B) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure. He lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing block and are increasingly housebound due to their illness. They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.*

The family doctor visits immobile patients in their home. The number of necessary visits depends on the

health status of the patient. As far as this example case is concerned, this would be once every week or two weeks. Occasionally, home visits can be carried out by a qualified nurse. During home visits, the physiological parameters of the patient are checked (through physical examination, on-site blood tests and blood taken for more complex laboratory tests).

If there is a need for complex diagnostics or treatment, the patient is taken to hospital. Patient transfer is provided by private companies, but paid for by the NHIFA.

Otherwise case management is similar to the previously described case (A). One remark: it is important to emphasize the importance of the personality of the family doctor in organizing the care best suited to the expectations of a patient. Relatives (such as the grandson mentioned in the case description) can be involved in the care process.

#### **8.4 Summary and conclusion**

In Hungary, a main concern remains the lack of coordination among the various sectors. Overall, there is no overarching national vision or strategy for directly controlling or managing chronic diseases. Instead, during recent years, government policy has been dominated by efforts to reduce public spending in health care in support of the country's wider fiscal stabilization

programme in response to the high state budget deficit in 2006 and subsequent global economic downturn. However, there are examples of measures that are aimed at addressing chronic disease. Historically, a form of chronic disease management was provided for through dispensaries and recent approaches have tended to build on this approach through integrating these into newly established networks for, for example, COPD or diabetes. Other examples include national programmes specific to cancer, cardiovascular diseases and public health as well as service delivery restructuring to increase the number of chronic and rehabilitation beds while decreasing capacity in the acute hospital sector (2007). The 10-year National Public Health Programme addresses three groups of chronic diseases (cardiovascular diseases, cancer and musculoskeletal diseases) with interventions mainly focussed on primary and secondary prevention, although it also includes approaches to treatment and management.

The unfavourable fiscal climate for health care in Hungary has however meant that very few programme plans or other approaches to chronic care were implemented in practice. For example, a threefold decrease in funding allocated to the National Public Health Programme between 2003 (1.8 billion HUF) and 2007 (0.6 billion HUF) presented considerable challenges for the capability of this programme to comprehensively address the prevention of chronic conditions.

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### **9.1 The health care system**

In Italy, health care is provided through the National Health Service (*Servizio Sanitario Nazionale*, SSN). Established in 1978, the SSN guarantees universal provision of comprehensive care throughout the country. The Italian health care system is funded through a combination of national and regional taxation, accounting for 78.2% of total health expenditure (2012), with another 20% financed from OOP payments; social security contributions and private health insurance play a minor role (WHO, 2014). In 2012, national health expenditure was 9.2% of GDP. OOP payments are mainly patient co-payments for diagnostic procedures, pharmaceuticals and specialist visits with exemptions for selected population groups, including people with chronic or rare disease and others (Lo Scalzo et al., 2009).

Following a gradual process of decentralization, regions have assumed considerable legislative, administrative and regulatory powers over the years. This included the devolution of responsibilities for taxation, provision and the regulation of health services within a system of 'fiscal federalism', which was substantially strengthened following the 2001 constitutional reform (Ettelt et al., 2008). As a consequence, the proportion of regional taxes as a source of health care financing has increased over time, from just over 2% in 1990 to an average of around 40% in the 2000s (France, Taroni & Donatini, 2005). To compensate for regional differences in revenue raising capacity, the government introduced, in 2001, a National Solidarity Fund (financed through central government

value-added tax revenue) to redistribute resources to regions unable to fund the basic package of services while agreement on an equitable redistribution formula has yet to be achieved (Lo Scalzo et al. 2009).

Responsibility for health care governance is shared between central government and the 20 regions. The central government provides the legislative framework for health care and defines the basic principles and objectives within which the SSN operates. It defines, through the Ministry of Health, the core benefit basket and standard of health services provided by the regions (*Livelli Essenziali di Assistenza*, ‘essential levels of care’) (Ettelt et al., 2008), with the state-regions joint commission (*Conferenza Stato Regioni e Unificate*, Standing Conference on the Relations between the State, the Regions and the Autonomous Provinces) playing an increasingly important role in priority setting and determining criteria for resource allocation.

The regions are responsible for organizing and funding health care and there is considerable variation in how regions exercise their autonomy (France, Taroni & Donatini, 2005). Health care delivery rests with geographically defined, population-based public agencies, the *Aziende Sanitarie Locali* (ASLs, ‘local health enterprises’) (Lo Scalzo et al., 2009). In 2012, there were 143 ASLs, down from 659 in 1992 (Ferré et al., 2014). The ASLs organize primary, secondary and tertiary health care by contracting with public and private hospitals and overseeing office-based GPs. Public hospitals are either directly managed by ASLs or are independent hospital enterprises (*Aziende Ospedaliere*, AOs), with a larger degree of financial and technical autonomy (Ettelt et al., 2008). Private hospitals require accreditation according to nationally defined standards to qualify for SSN reimbursement.

Primary care doctors and paediatricians operate under a national contract, complemented by regional agreements. They are paid a capitation fee related to the number of people on their list plus a share based on participation in public health interventions (vaccination and screening). Although there are financial incentives for primary care physicians to share premises, they usually work in solo practice (Lo Scalzo et al., 2009). Residents are free to choose a primary care practitioner to act as gatekeeper to specialist care, but may also access certain specialists, such as gynaecologists, directly.

Specialist care is provided by public and private providers in hospital outpatient departments, clinics and doctors’ offices. Since 1995, hospitals have been funded through a DRG-based prospective payment system, complemented by capitation and/or grants for a number of specific services (France, Taroni & Donatini, 2005; Ettelt & Nolte, 2010). Doctors working in public hospitals are salaried employees as are those working in public health and occupational medicine. About 20% of a doctor’s salary is determined by grade and performance; they may also practise privately, as long as they are not in competition with the employing hospital’s interests.

### Health care reforms of relevance to chronic disease

The 1978 Law 833, which established the SSN, constituted a fundamental reform of the Italian health care system. It has made possible policy-setting at national level, including the regular development of a three-year national health plan (*Piano Sanitario Nazionale*), a key instrument at national level, which sets out the national health strategy and defines health care objectives and targets (Lo Scalzo et al., 2009). The reform also introduced prevention and rehabilitation as essential activities of the health system. It further introduced local health authorities (*Unità Sanitarie Locali*, USLs), which were made responsible for hospitals. In 1992, Law 502 transformed the USLs into local public enterprises (ASLs), equipping them with considerable administrative and financial independence from local government. At the same time, the system underwent a gradual process of decentralization, with regions being assigned organizational and operative responsibilities that previously were the responsibility of national authorities.

Subsequent reforms included the 1999 Law 229, which introduced monitoring and evaluation systems for ASLs, hospitals and physicians. It also extended the autonomy granted to regions in managing and financing the range of services they provide to their citizens, including home and residential care. Regional competences and powers were further strengthened by the 2001 Constitutional Law 3, which (partially) increased the degree of financial autonomy within the framework of minimum standards in welfare services. More recent reform efforts have progressively afforded regions almost total financial autonomy, with 2009 legislation (Law 42) requiring central government to enact legislation, by May 2010, to guarantee the fiscal autonomy of regional

institutions (Lega, Sargiacomo & Ianni, 2010; Ferré et al., 2014). It also introduced accountability mechanisms and expenditure control systems, using economic and administrative incentives and sanctions tied to predetermined indicators of economic efficiency.

### Current legal, regulatory and policy frameworks

Population ageing is a key concern in Italy, where the proportion of those aged 65 and over is among the highest in the Organisation for Economic Co-operation and Development (OECD) countries (OECD, 2010). Yet, policies addressing chronic and age-related diseases have only been introduced relatively recently. This includes the 1998–2000 national health plan, which, within its overarching framework to strengthen health care quality in the SSN, set out a number of measures of relevance for chronic diseases, with one of its five objectives aimed at promoting healthy behaviour and lifestyles (Lo Scalzo et al., 2009). Other measures included enhancing the cooperation of providers across health and social care with legislative decree 299/1999 establishing the relevant regulatory framework to promote better integration of the two sectors. These provisions were further strengthened by the 2003–2005 national health plan, which set the target of achieving a higher level of integration between health and social services, including through significant reorganization (Ministero della Salute, 2003). The most recent national health plan 2011–2013 confirmed the emphasis of integration across sectors (Ferré et al., 2014).

At the same time, a 2003 agreement by the state-regions joint commission emphasized the need for ‘active prevention’, with a subsequent operational plan *Piano Nazionale Prevenzione Attiva 2004–2006* (‘national plan for active prevention’) specifying that ‘active prevention’ can be understood also in the context of disease management as a means to reduce the risk of disabling or fatal complications, with a particular focus on diabetes (Ministero della Salute, 2004). It identifies the key components of disease management to include a computerized monitoring system; involvement of multidisciplinary professionals and institutions in treatment; and active patient participation in the management of the disease through education and support provided by primary health care services networks. The subsequent national plan for prevention (*Piano Nazionale della Prevenzione*, PNP) 2005–2007 established national priorities in the field of prevention. It further strengthened activities in relation to diabetes as

part of a wider strategy to prevent cardiovascular diseases, along with cancer screening, immunization and the prevention of injuries; measures were to be coordinated by the *Centro Nazionale per la Prevenzione e il Controllo delle Malattie* (National Centre for Disease Prevention and Control) (Ministero della Salute, 2005). Among other things, the plan required regions to adopt measures to reduce complications arising from diabetes and to increase patient adherence to treatment, making specific reference to DMPs. Each of the 20 regions has responded to the plan by enacting regional laws and regulations for meeting the plan’s targets.

Following extension of the targets set out in the PNP 2005–2007, first to 2008 and then to 2009, with only few modifications, a new three-year prevention plan was eventually published in 2010, covering the period 2010–2012 (Ministero della Salute, 2010). It confirmed diabetes management as a priority for regional and local authorities, and supported the development of the IGEA (*Integrazione, Gestione e Assistenza per la Malattia Diabetica*) project described below.

Parallel developments included the adoption of the 2006 WHO Regional Office for Europe’s ‘Gaining health’ strategy for the prevention and control of noncommunicable diseases, within the *Guadagnare Salute* programme (2007) (Ministero della Salute, 2007). It focused on the prevention of common risk factors such as tobacco and alcohol use, lack of physical activity and poor diet, while also promoting the reorganization of health care services in line with the principles of disease management. It emphasized primary care over secondary care and patient engagement in the Italian health care system. In addition, to support the monitoring of population health and health behaviours, the Ministry of Health commissioned the development of a system for the ongoing surveillance of major behavioural risk factors and preventive measures for noncommunicable diseases, the ‘Passi’ system (*Progressi delle Aziende Sanitarie per la Salute in Italia*, ‘Progress by Local Health Units Towards a Healthier Italy’) (Baldissera et al., 2011). The system involves an ongoing nationwide collection of data using a standardized questionnaire. It covers almost all of the country’s ASLs and comprehensively monitors the health status, behaviours and preventive measures among the adult Italian population.

## 9.2 Approaches to chronic disease management

As noted in the preceding section, policies addressing chronic and age-related diseases have been introduced relatively recently, with the focus at national level mainly on prevention, while early detection, case management and disease management are encouraged and financially supported at the regional level, although only for a small number of conditions (de Belvis et al., 2009). We describe four approaches to chronic disease management that have been introduced in the regions of Italy from the early 2000s.

### IGEA – Integrazione, Gestione e Assistenza per la Malattia Diabetica

IGEA is a national strategy to support the implementation of disease management for type 2 diabetes at the regional level (Istituto Superiore di Sanità, 2014). It was developed in 2006, following the identification of diabetic complications as a priority intervention area by the 2004–2006 national prevention plan. The definition of disease management adopted by IGEA follows that proposed by the United States Centers for Disease Control and Prevention, referring to an ‘organized, proactive, multicomponent approach to health care delivery’ which integrates care along the spectrum of the disease and its complications (Maggini, 2009).

At the national level, the key actors involved in the development of the programme and the evaluation of regional performance were the National Centre for Disease Prevention and Control and the National Institute of Health (*Istituto Superiore di Sanità*, ISS). Regional government agencies are responsible for the coordination and implementation of the programme, acting as a link between central government agencies, regional governments and the ASLs (Istituto Superiore di Sanità, 2014).

The overall objective of IGEA is to improve the quality of care, placing the patient at the centre of the care process (Maggini, 2009). It has developed a series of tools to support the regions in the gradual implementation of disease management for people with diabetes, taking account of geographic differences while ensuring that interventions are uniform. The main strategies promoted within the IGEA project involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves access to a structured diabetes education programme provided by trained staff (specialists, nurses and GPs), the active involvement of patients in developing a care plan and the provision of self-management tools and routine assessments of problems and accomplishments. Particular attention is given to social determinants of health (ethnicity and socioeconomic factors), thus including socio-cultural mediators.
- *Delivery system design* includes the use of integrated care pathways involving multidisciplinary health care teams and case management for patients with complex needs. A specialist nurse develops care or treatment plans that are tailored to the needs of individual patients. Teams bring together a range of professionals, including endocrinologists and other specialists involved in the treatment of diabetic complications; these include nurses, dieticians, podologists, psychologists and pharmacists. Team composition varies in accordance with individual patients’ needs.
- *Decision support* involves evidence-based guidelines for the management of type 2 diabetes developed by the ISS for use within IGEA (‘Recommendations’ (Istituto Superiore di Sanità, 2007)). It also includes provider training, which is in two stages, a training-the-trainers stage at national and regional level and individual provider education. The programme not only targets diabetes management and communication training, but also promotes multiprofessional teamwork and communication among health professionals, people with diabetes and other relevant stakeholders. Periodic meetings seek to inform training and develop further disease management practice. A methodological guide to assist trainers’ teams and software to support the evaluation of training programmes have been developed (Istituto Superiore di Sanità, 2014). Participation in training is voluntary, however, and those who partake receive education credits (*Educazione Continua in Medicina*, ECM).
- *Clinical information systems* include the development of paper-based or electronic registries of enrolled patients, using administrative and ad hoc data collection. The format of registries varies among regions. For example, the Piedmont region uses a disease registry that only includes general information on enrolled patients while other regions

sought to implement diabetes registries capturing detailed clinical information. A document, 'The information system' sets out principles for the development of information systems as a means to harmonize the various regional experiences and as the basis for future activities of the IGEA project (Istituto Superiore di Sanità, 2008).

In addition, regional governments periodically present the results of the project to representatives of patient organizations. Patient representatives are also involved in the earlier stages of training activities in each region, which set out the overall design of the project to adapt it to the local epidemiological and organizational features. Furthermore, patient representatives were members of the multidisciplinary working group based on the GRADE (Grades of Recommendation, Assessment, Development and Evaluation) (Schünemann et al., 2008) methodology, which was specifically created to design the programme and outline the guidelines for its implementation in the single regions.

Disease management as implemented within IGEA is funded from usual sources, that is, within the Italian SSN. Because diabetic complications were identified as national priority in the 2004–2006 national prevention plan, and because the 2005–2007 national prevention plan made specific reference to regional projects, IGEA financing was complemented by national and regional funds earmarked for prevention and allocated by the Interministerial Committee for Economic Planning (*Comitato Interministeriale per la Programmazione Economica*, CIPE).

