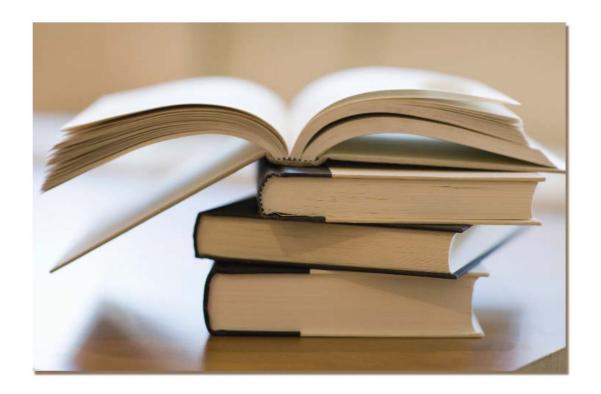
# Chronic diseases

# A clinical and managerial challenge





#### Introduction

HOPE, the European Hospital and Healthcare Federation, is a non-profit organisation representing national organisations of public and private hospitals and hospital owners in 26 Member States of the European Union, plus Switzerland. HOPE gathers 32 organizations: hospital associations, federations of local and regional authorities or national health services. HOPE mission is to promote improvements in the health of citizens, high standard of care, efficiency and humanity in hospital and healthcare services throughout Europe. One of the basic HOPE objectives is to support exchange of knowledge and expertise in Europe.

Since 1981, HOPE organises the Exchange Programme, a 4-week training in a foreign country targeted to hospital and healthcare professionals involved in management, which aims at leading a better understanding of the functioning of healthcare and hospital systems in Europe. Each year a different topic is associated to the programme. At the end of the training, participants gathered by country of destination work together to prepare a presentation about what they have learnt. During a final conference, hosted and organised by a HOPE Member, the annual topic is discussed and participants show their findings, underlying what they had discovered and learnt about their hosting country.

The HOPE exchange programme has reached in 2010 its 29th edition. In its long history, the chosen topics have always mirrored needs and priorities envisaged among hospitals in Europe, that is also demonstrated by the relevance such themes have in the European Union political agenda, as well as in the discussion among international organizations. During the last recent years, the topics of the exchange programme have concerned some of the most important innovations in the hospital and healthcare system: the role of IT (in 2008) and new roles and new skills for health professionals (in 2009). It is no coincidence that the topic of 2010 was "The Chronic Patient: a Clinical and Managerial Challenge".

According to WHO data, on average a quarter of Europeans is affected by at least one chronic condition and care for chronic patients absorbs more than half of hospital expenditure in Europe, the improvements in eHealth and professional qualification produce positive outcomes on this increasingly heavy burden. The recent evaluation studies have proved that good responses can be found in strong prevention activities, early detection, integrated treatments, coordination between different professionals, strong commitment of providers and policy-makers and improvement in the use of health technologies and ICTs. HOPE is involved in some EU projects and institutional dialogues concerning chronic diseases, such as cancer and benchmarking of cardiovascular treatments.

Participants of HOPE Exchange Programme 2010 were invited to explore and report to their colleagues about the best practices put in place in their hosting countries to tackle chronic diseases and improve well-being of chronic patients. Their findings were presented and discussed during the HOPE Agora 2010, which was held in Copenhagen in June, hosted by the Danish region. The HOPE Agora 2010 was a two-day event addressed to hospital professionals and experts, aiming at fostering knowledge and exchange of information about this pre-eminent issue. It gathered around 250 participants among national and local coordinators, HOPE members, guests and HOPE Exchange participants. During the first day, on 15 June, a conference, chaired by Jes Søgaard, Director of Danish Institute for Health Services Research, explored the complex issue of chronic diseases through a system, local and patient perspective. The second day, the 16 June event was entirely devoted to exchange programme participants, who had the task of illustrating in short presentations, the collective findings of their experience abroad.

The present report has the specific objective of presenting the content and findings of the HOPE Agora 2010. It is covering the presentation of the two days discussion and is also integrating information from the most relevant international sources, in particular the WHO publications on the issue of chronic diseases.

Chapter 1 gives a brief introduction and a general overview of the issue of chronic diseases.