As noted above, a core component of disease management as implemented within IGEA is the use of multidisciplinary teams; this also includes the formation of provider networks spanning the different levels of care, namely primary care (GPs) as the first point of contact for patients enrolling in the programme, and secondary and tertiary care (hospitals), as well as administrative structures (ASLs and regions). Patients join upon invitation by their GP, following diagnosis according to national guidelines. The participation of providers in regional projects is principally voluntary although some regions have introduced financial incentives for GPs whose patients sign up for the relevant DMP (for example, Piedmont). Other regions have made it a requirement for GPs to provide a minimum dataset (for example, Abruzzi). Again other regions have not introduced any specific incentives or requirements for GPs participating

in disease management activities within IGEA (for example, Campania). Non-financial incentives for GPs and other providers to participate include networking, information sharing, access to guidelines and peer pressure.

Although the IGEA project was developed in 2006, the implementation of DMPs at the regional level has been a gradual process and patient enrolment is ongoing. In addition, a number of local health agencies have already had DMPs in operation; one of the goals of IGEA is to harmonize existing projects by ensuring that general guidelines are made available and that certain minimum requirements are being met. For this reason, it is difficult to provide precise figures on the number of residents covered by IGEA.

Overall programme implantation has been advancing, albeit at slow pace. Where it has been fully embraced, GP participation rates have reached up to 100%, for example within several local health agencies (ASLs) in Piedmont and Emilia-Romagna regions, and one ASL in Sardinia. At the beginning of 2010, just over 1900 GPs in Piedmont were reported to have participated in the programme, equating to about 60% of GPs and covering about 50 000 patients, corresponding to 30% of the entire diabetes population in the region. There was an expectation that because IGEA has been promoted by governmental agencies, representing national and regional authorities, and because it is financed from public sources that GP participation would eventually reach 100%.

### *Evaluation*

Evaluation is a mandatory feature of IGEA. It is not aimed at measuring the efficacy or efficiency of single chronic disease management interventions, as this is assumed to have been established by the existing scientific literature and international guidelines. Instead, the evaluation is aimed at monitoring the implementation of IGEA in regional settings to identify critical points, institutions or operators that could improve the design and features of the interventions adopted. It also aims to monitor participation in and interoperability of the actors involved and to control the efficient implementation of the interventions by regions, local health agencies and GP practices and so secure sustained (financial) support by decision-makers.

Approaches to evaluation vary among the regions as does the range of indicators for which data are being collected, and the nature of the data. Regions have allocated a proportion of national and regional funds assigned to IGEA for evaluation. Data collection has to be performed at regular intervals, typically every six months. About half of the regions have adopted the set of clinical indicators proposed by the National Centre for Disease Prevention and Control's national guidelines for IGEA which include process and outcome measures. It is difficult to obtain more recent information but what is available suggests that Piedmont, Emilia-Romagna and selected local health agencies across Italy have undertaken. Piedmont region has largely adopted the indicators proposed by the Italian Association of Diabetologists (Associazione Medici Diabetologi, 2008). The first results are available, but they have not been formally published.

### Dalla medicina d'attesa alla sanità d'iniziativa project, Tuscany

Concern about population ageing and the rising burden of chronic conditions prompted the regional government in Tuscany, in its Regional Health Plan 2008–2010 to set out a three-year strategy for the development of a new organizational approach to health care, emphasizing proactive patient care (Regione Toscana, 2008). Described as *Dalla medicina d'attesa alla sanità d'iniziativa* ('From On-Demand to Proactive Primary Care'), the new approach was to be built on the principles of the expanded Chronic Care Model (Barr et al., 2003; Regione Toscana, 2009a), with care pathways developed for five conditions in the first instance: moderate to severe hypertension, diabetes mellitus, congestive heart failure, COPD and stroke, with possible extension to Parkinson's disease, dementia, severe chronic degenerative osteopathy and rheumatoid arthritis.

The strategy essentially constituted a structural reform of the regional health system in Tuscany, with implementation in two stages, an initial phase (from January 2010) and full implementation following evaluation of the initial phase, from January 2011 (Regione Toscana, 2009a). The key components of the approach involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves access to education and counselling on aspects of the disease, including

lifestyle and behaviours, recognizing the symptoms of complications and handling emergency situations, together with instruction in self-monitoring activities. Patients and their carers are actively engaged in developing the care plan with their GP, the nurse and, depending on the patient's level of need, a specialist; they have to sign up to the plan (giving informed consent) when commencing treatment, and provide feedback or suggestions to the GP or nurse throughout the process. This includes regular assessments by the nurse of problems and needs. Where necessary, patients will have access to devices such as postural and physical aids for stroke patients. Patients' quality of life and satisfaction with or experience of the programme is monitored regularly. Those with special needs as identified by age or socioeconomic status might also be supported by specifically trained social workers who will coordinate further support, such as nursing care or free aid tools, as required.

- *Delivery system design* includes the use of clinical pathways for each of the five conditions and delivery by multiprofessional teams ('modules'). Each team meets periodically for organizational audits with the community health doctor at the local health agency assigned to it for regular updates on progress. Staff roles are clearly defined with flow charts describing checkpoints and actions to be taken at the occurrence of any event, which may also include involving of nonhealth professionals such as social workers. The team is led by the GP responsible for the team's clinical activities; she/he sets up specialist assessments specific to a patient's medical needs, with the staff nurse playing a key role in case management and counselling. Care plans are tailored to individual patient's needs, and involve continuous controls and assessments by the team.
- *Decision support* involves the use of international and scientific guidelines to inform the development of clinical pathways and a comprehensive programme of peer education, targeting all professionals involved in the general delivery of the programme as well as single groups of professionals on specific issues, followed by an evaluation at completion. Each medical team ('module') includes specialists in disciplines appropriate for the patient's needs; these are called upon at specific points along the clinical pathways, but can also be referred to when necessary by the nurse, the GP and the patient. Nurses

are trained in case management and counselling techniques specifically for the project.

- *Clinical information systems* include paper-based or electronic databases using administrative data provided by the community health doctor at the ASL. They also monitor the performance of the practice team in regular meetings, based on predefined process and success indicators which are specific to the area of activity of team members. Information is shared among team members and recorded on the lead GP's electronic filing system, where it can be made available for subsequent reference; team members without Internet connections are provided with this by the region. An electronic booking system is in place to support continuity of care, maximize appropriateness and comfort and minimize patient drop-out; among other things it identifies content of follow-up and the responsible team member.

A core component of the programme is the use of multiprofessional teams ('modules'), led by a GP and including all GPs involved in the treatment of enrolled patients, supported by a community health doctor at the local health agency. The team always includes a specifically trained nurse who acts as the patient's first point of contact. The team may also include specialists and allied health professionals; its composition will vary in accordance with the patient's chronic condition, involving for example a cardiologist, dietician, rehabilitation specialist and social worker for patients with heart failure; or diabetologist, cardiologist, podologist, psychologist or psychiatrist, dietician and physiotherapist for diabetes patients.

The 'From On-Demand to Proactive Primary Care' project was funded from usual sources, namely from within the Italian SSN, with regional regulations stipulating a total allocation of resources to project implementation of €8 883 000 over a period of three years (Regione Toscana, 2009b). The participation of GPs is principally voluntary; participating GPs qualified for financial incentives determined by the level of involvement (namely, whether they coordinate teams or participate through enrolling patients into the programme) and the achievement of objectives. Payment of the fee is conditional on meeting certain criteria, such as adherence to the programme as assessed by process indicators (20%), submission of electronic register data for patients for each of the five conditions targeted by the

programme (20%), attainment of intermediate outcome measures for a given condition (30%) and final outcome indicators for that condition (30%) (Regione Toscana, 2009a). Assessment of goal achievement is performed for each team; each GP participating in the team is allocated, in accordance with the above criteria, a part of the maximum reimbursement proportional to the number of patients enrolled in the programme. Thus, GPs coordinators are eligible for a maximum annual payment of €1500 if the number of patients enrolled with the team is lower or equal to 15 000, and €2250 if the number is higher than 15 000. GPs who participate but do not act as coordinators are entitled to an annual fee of €4.5 per patient per year.

As noted above, project implementation was in two stages, with the initial start-up and pilot phase in 2010 involving the establishment of approximately 50 modules (teams) covering about 500 000 residents and initially targeting patients with diabetes and heart failure, with the subsequent addition of further modules and extending coverage to the remaining three conditions (COPD; stroke; hypertension). By April 2012 and following further extension, the programme covered some 106 modules and a total of 1.2 million (or 38%) of the resident population, with just over 1000 GPs (about one third of all GPs in the region) participating in the programme (Ruggeri, 2014). Building on this programme, Tuscany is currently embarking on a wider primary care reform which places the extended chronic care model at its centre, anticipated to cover 100% of the Tuscan population in 2015 (Quotidianosanità.it, 2013).

### *Evaluation*

The 'From On-Demand to Proactive Primary Care' programme in Tuscany has been evaluated on an ongoing basis, using a pre-post design with statistical control and benchmarking against regional standards, complemented by qualitative elements. The overarching goal of the evaluation was to assess the degree to which project implementation conformed with the approach set out by the expanded chronic care model in the management of patients with diabetes and chronic heart failure initially (Regione Toscana, 2009b). It used a minimum set of indicators defined in collaboration with GPs including structural as well as clinical and organizational process measures. Evaluation frequency varied with the indicators considered. The indicators with the highest frequency were assessed every three months. The majority of data were collected on a routine

basis (for example from administrative sources) while some are specifically collected.

The evaluation was carried out internally at the level of local health agencies and regional level bodies (the Regional Monitoring Committee for the Implementation of Proactive Primary Care). Objectives were defined by the local health agencies and, in the first year, to be expressed in terms of improvements relative to the initial levels while from the second year, every local health agency had to demonstrate improvement against a regional benchmark, based on the regional average of the given indicator.

### Leonardo pilot project, Apulia

The *Leonardo* programme for disease and care management was developed during a three year public–private partnership agreement, initiated in 2004, between Pfizer pharmaceutical company and the regional government of Apulia (Pfizer, 2014a). Designed as a pilot study for a new approach to chronic illness care, its objective was to improve the quality and effectiveness of health care for those with chronic conditions, including type 1 and type 2 diabetes, chronic heart failure and high cardiovascular risk. It targeted GPs to facilitate systematic integration into the existing organizational framework set by ASLs.

*Leonardo* was based on the principles of patient self-management, individualized care plans, case management and the use of electronic information systems, building on the components set out by the Chronic Care Model (Wagner et al., 1999). Its main purpose was to assess the feasibility of implementing an approach developed in the United States for use in the context of the Italian health care system. The project involved elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves access to patient education based on the ‘eight priorities’ approach defined by Lorig (2001). It uses a care manager, who is usually a specialist nurse trained in counselling techniques and communications skills, with an emphasis on the psychological aspects of assistance in breaking old habits and forming new ones. The care manager guides the patient through the different stages of raising self-awareness (pre-contemplation, contemplation, determination,

action, maintenance). Assessment of patient needs is systematic, with the care manager scheduling meetings with the patient, in person or by telephone, to discuss needs and conditions at care initiation and follow-up, introducing modifications to the plan in accordance to the individual patient’s needs.

- *Delivery system design* includes the use of the aforementioned care manager, who works with the GP to deliver the individual patient’s care plan. Staff roles are clearly defined, with the care manager assessing the patient’s needs and potential problems while the GP is responsible for treatment and supervising the care manager. Staff meets regularly, at intervals determined by the severity of the patient’s condition as assessed by the level of care intensity required. Flow charts describe the activities set out in the care plan and medicines management is a core component of the plan.
- *Decision support* involves the use of evidence-based principles of care management and scoring systems (for example, the New York Heart Association (NYHA) scoring system for heart failure) built-in specifically designed software (see below) and the training of staff, with care managers trained in counselling and communication techniques and GPs in the use of programme software. Access to specialist expertise is available where required.
- *Clinical information systems* includes access to a specifically designed software, InformaCare™, developed by Pfizer, which provided the IT platform for the project. Its features include reminders for providers to enable periodical assessments, diagnostic tests and treatments; data collection on process and outcome indicators for performance assessment; continuous monitoring of progress and information sharing. An electronic booking system is in place, as well as a preferential option for specialist consultations.

*Leonardo* disease and care management was designed to supplement the current practice of patient care by introducing a care manager who, in collaboration with the GP, works with patients in the doctor’s office, the patient’s home or via telephone. A public–private initiative, it was funded jointly, with contributions that included non-financial resources, such as the InformaCare™ software. Funds were set aside in the Apulia region’s budget for GPs, including both a lump sum at the beginning of the project to incentivize

participation, and a variable payment at the end, its volume determined by performance, as assessed using process and outcome indicators.

Overall, the project involved 85 GPs in the Apulia region (about 2.5% of GPs practising in the region), working with some 30 care managers, and covering just under 1160 patients for a project lasting 18 months at the local health agency ASL di Lecce (Pfizer, 2014a).

### Evaluation

As noted earlier, the *Leonardo* disease and care management programme was designed to test the feasibility of implementing a United States-based model in a defined area in Apulia in southern Italy, with a view to subsequent roll-out across the region. Using a before–after study design without control, it aimed to assess the level of satisfaction among all participants in the project, and to develop and tailor a chronic disease management intervention adapted to the features of Apulia's health care system. The long-term goal was to integrate this programme into the health care system, and to identify and develop further evaluation techniques for future application.

The evaluation was carried out, over the project period of 18 months, by a regional scientific committee, comprising representatives of the local health agency, the local scientific community and physician's associations (GPs, cardiologists, endocrinologists), citizens, and the Italian Society for Quality in Healthcare (*Società Italiana per la Qualità nell'Assistenza Sanitaria*, SIQUAS). While the focus of the project was on feasibility and implementation rather than efficacy or efficiency, the evaluation assessed a series of clinical process and outcome indicators as well as structural measures, using newly collected data.

### Raffaello project, Marche and Abruzzi

The *Raffaello* project was a research project designed to assess the effectiveness of an innovative model of patient care for the prevention of cardiovascular diseases on the basis of disease and care management in general practice (Pfizer, 2014b). It was launched in 2007, developed by the Marche and Abruzzo regional health agencies with support from the central Ministry of Health and Pfizer pharmaceutical company. Its introduction was informed, in part, by the *Leonardo* project described earlier, which also involved Pfizer.

Similar to the *Leonardo* disease and care management programme, *Raffaello's* core feature was the use of a care manager, a qualified nurse who supports the patient along the care pathway. The project involved elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves the active participation of patients in devising their care plan and in the decision-making process. Patients have access to a care manager who carries out counselling ('coaching') and follow-up activities by telephone, in the doctor's office or in the patient's home; the mode is determined in accordance with the individual patient's needs. Patients also have access to information material on the disease, lifestyle, and to services available in the geographical area.
- *Delivery system design* includes the use of a care manager, who works with the GP to deliver an individual patient's care plan. This 'personalized health plan' is tailored to the needs of the patient and developed through collaboration between the care manager, the GP and the patient. Staff roles are clearly defined with the GP managing the clinical–therapeutic component of the health plan, and the care manager overseeing it. The project further applies the principles of case finding through measures of primary prevention, screening of asymptomatic patients at risk for cardiovascular diseases, and treatment of patients with a history of cardiovascular diseases who are thus at high risk for complications.
- *Decision support involves* provider education, including a training-the-trainers component as well as individual provider training for both GPs and care managers, with the latter specifically educated in professional skills. An additional stage was added later to identify and address any problems that may have arisen following initial training (in three- to six-month intervals, starting from March 2008). Access to specialist expertise and experience is mentioned in the project, but while specialists are consulted and their opinions considered in developing and modifying the health plan, they do not play an active role in the team. Before programme launch, the simulation instrument DEOS (Discrete Event Object-Oriented) was used for a preliminary evaluation of the impact of the processes of disease and care management on the existing organization,

and to support decisions in improving the interventions.

- *Clinical information systems* include the use of a software specifically developed for care managers, enabling regular reminders for GPs of scheduled tests and appointments; facilitating communication between patient and staff members and ensuring adherence to evidence-based guidelines; and the evaluation of clinical outcomes. Similar software has yet to be integrated into the current information systems available to GPs.

The core feature of the *Raffaello* disease and care management programme was a collaborative relationship between the patient, the care manager and the GP, which places the patient at the centre of the care process. A public–private initiative, it was jointly funded by various actors, including regional health care funds complemented by additional funds from the Italian Ministry of Health’s ‘Special Programmes’ fund and co-financed by Pfizer, Italy.

Designed as a scientific project, the *Raffaello* project was limited to a defined group of patients recruited for participation, a total of 900 patients in the regions of Marche and Abruzzi, with 16 clusters of GPs participating in the experimental arm of the study (see below).

#### *Evaluation*

*Raffaello* was an epidemiological study, designed as a randomized clinical trial that aimed to assess the efficacy of the disease and care management approach implemented in Marche and Abruzzi regions, evaluating health outcomes, process indicators as well as social outcomes and undertaking a cost–utility analysis. The overarching aim of the evaluation was to assess the percentage of patients achieving the target reference in at least one cardiovascular risk factor, with a secondary objective to assess the economic impact of the approach (Pfizer, 2014b). The trial included 900 patients from Marche and Abruzzi regions enrolled in the experimental group with another 900 patients in the control group receiving ‘usual care’.

Evaluation was over a period of 12 months, completed by mid-2009. The findings of the trial were recently published by Deales et al. (2014). They found the intervention to be effective in controlling cardiovascular risk factors, in particular hypertension

and diabetes, although there were no differences in hypercholesterolemia, smoking status and obesity between the intervention and control group.

### 9.3 A patient journey

This section describes the journey of two hypothetical typical patients with co-morbid chronic disease in the Italian health care system.

*(A) A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is also slightly overweight (BMI of 27). She has been unemployed for three years and receives social assistance benefits; she lives on her own.*

The patient would typically be diagnosed by her GP, following her complaining of chronic dyspnoea or frequent urination with thirst and subsequent spirometry or oral glucose tolerance test requested by the GP. Alternatively, she is diagnosed in hospital, after dyspnoea re-acutization or painful leg ulcer, which triggered spirometry or oral glucose tolerance test requested by hospital doctors. The patient would then be examined by her GP and prescribed drug treatment for COPD and diabetes; she would be informed about the treatment and instructed in using the medication. The GP would typically directly supervise and monitor treatment and refer her on to a specialist for periodical eye examinations and nephrology tests; referral is largely on discretion of the GP. As the disease progresses, the patient will experience worsening of symptoms or complications. In case of a life-threatening exacerbation or significant deterioration in spite of initial treatment, she would either request an urgent appointment with her GP who may or may not refer her on to hospital or she directly attends the emergency department in hospital, followed by admission where required.

If the patient resides in an area where new models of care are implemented, such as structured disease management within the IGEA framework, or the Tuscany reform programme, the patient would still typically be diagnosed by her GP as in usual care. If the patient resided where the *Leonardo* or *Raffaello* programmes operate, her conditions would also be diagnosed by her GP, following planned screening for risk factors. In either case, she would then enter a structured programme, which involves systematic assessment by the GP and a case manager, typically a specialist nurse, and possibly

a specialist, and the development of an individualized care plan, which takes account of the individual's needs and suggestions. In line with the care plan, she would have regular assessments, usually in person. This may involve home visits in case her ulcer worsens. The care plan is revised when required, and in discussion with the patient. The team looking after her also includes a social worker who supports the case manager and evaluates the patient's eligibility for further formal support. A software system or a written plan provides for a reminder system for staff. The patient herself and her family will be educated about her conditions, including disease progression, self-monitoring for signs and symptoms, coping strategies and so on. She will also receive lifestyle advice and set personal goals with her case manager. This support programme is typically on a continuing basis.

Her care plan foresees regular consultations with specialists where severity of her conditions require, with additional consultations possible when needed. The specialist will normally be a member of the team looking after the patient so as to ensure care continuity, supported by regular team meetings and information sharing. The entire pathway is designed to delay disease progression, reduce the risk of complications and medication errors, and so the risk of hospitalization for the disease.

*(B) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure. He lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing block and are increasingly housebound due to their illness. They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.*

The patient journey for this elderly patient is principally similar to that described for the women with co-morbid diabetes and COPD in both usual care and structured disease management. Where pathways differ is in the role of social services support which, in case of the usual care pathway, would likely involve referral, by his GP, to social services for an assessment of eligibility for home care support or private nursing services. This service, where implemented, would typically operate in parallel with little or no collaboration between the GP

and the nursing service. In contrast, in the framework of a structured programme such as within IGEA or the Tuscany reform programme, he would receive free transportation for community services whenever he or his wife need to attend a medical service, such as diagnostic test or treatment and where this is not possible to perform in their home.

## 9.4 Summary and conclusion

In Italy, major initiatives to address chronic diseases are relatively recent but relevant strategies are receiving increasingly greater attention by policy-makers and health care providers. However, as a consequence of the increasing autonomy of regions, there is considerable diversity with regard to the extent and quality of such strategies across the country, or even across local health authorities within regions, with many initiatives tending to be located in the north of the country. In addition, as in other countries, there is considerable fragmentation between social (municipalities) and health care services (local health agencies).

Recent initiatives have aimed to overcome these challenges through implementing centrally planned and target-driven coordination. Examples include diabetes, for which there is a framework for initiatives of regional and local authorities, which are responsible for adapting the guidelines to their own specific organizational and epidemiological features and to achieving the targets agreed upon. This framework for diabetes was confirmed by the 2010 national plan for prevention, covering the period 2010–2012 and identifying diabetes management as a priority for regional and local authorities and which has been adopted by all regions. Furthermore, a small number of regions and local health agencies have cautiously introduced a number of experimental initiatives on chronic diseases that are not (yet) considered by national projects, mainly involving specific formation of GPs – often promoted by scientific organizations or pharmaceutical companies. Accordingly, attempts to implement disease management can be expected to spread slowly.

# 10 Latvia

*Taavi Lai, Maris Taube, Cécile Knai*

## 10.1 The health care system

The health care system in Latvia operates on a tax-funded national insurance basis with a purchaser–provider split. The central government is responsible for financing the statutory system through tax revenue, accounting for 56.7% of total health expenditure, with OOP payments contributing 20.2% (2012) (WHO, 2014). In 2012, health expenditure constituted 6.0% of GDP.

Tax revenue allocated to health care by the Ministry of Finance is transferred to the National Health Service (NHS), a state-run organization under the jurisdiction of the Ministry of Health, which signs contracts with all statutory health care providers. The NHS thus acts as principal purchaser of health services on behalf of the Latvian population (Mitenbergs et al., 2012).

Primary care and specialist services available under the statutory system are provided in a variety of institutional settings. Primary care providers are independent, self-employed practitioners, who may be directly employed by local governments or by health centre administrations. At the end of 2010, 97% of primary care physicians were trained as GPs, with the remainder trained as internists and paediatricians (Mitenbergs et al., 2012). Primary care is provided primarily by GPs in their role as family doctors. Patients can freely choose their primary care physician, who acts as gatekeeper to specialist care. About 96% (2010) of residents of Latvia are registered with a family physician. Direct access to specialists is possible in selected cases only, involving consultation with gynaecologists, ophthalmologists, paediatricians, psychiatrists (mental disorders), narcologists (substance

misuse), pneumonologists (tuberculosis), oncologists, specialists for sexually transmitted diseases and endocrinologists (diabetes mellitus).

Payment methods for services and health care professionals have evolved over several years and are complex. They are determined by government regulations and defined in contracts. Health care personnel working in health care institutions are salaried. GPs are paid through capitation, plus fees for defined activities, bonus payments, fixed practice allowances and a voluntary pay-for-performance scheme (Mitenbergs et al., 2012).

Specialists are paid by means of a fee or flat-rate for episodes of illness. Hospitals are remunerated on global budget in combination with fixed payment and case-based payment; plans to implement a DRG-based hospital payment system by 2014 have yet to be realised. Direct patient payments to bypass waiting lists for non-urgent operations (orthopaedics, cataracts or hernia), or costly examinations (such as computed tomography or magnetic resonance imaging) are possible.

Secondary health care is provided by state and local government or private institutions. Public hospitals are contracted by the NHS. Most hospitals are joint stock companies. There are a number of specialist hospitals for acute care and the long-term treatment of psychiatry and substance abuse, and in obstetrics and traumatology. Specialized hospitals are concentrated in the capital and in the largest cities.

The private sector in the Latvian health care system includes (privatized) polyclinics, dental care practices and pharmacies, as well as independent primary care practices that have emerged in recent years following efforts to develop this form of institutional setting for primary care. Private and independent providers must contract with the NHS to qualify for the reimbursement of services provided within the statutory health care system.

### Health care reforms of relevance to chronic disease

The reform of health care financing began in the 1990s, introducing a purchaser–provider split and involving a series of experiments with different approaches throughout the 1990s, including fee-for-service, capitation and capitation with fundholding, DRG and volume-based contracting systems. More recently, a

unified payment system has been adopted for providers throughout the country. The 1990s also saw the adoption of a GP-based model of health care as a strategic priority in 1996. In 1998 the State Compulsory Health Insurance Agency (SCHIA) founded the Primary Health Care Support Fund, which, with international assistance, paid for the retraining of physicians as GPs and provided assistance for setting up primary health care practices.

One of the most important ongoing reforms is the Master Plan, or ‘Programme of Development of Primary and Hospital Care Services for 2005–2010’, led by the World Bank. The aim of this reform was to ensure the further development of an integrated health care system by optimizing the quantity and distribution of service providers, thus increasing the quality, cost-effectiveness and rational accessibility of health care services while reducing administrative costs and improving the quality of care.

Latvia was seriously affected by the 2008–2010 economic crisis, resulting in substantial cuts to the state budget, especially in health care, and leading to major changes in agencies and institutions active within the Latvian health care system. The Public Health Agency and the Health Statistics and Medical Technology State Agency were closed, and others reorganized, despite widespread opposition from experts. At the same time, the economic downturn provided an important incentive for renewed health care reform, for example a reduction of inpatient care beds through the closure of economically unviable hospitals. However, these changes were also met by strong public opposition and the reform initiative has slowed.

Budget cuts in health care have reduced access to services, increased the length of waiting times and the proportion of OOP payments in health care financing. Currently, the only areas of health care financed almost fully from public sources are emergency care and health care services for children. A quota system is used for controlling service volume, the costs of specialist care, laboratory tests, hospital care, surgeries, and procedures. A potential risk involved in such approaches is an increase in informal payments to receive health care services. A draft on health care financing that seeks to address some of these issues was proposed at the end of 2013, principally through the introduction of SHI. However, the likelihood of this law being approved is seen to be small (Mitenbergs, 2014).

## 10.2 Approaches to chronic disease management

There is currently no documented explicit vision for chronic disease management in Latvia and relevant programmes have yet to be developed. Chronic conditions are managed at the primary care level; family doctors provide general health care for children, adults and elderly people, including rehabilitation, preventive services and health promotion (Mitenbergs et al., 2012).

The *Vaivari* National Rehabilitation Centre offers services related to chronic care, for example a neuro-rehabilitation programme for patients with stroke. The centre runs education programmes in disease prevention for patients and their relatives. It also provides a paediatric rehabilitation programme for children with conditions such as chronic lung diseases, myocarditis or rheumatism, and an adult rehabilitation programme that helps patients recover after heart surgery, chronic pulmonological diseases, myocarditis, rheumatism and other diseases.

However, there is growing consensus in Latvia that there is a need for a system of chronic disease management. Policy documents setting out a vision for chronic disease have been developed. Examples include the ‘Programme for controlling oncological diseases for 2009–2015’, ‘Improving the mental health of the population in 2009–2014’, a draft of ‘Public Health Guidelines 2011–2017’ and others. At the local level, the NHS has begun developing guidelines for the management of diseases and health conditions. These guidelines are intended to define roles, responsibilities and the interactions of different stakeholders and care levels (for example, prevention of diseases, health promotion, primary care, secondary care, criteria for specialist consultation and availability of health services).

Primary care is envisioned to have a central role in chronic disease management and further strengthening of this care level is planned. These include an increase of nursing staff for GP practices with a high proportion of patients with chronic disease, training for primary care staff on supporting patient self-management, health promotion and disease prevention, with the addition of home health care to the primary health care framework. A quality system for GPs has been established since 2005, and evolved from voluntary in 2011 to mandatory in 2013. This system is focused on health promotion, disease prevention and the control of chronic diseases

(for example, asthma, cardiovascular diseases, diabetes mellitus, etc.) (Mitenbergs et al., 2012).

### *Evaluation*

The overall acknowledgement of the need to evaluate programmes, activities and strategies is poor, and the policy and pressure for evaluation from funders is almost nonexistent. Thus the capacity to perform evaluations is low, exacerbated by the providers’ lack of interest.

## 10.3 A patient journey

This section describes the journey of one hypothetical typical patient with co-morbid chronic disease in the Latvian health care system.

*A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is also slightly overweight (BMI of 27). She has been unemployed for three years and receives social assistance benefits; she lives on her own.*

If the patient is registered as low income by the community social care services, she has free access to GP. She also has free access to specialist care but only upon referral by a GP. Until 2012, associated costs would have been covered by the World Bank support programme for Latvia. Within this system, the patient also had access to medicines free of charge. Special support programmes for persons in need have been upheld by the state after the World Bank support programme ended in 2012.

Initial diagnosis of both the diabetes and COPD is most likely done by the patient’s GP. Either condition is principally managed by the GP. However, given the evident disease severity and co-morbidities, it is most likely that the patient is referred to an endocrinologist and pulmonologist for further consultation. The specialist appointment is most often made by the patient based on the referral but can also be made directly by GP.

Depending on the specialist’s assessment of disease severity, the patient may be admitted to hospital, scheduled for routine treatment in ambulatory specialist care, referred for additional testing that is not available at the primary care level, or discharged to care by her GP with a verified diagnosis and specialist suggestions for the appropriate course of treatment. Care provided by the GP will also include lifestyle consultation (or provided by a primary care nurse), supported by disease specific

lifestyle advice from endocrinologist and pulmonologist (and other specialists if need be).