Chapter 2 illustrates the main initiative and innovations countries are putting in place to overcome this issue.

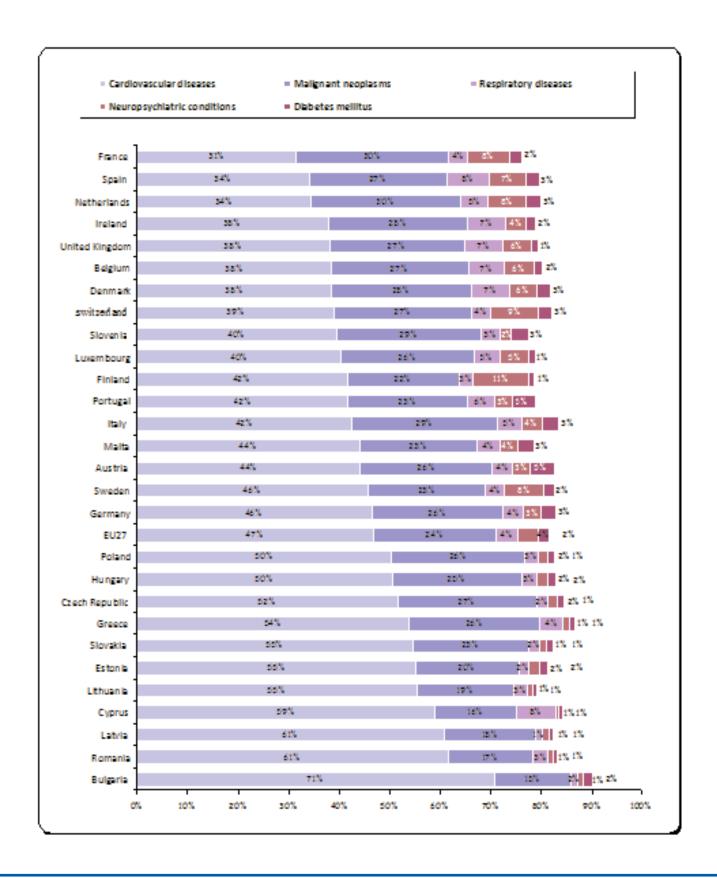
Chapter 3 reports the content of the presentations held by each team during the last day event of the Exchange programme.



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# CHAPTER 1 CHRONIC DISEASES, A CLINICAL AND MANAGERIAL CHALLENGE, WHY?



Chronic conditions represent today one of the most relevant threats and challenges in Europe. As illustrated in the chart on the left page, WHO data indicates that today between 80% and 90% of deaths are due to chronic diseases.

But what is particularly alarming, is the increasing incidence and prevalence among population as well as the increasing rate of population with multiple chronic conditions.

In all EU Member States chronic diseases creates new challenges in terms of healthcare organisation, balance between the different levels of care and system financing, in a context of growing expectations of the population and possible decrease in resources available. The issue of chronic diseases requires new paradigms of healthcare supply and changes within the system, which are happening effectively at different paces. The table below illustrates the main challenges linked to the management of chronic conditions, both under the clinical and under the economical and managerial perspective, as identified and illustrated by HOPE Exchange participants.

While it is obvious that an ageing population and chronic diseases rapidly spreading are major problems everywhere, it is worth noting that the lack of integration and coordination within the system if considered as one of the main weaknesses in most examined countries. This lack of integration concerns the different levels of the healthcare system: general practitioners, nurses, specialists, primary care institutions and hospitals, as well as community care. Another issue regards actions towards the population and patients to foster cultural change with actions of prevention, awareness and direct information. The most important transversal issue, however, lies in the financial constraints, which have negative effect both on the people's ability to access the system, and on the quality of care received.

## MANAGERIAL AND CLINICAL CHALLENGES IDENTIFIED BY HOPE EXCHANGE PROGRAMME PARTICIPANTS

Austria • Prevention

France

• Empowerment

• Strengthening of care integration

• Strengthening the system and continue guaranteeing high quality

Estonia Clinical challenges:

• Public health awareness

• Patient adherence

Clarification of roles and responsibilities

• Family doctors as partial gate-keepers

Managerial challenges:

• Integration of levels of care

Limited resources

• Recruitment of Family Nurses

• Development of Voluntary Sector

• Increasing proportion of the elderly (more likely to have more than chronic diseases)

• Caring for patients – town and countryside

• Lack of professionally qualified staff

Allocation of resources

 Reducing the burden for the system and help patient to understand and to manage their diseases

• Incentivize diseases prevention in medical practice

• Improve the quality of life of patients

HOPE - Chronic diseases October 2010

#### Germany

- Cost of medical treatments: 20% is diabetes-related
- Increasing people awareness of the risks
- Improving coordination and communication among different physicians within the system
- Giving consistency to the periodical prescriptions

#### Greece

- Financial circumstances which demand intervention
- Fast annual growth of chronic patients
- Waiting lists for chronic patients
- Need to establish a primary care system, merge different hospitals and/or community health centres (CHCs)
- Restructuring the relationship between private and public sector
- Establishing financial 'targets' doctors (and patients)

#### Hungary

- Inefficiency because of an unnecessary service delivery
- Ineffectiveness because of decentralized access to service delivery
- Inequity because of inhomogeneous infrastructure

#### Latvia

• Improvement of the quality of life of patients

#### Lithuania

- Structural changes in organization, reducing the number of hospital and beds and increasing treatments in outpatient basis
- Implementing new strategies to promote research
- Promoting screening programmes at primary care to reduce morbi-mortality
- Developing eHealth Systems
- Providing support for self-management of people and improving quality and accessibility of patient education

#### Malta

- Primary Health Care Cure but lack of prevention
- Acute Hospital Patient Discharge Problematic
- Rehabilitation Hospital Needs more support for community services
- Mental Health Care Services Increase independent life in community
- Community Services Needs a change of culture
- Elderly Residences need more services to support independent living

#### Netherlands

- Exploding costs budget constraints
- Future lack of health care workers
- Exploding the great potential of primary care system

#### Portugal

• Improving initiative, quality and self-management

#### Slovenia

- Lack of physicians at primary level
- Lack of middle-term institutions
- Low integration between Hospitals and Primary Care
- · High rate of alcohol abuse related mortality
- Lack of elderly house and long stays in hospitals because of the waiting lists for elderly accommodations
- Expensive home services
- Demographic problem (isolation)

#### Spain

- Inefficient coordination between the different levels of healthcare system
- Insufficient sharing of information between healthcare providers
- Difficult accessibility to health care system (distance, incapacity) and missing of healthcare resources at home
- Patients lack of health education

#### Sweden

- Ageing population
- Access to the right information at the right time
- Identifying chronic patients
- Flexibility of services

#### Switzerland

#### **United Kingdom**

- Coordination of care
- Prevention
- Information and communication technology
- Changes in lifestyles
- Research in new treatments



### CHAPTER 2 - STEPS FORWARDS: STRATEGIES TO TACKLE CHRONIC DISEASES

There are plenty of possible actions to address chronic diseases. Each decision-maker in the healthcare field has then a wide choice of strategies and solutions that could be combined. The specific situation at local, regional or national level should be looked through:

- the epidemiological condition of the population;
- the organizational structure, and in particular the distribution of competences among the different levels of decision makers;
- the organization, the distribution of responsibilities, the strengths and the weaknesses of the healthcare system:
- and the interaction between primary care, secondary care and social care.

The analysis of these elements may seem to indicate that it is preferable to invest on primary and secondary prevention rather than changing treatment pathways, or reinforcing the community care system rather than investing in the hospital care. But this is a simplistic vision that needs to take into account that each strategy will have a short medium and long-term impact, and that in the long term all the elements need to be addressed comprehensively.

The conference and the presentations of the HOPE exchange programme presented the main strategies and actions implemented by governments to face chronic diseases.

In the following paragraphs, broader and more structured strategies, such as the establishment of disease management programmes (DMPs) and of integrated patterns of care, are presented together with more specific actions, which are transversal to the various strategies and interventions put in place, such as self-management and patient education, policies of prevention, new roles for health professionals, ICT and research. More detailed reports of the presentations are presented in the next chapter.