The GP principally coordinates the overall treatment, the primary management of diabetes and, to some degree, the follow-up of specialist care (for example, provides reminders for specialist consultations). The GP will share these data with the specialist to whom the patient has been referred and will receive all results from the patient's consultations with the specialist(s).

Her social assistance benefits are most likely a form of disability benefit, which the GP will request on behalf of the patient. Both GP and specialist can contact social care specialist for the patient to be considered for social care services. However, this referral is most likely made by the GP with advice from the specialist. The same applies to referrals to rehabilitation services.

## 10.4 Summary and conclusion

While, at the time of writing, there was no documented explicit vision for chronic disease management in Latvia, there is growing recognition of the need to develop a more systematic approach to the management of chronic disease. Primary care is envisaged as having a central role in chronic disease management and further strengthening of this care level is planned. Reform efforts over the past decade have been hampered by the impacts of the financial crisis, which have posed considerable challenges to the government. Budget cuts in health care have reduced access to services and increased the proportion of OOP payments in health care financing. Currently, the only areas of health care financed almost fully from public sources are emergency care and health care services for children.

# Lithuania

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## 11.1 The health care system

The Lithuanian health system is principally funded through SHI, through the compulsory health insurance fund, administered by the National Health Insurance Fund (NHIF), an agency under the auspices of the Ministry of Health. Statutory insurance accounted, in 2012, for 60.1% of total health expenditure, complemented by tax revenue (10.7%) and OOP payments (28.5%) (WHO, 2014). In 2012, health expenditure constituted 6.7% of GDP.

The NHIF is responsible for overall compulsory health insurance fund performance, as well as for the procurement of medicines and other medical supplies. The health care system covers all public providers including those working under contracts with five NHIF regional branches (Murauskiene et al., 2013). The state budget contributes more than 30% of the NHIF's total revenue to cover certain population groups.

Overarching health policies are set by Parliament, with the Health Committee and National Health Council in an advisory function, and government, while the Ministry of Health is responsible for the general supervision of the health care system. It shares responsibility for operating two major university hospitals and after the abolishment of the regional (county) level of the public administration system from July 2010 the ministry is in charge of health care provision in about 20 health care institutions. Since 2003, gradual reorganization of the public health care facilities network is under way, with its goal to achieve safer, efficient and more cost-effective

care through the prioritization of family and specialist outpatient care, and the optimization of inpatient care (Republic of Lithuania, 2009). A new stage of the network consolidation has recently been declared: it is planned that in 2013–2016 functional clusters will be piloted and implemented starting from prioritized cancer, heart and cerebrovascular diseases, injuries, child diseases managing models (Ministry of Health of the Republic of Lithuania, 2014).

Access to health care is guaranteed for the vast majority of residents. Joining the state health insurance scheme is mandatory for the working population. Children, recipients of social assistance, the unemployed, and patients with certain diseases (about 60% of the population) are insured by the state. The insured population is eligible to receive all publicly financed health care services. Co-payments for medicines present the major share (approximately 75%) of private health care expenditure. Emergency care is free of charge.

Sixty local governments are responsible for the organization of primary care. The primary care system in Lithuania comprises family physicians, community mental health centres, ambulance units and nursing hospitals. These are typically financed as non-profit-making foundations. Staff are usually salaried and employed by health care institutions. Family physicians act as gatekeepers to specialist care provided in outpatient and inpatient care facilities. The private sector comprises mostly small dental practices and other outpatient facilities; it employs about 10% of physicians and 60% of dentists. Municipalities are also responsible for organizing and financing social care services. Social care policies are developed and overseen by the Ministry of Social Security and Labour.

Primary care providers are paid through capitation, calculated on the basis of the number and age structure of the enrolled population, with additional payment for people living in rural areas and incentive payments for certain listed services and performance. Outpatient specialist care providers are paid on a fee-for-service basis; payment for secondary and tertiary specialist care is uniform throughout the country. Providers are paid according to the actual volume of health services provided, according to the terms and conditions set by their contracts with the NHIF branches. Currently, AR-DRG (Australian Refined DRG) v6 is under implementation in Lithuanian hospitals.

### Health care reforms of relevance to chronic disease

A key defining feature of the Lithuanian health care system was the 1995 Primary Health Care Development Strategy, which focused on strengthening and expanding the role of family physicians (Ministry of Health of the Republic of Lithuania, 2005a). It also included the development of family physician practices and a network of community mental health centres. Contracting and financing were conducted under the health insurance scheme. The primary care system was further strengthened in 2007 (Ministry of Health of the Republic of Lithuania, 2007), involving an expansion of the concept of primary care to include primary personal health care, dental health care and primary mental health care; improving collaboration of family physicians and specialists; and involving family physicians in municipal health and social care programmes. The reform introduced a series of evaluation criteria for primary care involving the quality of treatment of chronic noncommunicable diseases and the scope and efficiency of prevention programmes, as well as nursing and social care at home. More recently, there is an intention to complement family practice by assistants, to increase competences and incentives including those for better collaboration with social workers.

### Current legal, regulatory and policy frameworks

There is no documented explicit strategy for chronic disease management in Lithuania. However, there is a growing interest in developing a more systematic approach to the management of chronic diseases, as for example highlighted in the 2008 annual report of the National Health Council. A range of related activities have aimed at strengthening the framework for more structured chronic disease control and management. These include the 2008–2010 National Family Health programme, which aimed to strengthen the health of families, improve prevention and early diagnostics, and secure good quality and accessible health care services. Assessment criteria for programme implementation included, among others, a reduction in the number of new mothers diagnosed with postnatal depression and an increase in the scope of palliative care and nursing services provided at home or in health care units. The latter includes more systematic efforts towards the development of continued care models for people with chronic diseases. The programme also identified the need for the management of mental health problems through

the development of new services, including occupational, social and home based services, patient advocacy and the involvement of family members.

Also in 2008, the government adopted the chronic noncommunicable disease research programme (Republic of Lithuania, 2008). Targeting cardiovascular diseases, cancer and diabetes, the programme aimed at providing insights into the management of morbidity and mortality from chronic diseases.

More recently, the 2011 Lithuanian Health System Development Dimensions (2011–2020) set out a strategic direction for health promotion, disease prevention and the reduction of morbidity and mortality (Parliament of the Republic of Lithuania, 2011). It aims to improve health management and financing as well as access to and quality and safety of care. The document foresees the creation of a financing mechanism for the integration of nursing and social care, piloting an integrated primary care model based on case management, and the integration of public health services into the provision of personal primary care services.

## 11.2 Approaches to chronic disease management

As indicated in the preceding section, there is growing interest in a more systematic approach to chronic disease management, emphasizing coordination and integration in particular. Experience so far can be broadly distinguished into approaches to improve intersectoral collaboration and the systematic use of clinical guidelines. Recently, policy initiatives to establish health care clusters addressed an issue of better coordination of health care delivery.

### Improving intersectoral collaboration

Gaps in intersectoral collaboration, especially between the health and social care sectors, have led the Ministry of Health and the Ministry of Social Security and Labour to issue rules on integrated health and social care, to be implemented at the municipality level, in all 60 municipalities.

The routine assessment of problems and accomplishments is carried out by multidisciplinary teams of physicians, nurses and social workers, who are responsible for defining and addressing patient needs, and considering

clinical, social and financial dimensions. Different types of care are provided and financed, mainly, from public sources. In terms of delivery system design, case finding is the most common tool considered for chronic disease management at the community level. Case management is being piloted for patients with HIV/AIDS and selected mental health problems. Some settings use more comprehensive approaches. For example, one clinic in Panevezys county provides, in parallel, primary care, nursing and social care at home and in the day centre. It has been recognized a best practice example for the public sector. Other examples include the provision of psychosocial rehabilitation for people with chronic mental disorders in Vilnius and Siauliai, seeking their re-integration into the labour market.

Intersectoral collaboration is further supported by the adoption of guidelines on joint nursing and social services, issued in 2007, by the Ministry of Health and the Ministry of Social Security and Labour. These identify major target groups, and define responsibilities and mechanisms for long-term care. Following the 2012 Programme of Integrated Care Development, 20 projects focusing on increasing social care and nursing at home delivery have been implemented in 2013–2015 across Lithuanian municipalities (Ministry of Social Security and Labour of the Republic of Lithuania, 2012).

### Clinical guidelines

Since 2002, clinical guidelines adopted by the Ministry of Health have covered the most costly and prevalent diseases. They were developed and adopted as clinical diagnostics and treatment algorithms. The development and introduction of clinical guidelines have been strongly motivated by governmental agencies and funders (Ministry of Health of the Republic of Lithuania, 2000; Budrys et al., 2001; Ministry of Health of the Republic of Lithuania 2004a–2004f, 2005a–2005d, 2009). Expert working groups have further developed the guidelines, on the basis of a meta-analysis of scientific evidence. Initially, guidelines were introduced to manage the reimbursement by the NHIF for the cost of medicines prescribed for outpatient treatment listed as reimbursable. Some guidelines were adjusted; these currently serve as diagnostic and treatment algorithms in clinical practice. Algorithms set the framework for collaboration between GPs and specialists. The NHIF also introduced, and finances, prevention and early diagnostic programmes in primary care; these cover programmes for breast,

cervical, prostate and colon cancer (Ministry of Health of the Republic of Lithuania 2004f, 2005b, 2005c) and for the screening and prevention of cardiovascular diseases among high-risk population groups (Ministry of Health of the Republic of Lithuania, 2005d).

### 11.3 A patient journey

This section describes the journey of two hypothetical typical patients with co-morbid chronic disease in the Lithuanian health care system.

*(A) A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is also slightly overweight (BMI of 27). She has been unemployed for three years and receives social assistance benefits; she lives on her own.*

*(B) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure. He lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing block and are increasingly housebound due to their illness. They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.*

Both cases would be ‘managed’ by the family physician, community nurse and community social worker. Typically, patients will be pre-diagnosed by their family physician and referred to the specialist for confirmation of the final diagnosis and the development of a treatment plan. The family physician will remain the main contact for the patient, supervising management by following the defined treatment scheme. In case of the women with type 2 diabetes, the family physician will monitor the course of the condition and she would consult with the nurse on her diet.

In both cases, where complications arise, the patient might be referred to specialists at secondary or tertiary health care level. Depending on severity, they might be admitted to nursing homes for a maximum four months per year, which will be covered by the NHIF. They can also access medical nursing care at home free of charge.

Medication is accessible and usually reimbursed by the NHIF. Access to self-management support is limited and at present accessible through selected active patient organizations only, such as the diabetes association or the patients’ nephrological association; there are also cancer patients’ organizations.

Again depending on the severity of their conditions, the patients described here may be considered as unfit to work, following assessment of their capacity to work, and may qualify to receive disability pension or, alternatively, social assistance. The patient in case A could also claim for some social services paid from the local budget, while the patient in case B likely receives retirement pension.

Any person, including the two examples considered here, who are in need of permanent or nursing care may qualify for additional benefits, for example, payments to buy additional social services or, less frequent, payments to the main caregiver where she/he receives care in their home, for example the wife of the person in case B. Institutional long-term care is co-financed on the basis of means-testing.

### 11.4 Summary and conclusion

There is growing interest in developing a more systematic approach to the management of chronic disease in Lithuania. Although there is no documented explicit strategy to that effect, the National Health Council, an independent advisory body reporting to parliament, has expressed commitment to promoting more coordinated care. Ongoing health care reform efforts are set towards the implementation of a strategic direction for health promotion, disease prevention and the reduction of morbidity and mortality overall. A range of initiatives are being implemented, principally organized around intersectoral collaboration and the systematic use of clinical guidelines, with primary care in the form of family medicine viewed as the cornerstone for enabling structured chronic disease management. Newly implemented health care policy initiatives focus on establishing health care clusters.

# The Netherlands

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## 12.1 The health care system

In the Netherlands, governance of the health care system is shared by the government and the corporatist sector. Health care financing is mainly from mandatory health insurance (2012: 72.6%), complemented by taxation (7.3%), OOP payments (5.6%), and VHI (5.2%) (WHO, 2014). In 2012, the national health expenditure in the Netherlands was 12.4% of GDP.

Following the introduction of a single insurance scheme under the 2006 Health Insurance Act (*Zorgverzekeringswet, Zvw*), all residents are required to take out private health insurance. Health insurers must offer access to a basic, but comprehensive, centrally defined package of essential curative health services (Schäfer et al., 2010). Residents contribute to this scheme through a flat-rate, or nominal, premium paid directly to the health insurer of their choice, and an additional income-related contribution deducted through payroll and transferred to the Health Insurance Fund. Funds are redistributed to insurers according to a risk adjustment scheme that compensates for differences in the risk profile of the insured (Klein-Lankhorst & Spreeuwenberg, 2008; Schäfer et al., 2010). There is a compulsory deductible (2013: €360) for all care except GP services, obstetrics and maternity care, and dental care for those under 18 years (Schäfer et al., 2010). Those who incur structural care expenses over time, for example due to chronic illness or disability, receive financial compensation. In addition to the compulsory deductible, insurers can offer their clients a voluntary deductible (between €100 and

€500) in return for a discount on their premium. OOP payments are required for certain medicines and medical devices, seated patient transport and maternity care, as well as for obtaining care from a non-contracted provider (Ministry of Health, Welfare and Sport, 2012). Those on low incomes may qualify for a ‘health care allowance’, funded from income-related contributions.

The mandatory private health insurance scheme constitutes the so-called second compartment of the Dutch statutory social insurance system. The first compartment comprises long-term care insurance, regulated under the Exceptional Medical Expenses Act (*Algemene Wet Bijzondere Ziektekosten*, AWBZ) (van Kemenade, 2007). It covers a range of services such as assistance, personal care, nursing care and treatment and is mainly financed from income-dependent contributions and means-tested co-payments under the AWBZ, complemented by state subsidies (Mot et al., 2010). The third compartment comprises complementary voluntary insurance to cover the costs of forms of care considered as non-essential, such as dental care for adults, psychotherapy, and items such as eyeglasses that are not covered under AWBZ or Zvw (Schäfer et al., 2010).

With the 2006 health care reform, the role of government has moved from direct steering towards one of overseeing and defining the rules for the health care system. It has reserved the right to intervene where the system is underperforming. It has also retained responsibility for public health in so far as local authorities are responsible for the provision of services concerning health protection, disease prevention and health promotion.

The Netherlands has a long tradition of nongovernmental health care provision, originating from private and often charitable, voluntary organizations (Schrijvers, 1997; Klein-Lankhorst & Spreuwenberg 2008). Thus, health services are generally delivered through private providers in both the ambulatory and hospital sectors. Office-based GPs act as gatekeepers to secondary (hospital) care (Schrijvers, 1997; Saltman, Rico & Boerma, 2006). They are remunerated through a combination of capitation and fee-for-service (Schäfer et al., 2010). Maximum remuneration fees for GP services, and for services provided by allied staff in GP practices, are negotiated between the National Association of General Practitioners (*Landelijke Huisartsen Vereniging*, LHV), the umbrella organization of health insurers operating in the Netherlands (*Zorgverzekeraars Nederland*, ZN),

and the Ministry of Health, Welfare and Sport. Health insurers may negotiate lower fees, although this is rare.

Specialist medical care is provided in hospitals, which have traditionally been owned and operated by private non-profit-making organizations (van Kemenade, 2007). Since 2005, hospital services have been reimbursed on the basis of activity, through ‘diagnosis treatment combinations’ (*Diagnose behandel combinaties*, DBC), a system of DRGs, which considers complete episodes of care. It describes a complete set of activities (diagnostic and therapeutic interventions) ranging from associated outpatient visits prior to admission to rehabilitation and care following discharge (Oostenbrink & Rutten, 2006; van Kemenade, 2007). The main objectives for introducing the DBC system were to increase transparency in hospital and specialist care and move from a supply-led to a demand-led system. In addition, the DBC system was expected to enhance efficiency and to stimulate regulated competition between health care providers (Oostenbrink & Rutten, 2006). However, as these objectives were only partly achieved, the DBC system was further reformed in 2012 (DOT: DBCs On their way to Transparency’) to reduce complexity (Hasaart, 2011). Medical specialists are either independent, organized in partnerships working in a hospital (75%), or are salaried employees. The latter is common for university and municipal hospitals. Since 2008, independent medical specialists have been paid through the DBC and subsequent DOT system.

### Health care reforms of relevance to chronic disease

The 2006 Health Insurance Act (Zvw) constituted a fundamental reform, which replaced the former dual system of public and private health insurance with a single mandatory scheme to ensure access to essential curative health care for all residents. It also aimed to improve the quality of care and reduce health care expenditure by strengthening market mechanisms in the health care system and promoting competition. Under the new regulatory framework, health insurers are private and may operate on a profit-making basis but are heavily regulated (Bartholomé & Maarse, 2006); they cannot reject application for membership and have to provide coverage irrespective of individual risk (Maarse & Ter Meulen, 2006). Insurers compete on prize (nominal premium), service level, and quality of care; residents may switch insurers or health plan at the end of each

calendar year. The percentage of people switching insurers has increased to 8.3% per annum in 2013 (NZa, 2013). Insurers have been granted extended powers to negotiate with provider organizations, including the option of selective contracting and the introduction of novel approaches to delivery of services such as the use of specialized nurses instead of doctors (Bartholomé & Maarse 2006; van Kemenade, 2007; Klein-Lankhorst & Spreeuwenberg, 2008). The new framework also offers the option to conclude contracts with collectives such as groups of patients with a specific chronic condition, for example through patient associations such as the asthma fund (*Astma Fonds*) and the diabetes patient organization (DVN), thus providing opportunities to target care delivery to the specific needs of those with chronic conditions. However, between 2006 and 2013, such contracts accounted for only about 2% of the collective market annually, which is dominated by employers (2013: 52% of market share) (NZa, 2013).

The 2007 Social Support Act (*Wet maatschappelijke ondersteuning*, Wmo) transferred the responsibility for certain forms of home care to municipalities, including domestic help, meals on wheels, home adjustments, and transport. The Services for the Disabled Act (*Wet voorzieningen gehandicapten*, Wvg) was integrated into the Wmo as part of the long-term care for the disabled and chronically ill previously included in the AWBZ. The Wmo aims to enable chronically ill and/or disabled people to live independently and fully participate in society (Tjalma-den Oudsten et al., 2006; Mot et al., 2010). Municipalities are free to set their own policies under the Wmo, leading to some extent to inequalities in access to care. More recently, the 2009 Act for Allowances for the Chronically Ill and Handicapped Persons (*Wet tegemoetkoming chronisch zieken en gehandicapten*, Wtvc) replaced the regulation that made health care expenses tax-deductible, with an entitlement for chronically ill and disabled people to receive a fixed allowance to compensate for excessive health care expenses (Schäfer et al., 2010).

In parallel, in a move to facilitate the use of nurses in the care for chronically ill and elderly people, the 2009 Order of Council amended the 1993 Individual Health Care Professions Act (*Wet op de beroepen in de individuele gezondheidszorg*, BIG). It provided clinical nurse specialists with a set of qualifications to autonomously perform common and minor medical procedures in the areas of preventive, acute, intensive or chronic care (Buijse & Plas 2007; van Rooijen & van Meersbergen, 2008).

Previously, nurses could do so solely when instructed by authorized physicians; this was perceived as hindering the development of the functional independence of specialist nurses and the efficient delivery of health care (Dutch Council for Public Health and Health Care, 2002; Eijkelberg et al., 2003; van Rooijen & van Meersbergen, 2008). The new stipulations were for an initial period of five years, following which the government was to determine whether to formally include clinical nurse specialists as an independent profession in the health professions register.

### Current legal, regulatory and policy frameworks

In the Netherlands, improving the continuity and quality of care for people with chronic conditions has been a major objective since the 1990s, giving rise to the concept of shared care (*transmurale zorg*) (van der Linden, Spreeuwenberg & Schrijvers, 2001). Spreading rapidly throughout the 1990s, shared care approaches focused primarily on managing the interface between acute hospital care and alternative settings for those not able to return to a fully independent life (Klein-Lankhorst & Spreeuwenberg, 2008). More recently, there has been interest in the development of disease management approaches, with nurse-led clinics at their core. Aimed at supporting the integration of processes along the care pathway for those with chronic conditions, some of these approaches have evolved from shared care projects (Vrijhoef et al., 2001a). Initially, interest in their wider uptake was limited (Steuten et al., 2002); this was mainly attributed to a lack of a structured framework facilitating roll-out (Klein-Lankhorst & Spreeuwenberg, 2008).

Following a report of the Taskforce Diabetes in 2005, the government commissioned the Netherlands Institute for Health Research and Development (ZonMw) to launch a research programme on integrated diabetes care. Within this programme, 10 'care groups' (*zorggroep*) experimented with a provisional bundled payment system (*keten-dbc*, 'chain-DBC') (Struijs et al., 2012a) as a new approach to funding a 'bundled care package' for stable diabetes patients. The provisional bundled payment system enabled this care package to be purchased, delivered and billed as a single product or bundle of services. The minimum care requirements to be offered were set out in the national care standard for diabetes, developed by the Dutch Diabetes Federation (Nederlandse Diabetes Federatie, 2007).

Initially implemented in an experimental setting, the creation of care groups delivering structured diabetes care soon expanded beyond the 10 groups selected for the ZonMw research programme, and by 2010 around 100 care groups had been established or were being created, with an estimated 80% of Dutch GPs participating in a care group (van Til, de Wildt & Struijs, 2010). These developments were supported by a range of governmental proposals such as the 2008 ‘programmatische aanpak van chronische ziekten’, which stipulated the need for chronic illness care to be based on evidence-based care standards (Box 12.1) (Ministry of Health, Welfare and Sport, 2008a), and the 2008 ‘Letter regarding performance-based financing of integrated chronic care’, in which the government announced the permanent implementation of bundled payments for diabetes, COPD and vascular risk in 2010 (Ministry of Health, Welfare and Sport, 2008b).

**Box 12.1:** Care standards in the Dutch health care system

Different from clinical guidelines, care standards as defined in the Dutch context set out the minimum requirements for appropriate, patient-centred care, encompassing prevention, early detection, education and self-management, diagnosis, treatment and rehabilitation. Standard development has to involve all relevant stakeholders, including patients and funders, with patient versions to be made available to inform patients of their rights and the contributions they can make to the success of treatment. Care as described in care standards must be provided by multidisciplinary care teams and its delivery in practice is to be targeted at individual patients' needs. Substitution is encouraged; care standard implementation is to take account of local circumstances while leaving scope for care innovation. By 2014, a range of care standards had been developed or were implemented, including care standards for obesity, stroke, asthma, dementia, depression, cancer and heart failure (Coördinatieplatform Zorgstandaarden, 2014).

In 2010, the Dutch Ministry of Health, Welfare and Sport assigned the Committee on the Evaluation of Bundled Payment to monitor the implementation and effects of the bundled payment system for a period of three years. The committee concluded that the existing, disease-oriented payment method should be considered ‘work in progress’ that needs to be developed further into a system that facilitates population health management based on individuals' health needs rather than their condition (de Bakker et al., 2012). More recently, population management initiatives aiming to reconfigure health services and promote intersectoral collaboration

have emerged in various regions in the Netherlands. Nine initiatives have been designated as ‘pioneer sites’ by the Ministry of Health, Welfare and Sport, and these will be monitored over the next years to ‘gain insight into the implementation process, the determinants of successful population management in the Dutch context, and the impact of the initiatives in terms of population health, quality of care and health spending’ (Drewes et al., 2014).

## 12.2 Approaches to chronic disease management

In the Netherlands, the fragmentation of services between primary and secondary care, and along the secondary care and rehabilitation interface has been viewed as a major barrier towards the development of more coordinated approaches to care for those with (complex) health care needs. Thus, as noted earlier, improving the continuity and quality of care for people with chronic conditions has been a major objective in the Dutch health care system since the 1990s. We here describe four approaches to chronic disease management that have evolved since late 1990s and early 2000s.

### Maastricht Diabetes Organization: The Matador Disease Management Programme

The Matador disease management programme was developed by the Maastricht University Medical Centre (MUMC), the Regional General Practitioners Association Heuvelland (*Regionale Huisartsenzorg Heuvelland*, RHZ), the Foundation Green Cross, Health Insurer VGZ and the Dutch Diabetes Association (DVN) region Maastricht. Implemented in 2000, its origins date back to a pilot scheme established by the MUMC in 1996, which used specialized diabetes nurses to reduce the number of patients seen by medical specialists in outpatient settings (Klein-Lankhorst & Spreeuwenberg, 2008). Following the findings of an evaluation of the pilot programme, which demonstrated beneficial effects in terms of process and outcome measures (Vrijhoef et al., 2001b), it was subsequently transformed into the Matador programme, in which nurses had the primary responsibility for the treatment of diabetes patients.

The programme was open to all GPs and patients with type 2 diabetes in the Maastricht/Heuvelland region; participating patients were registered with a GP. Patients were supported by a core team comprising their GP, an endocrinologist and a specialized diabetes nurse. The

main strategies of the Matador programme involved elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support*: Towards the end of the Matador programme, in 2005, patients were offered access to a 'Diabetes Interactive Education Programme' (DIEP), developed by the MUMC. DIEP comprises a lifestyle intervention training component for providers designed to actively engage patients through assessing their situation and their motivation for change and involving them in the development of an individualized treatment plan and objectives, following the national diabetes care standard; it also provides information through a specifically designed website (Heinrich, Schaper & de Vries, 2009). In 2006, DIEP received the Novo Nordisk Quality in Diabetes Care Award.
- *Delivery system design* included the stratification of patients according to disease severity into three levels of care intensity and clinicians (high intensity: endocrinologist; medium intensity for unstable patients: diabetes specialist nurse; low intensity: GP). The roles of the core team were clearly defined, assuming responsibility for the patients allocated to them. The specialist diabetes nurse acted as liaison between the hospital and primary care for all patients. Members of the core team met on a regular basis; they closely cooperated with other care providers, such as dietitians, community nurses, podiatrists and ophthalmologists. Patients had quarterly consultations with a nurse specialist and every other year patients would also see an endocrinologist.
- *Decision support* involved the use of the Matador-protocol which set out the responsibilities and tasks of the various providers involved in the programme. The endocrinologist supervised the specialist diabetes nurse and acted as a consultant to the GP; she/he also contributed to their specialized training. The specialist diabetes nurse supervised and acted as a consultant to the GP on diabetes care. The GP informed the nurse on other aspects related to the patient and of relevance to the care process.
- *Clinical information systems* were not integrated. Data on patient contacts and outcomes were gathered in GP and hospital information systems.

The Matador programme was financed from different sources, involving usual sources for providers including

GPs, endocrinologists and other medical specialists, dietitians and other health professionals. Specialist diabetes nurses were funded under the previous Exceptional Medical Expenses Act (AWBZ) (Klein-Lankhorst & Spreeuwenberg, 2008).

In 2006, a total of 63 of 90 GPs (70%) in the Maastricht region participated in the Matador programme. The academic setting of the programme has been viewed as a key factor in stimulating uptake by providers. Since medical specialists in university hospitals received a salary that was not linked to the number of patients treated, they were not opposed to transferring patients to primary care. By the same token, the GPs, who were reimbursed on a per capita basis, benefited from the treatment of diabetes patients in primary care.

In 2006, the programme covered approximately 3000 patients with diabetes in the Maastricht region. In 2007, Matador was transformed into the bundled care package for diabetes developed by the RHZ Maastricht/Heuvelland which was further transformed into the primary care group ZIO (see below).

#### *Evaluation*

The Matador disease management programme was evaluated extensively, with a central focus on assessing its ability to improve the quality of care for type 2 diabetes patients within existing budgets as measured by cost-effectiveness, quality of life and patient self-management (Steuten, 2006; Steuten, Bruijsten & Vrijhoef, 2007; Steuten et al., 2007). In the absence of a suitable comparison region, it used a single-group, pre-post test design with the long-term cost utility assessed using a probabilistic decision model (Markov). Related evaluations centred on the feasibility and impact on the quality of care of substituting specialist nurses for GPs in the care of patients with type 2 diabetes (Vrijhoef et al., 2001a; Vrijhoef et al., 2001b; Vrijhoef, 2002; Denis-Thissen, 2003; Eijkelberg et al., 2003). Overall, the evidence from the Matador programme pointed to statistical significant improvements in glycaemic control, health-related quality of life, adherence and most aspects of patient self-management although no significant changes were found in the total cost of care. The acceptability of the programme was demonstrated by the large number of participating GPs and patients. The development of a Master of Arts in Advanced Nursing Practice in the Netherlands has been attributed, at least in part, to the acceptance of the Matador programme.

The goals of the Matador disease management programme were not SMART-defined (namely, specific, measurable, attainable, realistic and timely) and there were no incentives or penalties linked to the success or failure of the programme. It was nevertheless considered successful, because it improved the quality of care within existing budgets. This success has been attributed to the observation that the programme was organized by integrating various levels of care, with key organizational aspects including strong leadership, a shared vision about care delivery, and communication and transparency regarding the programme's objectives. The programme has been described as 'prime example' for well-developed disease management for diabetes by the ZonMw, which committed to the further dissemination of the so-called 'Maastricht Model' across the Netherlands (ZonMw, 2012).

### Primary care group ZIO (Maastricht–Heuvelland)

The RHZ Heuvelland was among the first in the Netherlands to develop, in cooperation with MUMC, a primary care group for type 2 diabetes mellitus, established in January 2007. The care group was established in parallel to (but not as part of) the ZonMw-funded research programme on integrated diabetes care described earlier. It developed a care package for type 2 diabetes, which describes the whole continuum of care for diabetes patients (Duimel-Peeters & Schulpen, 2007), funded on the basis of the bundled payment system. The RHZ care group was subsequently transformed into ZIO primary care organization, which covers a broader spectrum of conditions (ZIO, 2014). In the following we focus on the diabetes care package as developed originally by the RHZ.

The programme as developed by RHZ is based on the principle of disease management, building on earlier experiences in the Maastricht region described earlier. In contrast to most other care groups that have evolved since 2006, the Maastricht–Heuvelland programme also includes care delivered by hospital-based specialists. The main strategies of the diabetes care programme involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves at least quarterly check-ups that include education on self-management provided by practice nurses or specialized diabetes nurses, depending on the level

of need, with the latter also defining the frequency and duration of consultations to be conducted for educational purposes.

- *Delivery system design* includes the stratification of patients according to disease severity and required intensity of care into four regular modules: year of diagnosis (module 1); disease control with oral medication or diet (module 2); year of insulin initiation (module 3); and disease control with insulin (module 4). These are complemented by two modules targeted at patients requiring additional care for problems (module E) or complex problems (module E+). The roles and responsibilities of health professionals involved in care delivery are defined, with the GP acting as central coordinator ('director') of diabetes care; the practice nurse is responsible for care management and documentation in modules 1 and 2; the specialized diabetes nurse takes over this role in modules 3 and 4 and also provides care within modules E and E+ for patients with complex problems. The GP oversees referral to secondary care and ensures follow-up.
- *Decision support* involves the use of nationally defined standards for diabetes care and a multidisciplinary care protocol that sets out the responsibilities and tasks of the various providers involved in the care programme, including criteria for the initiation of modules E and E+. Referral to care providers such as ophthalmologists, dieticians, or podiatrists, and to secondary care follow clearly stipulated criteria. An internist acts as consultant to the specialized diabetes nurse on patients with (complex) problems through the modules E and E+.
- *Clinical information systems* include the use of a disease-specific multidisciplinary electronic patient record ('MediX'), which contains all data from check-ups and referrals within the care programme. MediX was developed specifically by the RHZ to enable access to patient data by the various professions involved in care delivery, to allow for the generation of management data and to support the documentation of risk factors, co-morbidities and additional information, for example, medical history. It can be linked to laboratory data and functional measurements to facilitate risk-analyses and treatment selection. Protocols can be entered to help caregivers adhere to care standards and protocols and to automatically generate prescriptions for medication.

In addition, the programme comprises continuous monitoring, evaluation and feedback of quality indicators as set by the national care standard for type 2 diabetes. Data are gathered from the clinical information system and through focus groups of patients and providers.

The programmatic approach to chronic care as envisioned by the government foresees the establishment of 'multidisciplinary care groups', but the RHZ Maastricht–Heuvelland, which is the contractor of the bundled care package for type 2 diabetes in the region, is not multidisciplinary per se. However, it aims to contribute to the creation of a strong primary care sector by developing multidisciplinary protocols for, among other things, diabetes care, and has moved towards this goal with the transformation into the ZIO primary group, which was completed in 2012 (ZIO, 2012).

In 2011, all regional GPs that were members of RHZ Maastricht–Heuvelland participated in the diabetes care programme, which covered some 8300 patients with type 2 diabetes. The health insurer VGZ acted as principal contractor for the type 2 diabetes programme in Maastricht–Heuvelland region, on the basis of a bundled payment contract.

As noted earlier, RHZ Maastricht–Heuvelland was among the first to implement an integrated care package for type 2 diabetes on the basis of a bundled payment contract and has since evolved into the primary care group ZIO. Similar approaches involving multidisciplinary care and building on the principles of chronic disease management have evolved across the Netherlands. In the early 2010s, there were about 100 care groups in the Netherlands; these were mostly for diabetes care, with only a few groups operating contracts for vascular risk management or COPD care programmes (NZa, 2013). Over 80% of all Dutch GPs participate in a care group, with an average of 76 GPs partaking in each group (Struijs et al., 2012a; de Bruin et al., 2013).

### *Evaluation*

As noted earlier, in 2006, the government commissioned ZonMw to launch a research programme in which ten care groups would experiment with bundled payments for integrated diabetes care. These groups were to receive financial support for a period of 16 months from start of operations in 2007, with an accompanying evaluation by the National Institute for Public Health and the Environment (RIVM) (Struijs et al., 2012a; Struijs et

al., 2012b). Findings from the evaluation of year one showed that notwithstanding the national care standard, diabetes care groups varied in number and type of participants and in the content of the packages of care. While bundled care packages provided the core elements of care defined by the national diabetes care standard, there was variation in the extent to which they offered additional diabetes-related GP consultations, guidance to reduce or give up smoking or foot care. After three years of evaluation, several changes in care processes were observed, including task substitution from GPs to practice nurses and increased coordination of care. Patient involvement in their care remained limited, as did the level of support provided for self-management of type 2 diabetes (Struijs et al., 2012a). Evidence of impact on process and outcome indicators remained inconclusive, with only modest improvements demonstrated on most indicators. An expectation that diabetes care groups would, through improving the quality of diabetes care, lead to cost reductions is as yet to be demonstrated. Struijs et al. (2012b) found that utilization of specialist care among patients participating in a bundled payment diabetes management programme was lower compared to those receiving usual care (the number of patients using specialist services was 25% lower; the number of those using diabetes-related specialist care was 40% lower). During the first year, an observed increase in cost per patient treated in a bundled payment diabetes programme was higher than for patients receiving usual care.

The Maastricht–Heuvelland diabetes care programme was not part of the experimental group participating in the ZonMw research programme on integrated diabetes care. So far, it has been monitored and evaluated internally, by the RHZ, using routinely collected data and focus groups on indicators of effectiveness, clinical parameters, health-related quality of life, self-management behaviour and patient and provider satisfaction (Duimel-Peeters & Schulpen, 2007).

### *Stroke Service Delft (shared care for cardiovascular illness provided by a regional collaborative)*

The Stroke Service Delft evolved from a shared care project, which was one of three pilot projects for improving stroke care initiated in 1997 and funded by ZonMw (with the other two based in Haarlem and Nijmegen, respectively). Each established a regional

multidisciplinary care team for stroke care ('stroke service') (Huijsman et al., 2001a). The Dutch Heart Association actively stimulated the development of innovative models of care for stroke.

A stroke service involves a chain of caregivers, medical specialists, nurses, and therapists, who form a network to provide integrated, expert, and coherent treatment and care for stroke patients along the continuum of care, including acute, rehabilitative and chronic care. The Stroke Service in Delft comprises one hospital with a stroke unit, one major nursing home, one rehabilitation centre and one home care organization, with specialized stroke nurses trained in case management. Shared care stroke nurses are responsible for patient transfers within the stroke service. The main strategies of the stroke service involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves access to different forms of education and support; in accordance with a national multidisciplinary guideline for stroke issued by the then Dutch Institute for Healthcare Improvement (CBO) (Kwaliteitsinstituut voor de Gezondheidszorg, 2009), the method and format of education is adapted to the wishes and needs of individual patients and their carers. It can involve verbal or written education in group sessions, alternating with individual sessions or through media such as the Internet or DVD.
- *Delivery system design* includes a network of providers who work together in a multidisciplinary, coordinated way through organized patient transfers and protocols. Common elements include: hospital stroke unit; specialist multidisciplinary team of caregivers; protocol-based care; special staff training; and agreements about patient referral. Other elements include regular (weekly) multidisciplinary staff meetings in the various settings (hospital, rehabilitation centre, nursing home) and structured follow-up by specialist nurses of stroke patients following discharge to their home. Patients are guided by a shared care stroke nurse during the entire care process.
- *Decision support* involves the use of shared care protocols, stipulating providers' tasks and responsibilities, criteria for patient transfers, agreements regarding information sharing and so on. The stroke service in Delft also builds

on the national multidisciplinary care for stroke guideline developed by over 70 professionals from various backgrounds, representing 26 societies or institutions dealing with stroke patients.

- *Clinical information systems* include a shared care, multidisciplinary electronic patient record known as the 'Portavita Stroke Application', primarily developed for use in hospital settings and based on the national stroke guideline. It permits documentation and sharing of information on examinations and treatments between the various providers involved; tracking and registering of medications; requesting, planning and registering of (complementary) examinations; and workflow support through creating worksheets per person and discipline.

In addition, the stroke service in Delft comprises routine monitoring, evaluation and feedback of quality indicators as developed within the Evaluation of Dutch Integrated Stroke Service Experiments (EDISSE) study (see below) (Huijsman et al., 2001a).

Care provided within the stroke service Delft brings together medical specialists in hospitals, including neurologists, cardiologists and radiologists; nonmedical providers such as physiotherapists, speech therapists and occupational therapists; specialized nurses in home care, shared care stroke nurses, rehabilitation physicians and physicians working in nursing homes. GPs are not a key partner in the network, but they are involved in the care process in their role as a family physician.

Integrated stroke services such as those provided in Delft are funded within the regular social health insurance system, with reimbursement for the various components covered under the basic health insurance system (GP and hospital services based on contracts with health insurers), the AWBZ (for example, rehabilitation centre; nursing home) and the Wmo (home care). The shared care stroke nurse, who is involved in all parts of the stroke service's chain of care, is financed by all three partners, hospital, nursing home and rehabilitation centre according to a specific allocation formula.

Following the experiences of the three pilot projects, and their evaluation within the EDISSE study, the government, through ZonMw and the then CBO, actively promoted the further implementation through 'breakthrough projects' and benchmarking of stroke

services in the Netherlands. As a consequence, stroke services evolved across the Netherlands, and by 2003 each region had developed at least one stroke service (a total of 69 in 2003) (Cools, 2005).

At the same time, the participation of health insurers in stroke services fell, from 76% in 2000 to 62% in 2003, mainly because most projects were no longer considered to be in an experimental stage by 2003. With the introduction of the 2007 Social Support Act (Wmo), municipalities have assumed a greater role in the financing of certain aspects of stroke care, covering services that enable those with (complex) care needs to live independently, such as transport, wheelchairs and special home facilities.

The precise number of patients receiving care within stroke services is not known; however, according to the Dutch Heart Foundation, the 69 stroke services available in the Netherlands since 2003 are distributed in a way that likely covers all stroke patients in the country.

### Evaluation

The stroke service in Delft was evaluated as part of the EDISSE study, which analysed the health and economic impacts of integrated stroke services with respect to costs, health outcomes, quality and the organization of care. It was conducted by ZonMw and Erasmus University Rotterdam. It demonstrated a number of beneficial effects in relation to mortality, place of stay and health-related quality of life at 6 months following stroke that were significantly improved in comparison with usual stroke care, at comparable costs per patient (Huijsman et al., 2001a; Huijsman et al. 2001b; van Exel et al., 2003; van Exel et al., 2005). As such, the service was deemed effective as well as efficient.

The organizational structure of the Delft stroke service has been branded 'Delft best practice' and, as noted above, it was rolled out across 23 regions through breakthrough projects organized after completion of the EDISSE study.

### National care standard for vascular risk management

The national care standard for vascular risk management was developed under the supervision of the *Platform Vitale Vaten* (platform vital vessels) (Platform Vitale Vaten, 2009), an initiative of patient organizations in

the area of vascular disease (including stroke) and the Dutch Diabetes Association. A total of 28 organizations, including providers, patients, health insurers, the Dutch Healthcare Inspectorate and others collaborate in this platform.

Similar to the care standard for type 2 diabetes, the 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. Care as described in the standard must be provided by multidisciplinary care teams, bringing together providers from various disciplines to cooperate in achieving high-quality care for their patients.

We here describe the principles of the care standard for vascular risk management, setting out an ideal-case scenario rather than the actual approach being implemented. As such, the standard incorporates elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves active engagement of the patient in vascular risk management through shared decision-making and goal setting. Patients acquire self-management competences through 'task-oriented communication', motivational interviewing or 'emotion-oriented communication', each touching on different aspects relevant to developing competences. Further components include the development of an individual care plan, which sets out the treatment goals and steps towards achieving them and the scheduling of follow-up. The care plan includes characteristics of the process (who does what and when) and results (risk profile and separate risk factors).
- *Delivery system design* includes a clearly defined staged process involving identification, examination or diagnosis, and treatment, including follow-up with control and guidance. The care standard defines the tasks, competences and responsibilities of the health care team for each of the stages. It also sets out the types of providers who may be involved in vascular risk management as well as the agreements that ought to be made regarding individual and shared responsibilities, for example the identification of the central caregiver who acts as first point of contact and coordinator of care for the patient and members of the health care

team. The central caregiver is trained in vascular risk management and skilled in supporting self-management; they oversee referrals to more specialized care providers where necessary.

- *Decision support* involves use of the multidisciplinary care standard for vascular risk management to determine the goal and the content of vascular risk management. It includes information about risk factors for vascular disease; the identification of patients with elevated risk; assessment of high risk; and recommended treatment policy and follow-up. In day-to-day work, the use of the standard is ensured through reminders, feedback and other methods. If necessary, experts are consulted.
- *Clinical information systems* are used to register, share and interpret patient data as part of vascular risk management, both at the individual and aggregate level. Individual level data include clinical information (health status; vascular risk management regime; treatment outcomes, including of behavioural interventions). Group level data provide information on patients who need additional care; they also permit an assessment of whether vascular risk management meets the requirements set by the care standard's quality indicators, allowing further optimization of the quality of vascular risk management. Feedback is provided to the patient as well as to the health care team in a structured manner.

The composition of providers involved in the management of patients with elevated vascular risk depends on the risk profile, the presence of co-morbidities, and the patients' needs and wishes. The team may therefore involve GPs, medical specialists, pharmacists, specialized nurses, practice nurses, physiotherapists, dieticians, psychologists and behavioural therapists. In addition, patients can access smoking cessation programmes, and programmes provided by municipal public health services and primary care (on diet, nutrition, and physical exercise), self-help groups, rehabilitation programmes and support from patient organizations.

The provision of vascular risk management according to the national standard for vascular risk management is financed by health insurers. As of 1 January 2010, the provision of vascular risk management according to the national care standard is being financed on the basis of bundled payment contracts that define which

components of vascular risk management are purchased as an all-inclusive product by health insurers.

At the time of writing, relatively few care groups had a contract in place with a health insurer for the provision of vascular risk management on the basis of the national care standard, as compared with diabetes, although this number is increasing. Of 65 care groups surveyed by the RIVM in 2011, 25% had a bundled payment contract in place for vascular risk management, whereas another 27% were preparing to contract.

### *Evaluation*

Several care groups experimented with the national care standard for vascular risk management as part of the 'Disease Management for Chronic Illness Research Programme' of the ZonMw. This programme comprised a total of 22 regional disease management projects, which were evaluated by Erasmus University Rotterdam between 2010 and 2012. Overall, the evaluation demonstrated substantial improvements in the quality of chronic care delivery over these years. Moreover, programmes appeared to have improved patients' health behaviour, physical quality of life and clinical outcomes. Cost-effectiveness of disease management could not be demonstrated after two years, although individual projects showed different results.

## **12.3 A patient journey**

This section describes the journey of two hypothetical typical patients with co-morbid chronic disease in the Dutch health care system.

*(A) A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is also slightly overweight (BMI of 27). She has been unemployed for three years and receives social assistance benefits; she lives on her own.*

Diabetes is typically diagnosed opportunistically, as part of a routine consultation or when the patient visits a physician because of other complaints. Few GPs systematically check the glucose levels of patients considered at risk of diabetes. Once the diabetes has been confirmed, the patient is likely to be initially treated by her GP, who will refer her to an ophthalmologist. The management of the leg ulcer depends on its localization and severity. The GP may refer her to the district nurse for dressing the ulcer. She may also be referred

to a podiatrist or dermatologist. In the event that the respiratory specialist physician who saw the patient for her COPD referred her to an internist, she will receive treatment and will then be referred to a specialist nurse, a dietician, an ophthalmologist and a dermatologist. The Dutch College of General Practitioners (NHG) guidelines propose a quarterly follow-up to measure HbA1c, urine, weight and blood pressure. The patient will also have thorough annual check-ups. The GP will take on responsibility for her management directly or delegate this to the practice nurse or a diabetes nurse specialist. As the patient also has COPD, it is likely that the GP takes on responsibility of her management and because of her specific social situation, the follow-up is likely to be carried out by a nurse. The nurse also plays an important role in education and information, that is, by sharing information from the Dutch Diabetes Association, interactive programmes, brochures and leaflets as well as accessible support systems. Ideally the patient will be involved in the decision-making process. In case of a complication, the patient is expected to call upon her GP. Usually, the patient will be seen on the same day. In serious cases the emergency services will be called upon. There is some experimentation with call centres and support systems to assess complications and so direct patients to the services they require.

*(B) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure. He lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing block and are increasingly housebound due to their illness. They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.*

Asthma is generally diagnosed by a GP, who most often also assumes responsibility for the treatment. Practice supporters and specialist nurses may also be involved in the treatment of asthma in primary care. In case of complications or severe asthma, the patient will be referred to a hospital-based pulmonologist. Heart failure is diagnosed by a cardiologist after referral by a GP. Depending on the severity of the condition, the patient will be treated by either his GP or by a cardiologist or specialist heart failure nurse in an outpatient hospital clinic. Since high blood pressure is an important risk

factor for heart failure, the patient will receive medication to lower the blood pressure and will receive self-management training. The patient will be encouraged to adapt his diet (for which he may be referred to a dietician), engage in physical exercise, and give up smoking. Programmes are available to help patients reach these goals; health insurers are increasingly funding such programmes. To remain independent, the patient and his wife will receive the necessary assistance from the municipality where they reside, on the basis of the regional Wmo. If necessary, they will receive household assistance, including modifications to their home where necessary, transport and so on. As the grandson lives nearby it is likely that the total package of support services that the couple is entitled to receive is reduced.

## 12.4 Summary and conclusion

In the Netherlands, the control and management of chronic diseases have become a priority in health care policy, with a nationwide push to improve the quality of care for these conditions in the form of the 2008 programmatic approach to chronic illness care. Its key features include the use of nationally developed, evidence-based care standards and quality indicators, the promotion of multidisciplinary care teams, a focus on self-management and the promotion of performance-based financing on the basis of bundled payments. The overall process has been of an incremental nature, principally evolving from an experiment with a limited set of providers and informed by earlier experience of a delivery model developed in the 1990s (Klein-Lankhorst & Spreeuwenberg, 2008), followed by a select set of pilots experimenting with bundled payment during the late 2000s that were evaluated for subsequent roll-out; however, it should be noted that national roll-out was advocated by the government before evaluation findings were available. A key challenge remains the development of care models that meet the needs of those with multiple conditions. However, the Dutch care groups, while principally disease-specific, are envisaged as multidisciplinary care teams and, through stratification of patients according to severity and required care intensity may go some way to meeting the requirements of those with multiple health problems.

# Switzerland

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## 13.1 The health care system

Switzerland is a democratic federal state characterized by a high level of political decentralization. The 26 states (cantons) have their own constitution, parliament, government and courts. The Swiss health system is financed mainly from mandatory social insurance (2012: 43.7%), complemented by OOP payments (28.1%), taxation (18.0%) and voluntary insurance (9.4%) (WHO, 2014). In 2012, national health care expenditure in Switzerland was 11.3% of GDP.

Decision-making in the health system is shared between the federal and regional level, with the federal government legislating in areas such as public health, social insurance and professional qualifications, while the cantons are responsible for disease prevention and health education and for the provision of health care; they also partially finance hospital costs. As a result of the high level of decentralization, the Swiss health care system is sometimes considered as being comprised of 26 (slightly) different systems.

The 1996 Federal Health Insurance Act (*Loi fédérale sur l'assurance-maladie*; LAMal) stipulates that all Swiss residents purchase basic health insurance which covers a comprehensive basket of goods and services defined at the federal level (Paris & Docteur, 2007). All insurers are private; those offering the basic basket must be non-profit-making and they must accept all applicants for membership during specified open-enrolment periods (Leu et al., 2009). Insurance premiums are community-rated and although a risk-equalization scheme is in

place, risk selection remains a problem; in 2012, 29% of the population received state subsidies (from taxation) because of low income (Federal Office of Public Health, 2013a).

There are several cost-sharing arrangements, with all individuals contributing to the cost of health services through a deductible, co-insurance and co-payments (minimum annual deductible of CHF 300 and co-insurance of 10% up to a maximum of CHF 700 for all care) (Camenzind, 2013). Swiss cost-sharing is considered high by international standards (Leu et al., 2009). Many residents have complementary insurance to cover services excluded from the basic basket.

Ambulatory care is provided by primary care physicians and specialists working mainly independently in solo private practice and in small group practices. About half of the primary care physicians are embedded in one of 86 managed care organizations (networks of physicians and health maintenance organizations). This is mostly the case in the German-speaking part of Switzerland, but less so in the French- and Italian-speaking parts of the country. Hospitals also provide regular ambulatory as well as emergency care. Patients generally have direct and unrestricted access to primary care physicians and specialists. In 2014, about 24% of residents were enrolled in some form of managed care plan (Forum Managed Care, 2014a), of which two-thirds feature GP gatekeeping although specialists can also act as gatekeepers (Squires, 2009). Independent private practitioners (physicians) as well as other independent health care professionals (for example, nurses, physiotherapists, dentists) are generally paid on a fee-for-service basis; some managed-care plans operate capitation models.

Hospital care is provided by public and private hospitals, with the latter qualifying for financial subsidies from the state if they are considered of 'public interest'. Public hospitals include the five Swiss university hospitals as well as cantonal and regional hospitals; they constitute the main form of inpatient care. Until 2011, hospitals were mainly reimbursed on a per-diem basis. Since 2012, prospective payment using DRGs (SwissDRG), adapted from the DRG system in place in Germany, is being implemented (Camenzind, 2013). Hospital-based physicians are paid either a salary or a mix of salary and fee-for-service, depending on seniority (Squires, 2009).

### Health care reforms of relevance to chronic disease

The 1996 Federal Health Insurance Act and its subsequent revisions, in particular in relation to managed care and hospital financing, form the key health reforms of importance for chronic disease management in the Swiss health care system. As mentioned above, it introduced universal access to comprehensive health care services for all Swiss residents. Its third revision, in progress since 2004, further considered, among other things, legislative modifications of managed care (see below) and hospital financing. The latter resulted in the full conversion of hospital payment to the SwissDRG system in 2012 as noted earlier. However, the proposed revision promoting managed care was rejected by popular referendum in June 2012.

Since 2007, the Federal Council has also been developing a federal law on health promotion and disease prevention, aimed at improving the conduct, coordination and evaluation, at a national level, of health promotion and disease prevention. It was expected to define the roles of the confederation, cantons and nongovernmental organizations, as well as specifying national targets for health promotion and disease prevention and the allocation of funding according to this strategy. The development of the federal law on health promotion and disease prevention was however adjourned in September 2012.

More recently, in January 2013, the Federal Council presented 'Health2020', a comprehensive health care strategy, which seeks to prepare the Swiss health system for 'the challenges ahead at affordable costs' (Federal Office of Public Health, 2013b). It identifies four priority areas: quality of health care provision, quality of life, equality of opportunity and transparency, and its strategy focuses on chronic disease prevention and care, financing and insurance transformations, data transparency and e-health, as well as education and training of health care professionals.

Reform efforts that are currently being discussed and that are likely to contribute to the prevention and care of chronic diseases include the proposed consideration of primary care medicine in the Swiss constitution, following a national vote in May 2014, and the master plan family medicine, aimed at reinforcing primary care.

### Current legal, regulatory and policy frameworks

Switzerland has so far not developed a national regulatory framework targeting chronic diseases prevention and management care although national programmes and strategies targeting specific areas such as tobacco, alcohol, physical activity and diet have been in place for some time. Strategies addressing chronic diseases more generally are more recent. However, all these strategies are not binding, and cantons remain free to organize health care delivery.

Currently, managed care as set out in the Federal Health Insurance Act represents the principal regulatory and policy framework for chronic disease management in Switzerland. However, it is not obligatory to implement chronic care initiatives within that framework. Within managed care, patients enrol with a physician who acts as a gatekeeper to specialist care in return for reduced premiums. The most common forms of managed care are physician networks and health maintenance organizations (HMOs). Within HMOs, physicians work in a group practice owned by a health insurer or by physicians while physician networks bring together office-based doctors in ambulatory care, usually in the form of family physician or gatekeeper models although increasingly also involving specialists (Strehle & Weber, 2008). Throughout the following text, we will refer to physician networks only.

The development of managed care schemes in Switzerland dates from the early 1990s; by 2014, there were 75 physicians networks, four-fifths of which had agreements to share part of the financial risk (Forum Managed Care, 2014b). About 24% of residents across Switzerland are currently enrolled with physician networks although coverage varies widely, with up to one-third of the population enrolled in some cantons while other regions have yet to implement networks. About half of all primary care physicians participate in networks.

As indicated above, from 2004, the Federal Council considered a further advancement of managed care models within the third revision of the Federal Health Insurance Act, with the main objective to promote the quality of care at reasonable and appropriate cost. The proposed legislation foresaw the strengthening of managed care, broadly referred to as integrated care (networks), through, among other things, requiring health insurers to contract with at least one integrated

care network to be offered to their insured population (Cassis, 2010). However, as noted, following several years of development, the ‘managed care’ proposal was considered in a popular referendum and 76% of the population and all 26 cantons rejected the proposed plans.

Individual cantons have also engaged in advancing the regulatory and policy framework for chronic disease management, with, for example, the canton of Vaud, in its 2008–2012 health policy (*Rapport du Conseil d’État sur la politique sanitaire 2008–2012*) aiming to adapt health care services to chronic diseases, in particular reinforcing cooperation and coordination, and to promote health, prevent diseases and conduct priority public health programmes. In that context, the Ministry of Health of the canton of Vaud developed a cantonal diabetes programme, aimed at controlling the incidence of diabetes and at improving care for diabetic patients (see below).

### 13.2 Approaches to chronic disease management

Given the diversity of the Swiss health care system, and in the absence of a unified strategic approach to the management of chronic diseases, we here describe selected local and regional initiatives. We focus on approaches implemented in the French-speaking part of Switzerland. While recognizing that these are not representative of the entire country, we consider them typical of ‘cantonal’ approaches to chronic disease management in Switzerland. Unpublished data from a survey conducted by the lead author showed that initiatives are being developed throughout Switzerland.

#### Diabetes disease management programme Diabaide, canton of Vaud

*Diabaide (Filière de soins Diabaide*; ‘diabetes care network’) was developed in 2004 in western Switzerland. The programme was mainly led by a physician (endocrinologist–diabetologist) and a diabetes nurse-specialist. It was based on an inventory of the needs of diabetic patients in the region and the creation of a working group including a range of health care stakeholders involved in diabetes care. Initially, the programme included the provision of information material and continuing education for health care

professionals only. It was expanded to form a more comprehensive programme directly targeting the patient.

The programme was jointly run by the *Association Réseau de Soins de la Côte* (one of five care networks operating in the canton of Vaud<sup>3</sup>) and two regional hospitals (*Ensemble Hospitalier de la Côte* and *Groupement Hospitalier de l'Ouest Lémanique*). While the hospitals provided the setting for service provision within *Diabaide*, services were not targeted at inpatients but are community-based.

The key components of *Diabaide* were disease management and multidisciplinary teams (*cellule multidisciplinaire diabaide*). The programme is currently being reorganized (see below); in the following we describe the core components implemented originally. This included the programme's main strategies which involved elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involved the provision of information material (French language), customized face-to-face self-management education and follow-up, and support by trained staff (nurse specialists, dieticians and specialist physicians). The patient's overall situation was regularly assessed and patients were actively involved in goal setting and developing a treatment plan.
- *Delivery system design* included the clear definition of the roles and tasks of each participating health professional, monthly meetings of the entire team and weekly coordination or organizational meetings, and the development of care plans for typical 'clinical situations' such as the introduction of insulin, gestational diabetes, which were then adapted to the specific context of the individual patient. Patients were followed up (in person or by telephone) following a predetermined schedule, including telephone contact at least once a year.
- *Decision support* involved the use of care protocols developed according to international and Swiss guidelines, and the involvement of specialist physicians in the programme.
- *Clinical information systems* included the implementation of a shared electronic medical record permitting restricted information sharing among health professionals involved in the care process

('customized' access). This system also included an electronic booking system.

The programme offered specialized ambulatory care, along with access to a network of specialists such as endocrinologists, dieticians, diabetes nurses and podologists (Peytremann-Bridevaux & Burnand, 2009). GPs and family physicians did not assume an active role in the programme.

Any patient with type 1 or type 2 diabetes residing in the region of Nyon-Morges in the canton of Vaud was able to join the programme. However, participation in the programme was strongly dependent on whether or not the primary care physician referred patients to the programme. In addition, patients seen once were not to be followed further.

Initially supported by health insurers and the canton of Vaud, the programme is currently funded by the canton of Vaud (around 50%) and from care activities charged to the patient and reimbursed by their health insurers (around 50%). The objective of *Diabaide* was to cover 30% of the estimated diabetic population in the region of Nyon-Morges (around 6000). By 2009, a total of 720 patients (12%) had been reached. This equated to 100–150 new patients, who were seen at least once a year.

Despite these encouraging results, there has been a lack in the steering, management and organization of *Diabaide* and as a consequence, *Diabaide* has been in the process of reorganization since 2013. This reorganization is moving towards fragmentation of its activities with specialized 'poles' developed by local institutions in collaboration with independent health care professionals. An external evaluation is under way which aims at a better understanding of the situation and previous experiences, and to explore how experiences can be used for further cantonal developments.

### Evaluation

In 2006, *Diabaide* was formally evaluated by the Institute of Social and Preventive Medicine of Lausanne (Arditi & Burnand, 2008). The external evaluation aimed to assess (1) the activities of *Diabaide* and to describe the characteristics of the patients participating in the programme; (2) the effectiveness of the programme on clinical outcomes; and (3) the cost-effectiveness of the programme as compared with usual care. Using

<sup>3</sup> Care networks as defined by the 2007 Vaud cantonal legislation include regional health care providers and other interested parties representing the entire range of services, including preventive, curative, palliative medical and social rehabilitation. Their main purpose is to strengthen the coordination across the continuum of care.

a pre–post design assessing the period between the start of the programme (2004) and 2006 and a mix of routine and newly collected data, the evaluation considered process indicators, including the number of patients enrolled and the number of consultations as well as intermediate outcome measures such as glycemic (Hb1AC and fasting glucose) and lipid levels, blood pressure and BMI. The evaluation found that the programme had been successfully implemented. However, the small number of patients included reflects the low participation of GPs and family physicians. It also indicated that among patients included in the analysis, outcomes had improved in terms of a reduction in mean HbA1c, total cholesterol level and blood pressure.

### Breast cancer clinical pathway, Lausanne University Hospital and University of Lausanne

The breast cancer clinical pathway in Lausanne was implemented in 2008/2009 at the initiative of clinicians and clinical managers at Lausanne University Hospital to improve the quality and efficiency of health care. It was accredited by the Swiss Cancer League and the Swiss Senology Society label for breast cancer in November 2013. The breast cancer pathway, initiated by the Medical Directors' Board, heads of hospital departments and hospital clinicians, was designed to improve the quality of care, and developed de novo. It is hospital-based and targets adults with breast cancer who are primarily treated at Lausanne University Hospital. As such, it does not involve primary care physicians.

The key components of the breast cancer clinical pathway are coordinated and integrated care as well as multidisciplinary teams. The pathway's main strategies involve elements of self-management support, delivery system design, decision support and clinical information systems.

- *Self-management support* involves information for patients using written documentation on a range of topics including the disease process as well as treatments and therapies; dedicated time during the individual consultation including information and regular reassessment of the patient's situation; shared decision-making within a limited frame; and self-management support by trained nurses and social workers; and possible access to peer support groups. Self-management education following resection of axillary lymph nodes is also available.
- *Delivery system design* includes a detailed description of each step of the clinical pathway; regular meetings with staff and project leads; and planned, predetermined and structured face-to-face consultations. This component also considers regular assessments of pathway implementation (routine process indicator measures).
- *Decision support* involves the adaptation of (inter) national guidelines developed by the National Cancer Care Network and the Consensus of Saint-Gall (European guidelines) as well as provider education on specific components of the programme. Physicians and nurses involved in the programme also receive education in the field of senology–oncology and in communication. Hospital specialists are entirely integrated in the programme. Clinicians are further supported by written documentation detailing the diagnosis and pre-operative phase, the peri- and post-operative phase, and pre-operative chemotherapy, radiotherapy and surgical reconstruction, with additional guidance under development.
- *Clinical information systems* include the establishment of a database and biobank. Providers receive feedback on delays (for example between diagnosis and treatment) and the number of new cases of breast cancer per year (a target is set at 150 new cases of breast cancer included in the clinical pathway per annum). Surgeons also receive specific information relating, for example, to the number of reoperations needed because safe histological margins were not reached, or the number of times that a surgeon was the main operator in relation to the total number of breast cancer operations.

All health professionals involved in the programme are employed by Lausanne University Hospital. Specialist physicians include oncologists, surgeons, plastic surgeons, fertility specialists and geneticists, radiologists and pathologists. Nurses are represented by breast cancer nurse specialists, oncology nurse specialists and generalist nurses. Allied health professionals such as physiotherapists, psychologists and social workers are also part of the team; however, social workers are not employed by the hospital but are associated with the *ligue vaudoise contre le cancer*.

Currently, Lausanne University Hospital takes care of approximately 200 new breast cancer patients per year. The main objective of the programme is to reach at least

150 patients included each year, which corresponds to the minimum requested for the Swiss Cancer League label. The programme is also aimed at increasing the recruitment of patients by working in a network with regional hospitals, in order to reach 40% of new breast cancer patients in the canton of Vaud. The programme is financed by the hospital itself with the Medical Director Board and chief executive actively encouraging the continuing implementation and development of the programme as well as reaching targets.

### Evaluation

The programme has been evaluated, both in terms of implementation and outcomes within the accreditation process of the Swiss Cancer League Label. Based on results achieved by the clinical team, long-lasting resources were secured by Lausanne University Hospital to sustain this pathway. Internal and external systematic monitoring of process and outcome indicators will continue to be undertaken every year. The external monitoring is undertaken by the Swiss Cancer League; data will be collected in the Swiss Breast Center DataBase

The programme forms part of the strategic plan of Lausanne University Hospital, which targets the launching of a comprehensive cancer centre; it does not involve specific incentives for the development of or participation in the pathway. Incentives are indirect, for example, the need to attract patients by means of a Swiss quality label.

### Programme cantonal diabète, canton of Vaud

In 2008, the Ministry of Health of the canton of Vaud (*Département de la santé et de l'action sociale*) initiated the development of a cantonal diabetes programme within the framework of the canton's 2008–2010 health policy strategy (*Rapport du Conseil d'État sur la politique sanitaire 2008–2012*) (Canton de Vaud, 2008). It involved representatives from the range of providers involved in the delivery of diabetes care and other stakeholders in the health care system, including public hospitals and health insurance funds. The cantonal programme aims to sustainably reduce the impact of diabetes on the population of Vaud by reducing its incidence through appropriate preventive measures and improving the management of those with established disease (Canton de Vaud, 2014).

The programme is principally based on the Chronic Care Model developed by Wagner (1998). It plans to emphasize quality and access to self-management education, multi/interdisciplinarity, coordination and the integration of evidence-based care, health professionals' training and health promotion and disease prevention at the general population level. This is expected to be accompanied by some form of information system.

The programme is still under development, involving a stepwise, bottom-up and top-down approach. By the end of 2013, around 40 projects had been launched (Canton de Vaud, 2013). After a first concept and campaign for early diagnosis and targeted screening for diabetes and associated risk factors, further achievements were, among others: (i) the establishment of a cohort of patients with diabetes to monitor the quality of their care, patient needs, the knowledge and exposure to the programme and its effect on the population of patients with diabetes; (ii) the adaptation of diabetes guidelines to the Swiss context; (iii) the development of a diabetes risk assessment website; and (iv) the implementation of programmes targeting physical activity of type 2 diabetic patients, of programmes promoting self-management and of patient education programmes awareness for health care professionals. The programme cantonal is also participating in partnerships to promote healthier lifestyles and considers an implementation as well as effectiveness evaluation.

### Réseau de santé Delta, canton of Geneva

The *Réseau de santé Delta* was developed in 1992 as a health maintenance organization (HMO), on the initiative of two physicians at the University of Geneva. Initially restricted to university staff and students, the HMO was subsequently (1994) opened to other members and transformed into a network of physicians ('Delta') (Werblow, 2004). It is accessible to any resident of the canton of Geneva opting for the Delta network health insurance scheme. The network also operates in the canton of Vaud.

Delta's main strategies involve elements of delivery system design and decision support.

- *Delivery system design* includes the development of chronic disease management programmes for diabetes, heart failure and asthma.

- *Decision support* involves the organization of regular quality circles for all physicians participating in the network.

While formal self-management support strategies are not documented, patients receive regular information (two information letters per year), detailing provisions for access to health promotion and disease prevention consultations and activities. A website is also available.

Primary care physicians (GPs, generalists, internists, family physicians) act as gatekeepers and refer patients to specialists; paediatricians, gynaecologists and ophthalmologists are directly accessible. The Delta network of physicians also includes psychologists and a network of 40 pharmacies.

The Delta network is reimbursed on a capitation basis, with re-insurance for expensive cases (Schaller & Raetzo, 2002). Participating physicians continue to be paid on a fee-for-service basis, and the capitation fee per insured person is negotiated annually between the network and the health insurance funds whose members have enrolled with the Delta network. In addition to their income, physicians receive a lump sum of CHF 200 each time they participate in a quality circle.

In January 2013, the Delta network comprised some 350 primary care physicians (70–80% generalists, internists, GPs) covering about 110 000 insurance members across the cantons of Geneva and Vaud (Delta Réseau de santé, 2014).

#### *Evaluation*

An external formal evaluation of the HMO was performed during its first three years of operation. Using a controlled before–after design based on claims data, it found a reduction in health care costs of the HMO compared with a regular insurance plan during the first year of operation, mainly through a reduction in the utilization of technical procedures such laboratory tests (Etter & Perneger, 1998). However, it also found evidence of self-selection of ‘better’ risks into the plan. Overall utilization of services did not change and there was no evidence of changes in the health status among those enrolled with the HMO.

There is no documented evidence of further evaluations being carried out following Delta’s transformation into a network and the introduction of capitation payment

in 2000. However, according to evaluations performed by the involved health insurance companies, economies within the network range between 15–18% when considering age, gender and co-morbidities (Schaller, personal communication, 2014).

### 13.3 A patient journey

In Switzerland, there are only few opportunities to participate in structured chronic disease management programmes for diabetes or other chronic conditions. Therefore, the quality, coordination and integration of care will mainly depend on primary care physicians, and specialist physicians, and occasionally, on nurses as well as other health care professionals.

This section describes the journey of two hypothetical typical patients with co-morbid chronic disease in the Swiss health care system.

*(A) A 54-year-old woman with type 2 diabetes and COPD who has a leg ulcer and moderate retinopathy. The patient is also slightly overweight (BMI of 27). She has been unemployed for three years and receives social assistance benefits; she lives on her own.*

Her diabetes would typically be diagnosed by a primary care physician (GP or general-internal physician), who checks glucose levels because of the presence of overweight or other risk factors for diabetes or metabolic syndrome. Following confirmation of the diagnosis, the physician would then look for evidence of complications (heart, kidney, eye) and for other cardiovascular risk factors (dyslipidemia, physical inactivity, alcohol or tobacco use). The initial management by the primary care physician will include counselling on cardiovascular risk factors with particular attention to addressing overweight in this patient.

If disease progression is at an early stage, the primary care physician would only occasionally refer her on to an endocrinologist or diabetologist except in cases of switch to insulin, uncontrolled glycaemic levels, difficult treatment adaptations or adjustments, complexity of the case, or on specific request by the patient (second opinion or specialist visit desired). She would however be referred to an ophthalmologist for the first and subsequent eye checks. She would also be referred on to the appropriate specialist (angiologist, dermatologist or orthopaedist)

for her leg ulcer, as well as to a nephrologist, if judged necessary.

Appropriate self-management education is not routinely available and access varies according to the region of residence of the patient (rural versus urban residence, for example) or the type of practice the patient is attending (hospital outpatient clinic, community-based solo or group private practice). Some primary care physicians may refer patients to a specialist nurse or a dietician for self-management education.

The diagnosis of COPD may be suspected on the basis of the patient's history (respiratory symptoms, history of smoking), and she will either undergo basic lung function tests directly at the practice, or be referred on to a pulmonologist for full lung function tests. In the latter case, the specialist issues the diagnosis and also provides treatment recommendations following which the patient would usually return to her primary care physician to commence treatment of her condition. Her primary care physician might also refer her to obtain a second opinion or when the recommended treatment is not effective. Whether or not she will also be referred to pulmonary rehabilitation, self-management education or smoking cessation will depend on her primary care physician, but this does not occur frequently. There may also be additional barriers to participate in such programmes such as location of the patient (remote area).

In some cases, diagnoses of a given chronic diseases and initiation of treatment takes place during an incidental hospitalization for some other reason. In such case, the patients would return to her primary care physician for further management of the chronic condition.

As the patient receives social assistance, she will be in contact with social workers located in her community residence. However, the primary care physician would pay particular attention to her psychosocial situation, and organize home health care if necessary. Since basic comprehensive insurance coverage is compulsory in Switzerland, she should not encounter problems in accessing medication. If financial problems arise, she may qualify for financial assistance to help her pay health insurance premiums. Self-management education sessions provided by nurses or a dietician are generally reimbursed within the basis basket of service. However, foot control or treatment are only reimbursed if they are provided by a specialist nurse for established foot or leg ulcers or lesions; visits are not reimbursable when

scheduled for preventive purposes or when provided by podologists.

*(B) A 76-year-old retired engineer with chronic heart failure, severe asthma and high blood pressure. He lives with his 73-year-old wife who cares for him, while herself suffering from arthritis. They live on the third floor in a housing block and are increasingly housebound due to their illness. They are determined to remain independent; their grandson, who lives nearby, does the daily shopping for them.*

The diagnosis of heart failure will likely have been made by the primary care physician, on the basis of symptoms, examination or basic investigation such as chest X-ray. His physician will then initiate treatment and follow-up of the patient as needed. Referral to a cardiologist is not systematic, especially for very old patients, even if only for a diagnostic echocardiography.

Most often, the diagnosis of asthma is suspected on the basis of the patient's history. He will then either undergo basic lung function tests directly at the practice, or be referred to a pulmonologist for full lung function tests. In the latter case, the specialist issues the diagnosis and also gives treatment recommendations following which the patient would usually go back to his primary care physician to commence treatment of his condition. His primary care physician might also refer him on to obtain a second opinion or the recommended treatment is not effective. Blood pressure will be routinely checked and hypertension diagnosed by the primary care physician. The physician will also initiate treatment and provide counselling on cardiovascular risk factors such as diet, physical activity and smoking cessation where relevant and appropriate.

Access to self-management education for heart failure or asthma may be organized, but as with the case of the diabetes patient described earlier, this will depend on the treating physician or regional access to such programmes. Nevertheless, this occurs less frequently than in the case of diabetes.

Home health care organizations will be contacted swiftly for a comprehensive psychosocial assessment that takes account of the patient's wishes. Home health care may include basic care (medication, personal hygiene) by health auxiliaries as well as medical care such as blood pressure and weight checks, delivered by a nurse. As long as it is prescribed by a physician, such care is reimbursed by the health insurance. Additionally, this patient could

attend a day-care centre or benefit from short stays (maximum three weeks) in nursing homes (long-term care facilities).

### 13.4 Summary and conclusion

One of the main challenges facing the Swiss health care system remains continued fragmentation as a consequence of the federal structure and the division of responsibilities. This constitutes a major barrier for the implementation of a nationwide public health strategy and a more rational organization of health care. Much of the health reform agenda during the past decade was driven by cost-containment efforts. Despite the absence

of a national regulatory framework targeting prevention and care of chronic diseases, national strategies and programmes have been developed within a growing recognition of the need to address chronic disease in the health care system. In addition, several small-scale pilot and preliminary structured care programmes have been implemented in selected localities. The latter are however still too few and limited in scope to cover the needs of the majority of patients with chronic diseases residing in Switzerland. Given the continued high satisfaction with the system among health care users, of around 80%, pressure to actually initiate larger scale changes might not yet be sufficiently strong.

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Many countries are exploring innovative approaches to redesign delivery systems to provide appropriate support to people with long-standing health problems. Central to these efforts to enhance chronic care are approaches that seek to better bridge the boundaries between professions, providers and institutions, but, as this study clearly demonstrates, countries have adopted differing strategies to design and implement such approaches.

This book systematically examines experiences of 12 countries in Europe, 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.

The study focuses in on the content of these new models, which are frequently applied from different disciplinary and professional perspectives and associated with different goals and does so through analyzing approaches to self-management support, service delivery design and decision-support strategies, financing, availability and access. Significantly, it also illustrates the challenges faced by individual patients as they pass through the system.

This book complements the earlier published study *Assessing Chronic Disease Management in European Health Systems*; it 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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