#### **DISEASE MANAGEMENT PROGRAMMES**

The World Health Organization (WHO) defines chronic disease management as the "ongoing management of conditions over a period of years or decades". Disease Management Programmes (DMPs) are pathways of care designed around a specific disease within a specific population (WHO 2008) with the scope of improving the management of chronic diseases. DMPs have been implemented in several European countries, following specific clinical guidelines; they offer a comprehensive, continuum and multidisciplinary care during the entire disease cycle, trying whenever possible to involve the patient in his own cure pathway.

In Denmark, patients are admitted to healthcare centres, where all services related to the specific disease - from prevention and rehabilitation to educational classes - are provided by a multidisciplinary team of healthcare professionals.

In Germany, DMPs have been implemented at the beginning of 2000. They are realised on a contractual basis between the social health insurance funds and the association of doctors. Patients are referred to DMPs by General Practitioners, then they usually have to stay in contact with all professionals from which they receive coordinate care based on their specific case.

In the Netherlands, disease management programmes are based on early detection, self management and patient empowerment, multidisciplinary care and continuous evaluation.

In Austria, less intensive and cheaper care to COPD patients is provided in the weaning centres, which are equipped with Intensive Care Unit (ICU), Respiratory Care Unit (RCU) and connected with outpatient services through the Respiratory Monitoring Unit (RMU).

It is evident that multidisciplinary teams are basic bricks to design and implement effective DMPs. In Belgium, multidisciplinary teams are patient-oriented and well-integrated; they meet and communicate timely, switch competencies and information appropriately, and guarantee proper and efficient continuity of care. In Portugal, multidisciplinary teams put together healthcare professionals, social workers, patients and their families, offering a wide range of adequate and opportunely coordinated services, supporting self-management and empowerment. In Spain multidisciplinary teams, supported by technological instruments and patient records, put together a complex number of healthcare and social workers from different specialties, so that multiple chronic patients can receive an integrated answer and professionals involved can coordinate their work and activities, optimizing time schedules and financial resources. Malta put special efforts in guaranteeing management and leadership training for professionals involved in multidisciplinary teams, those in fact are always activated at the admission to rehabilitation hospitals with the scope of designing an integrated personalised programme for the patient. Finally, the Spiez healthcare centre in Switzerland is an example of effective integration of services and complete care of the chronic patients. The multiprofessional staffs work with patients to enhance each person's individual potential for development, ensuring high professional treatments and interventions that support quality of life and personal autonomy.

#### INTEGRATION OF MANAGEMENT

The treatment of chronic diseases increasingly requires the intervention of different providers and different levels of care. This is due both to the complexity of chronic conditions and to the fact that patients, especially the elderly, often suffer from more than one single chronic disease. Some countries, such as the United Kingdom and Spain, are experimenting integrated care models.

The United Kingdom is strengthening the role of community care and is introducing post-hospitalization services. Within the communities, interdisciplinary teams provide education for self-care and support patients to stay at home. Instead, post-hospitalization services are generally devolved to consultant-nurses, often established in nurse-led clinics, who are responsible for the clinical assessment of patients prior to treatment, for developing research and perform patients' audit.

Spain is implementing a model of integrated care based on multi-channel health service centres, multidisciplinary teams, support programmes for poli-medicated patients and units for highly complex cases that provide case management for pluri-pathological and pluri-medicated patients with frequent use of emergency services and post-hospitalisation care, IT programs to share information, telemedicine and "Expert Patient Programmes".

Finland has also developed an effective model of coordination between primary, secondary and rehabilitation/long-term care. In particular, good specialized care is granted by primary care and nurse triage, which plays an important role in acute hospitals, but also by the coordination among healthcare and social care, both under the responsibility of municipalities.

Estonia is working on reinforcing and reforming its healthcare system; it especially needs a clarification in the distribution of roles and responsibilities in the healthcare organization, to strengthen the gate-keeping system and to effectively integrate the different levels of care. With these purposes, the Ministry of Health is developing clinical and referral guidelines that give indications about the relationships among different levels of healthcare, in particular supporting communication and coordination between family doctors, long term care and home nursing and enabling patients with chronic conditions to be managed in the most appropriate care setting.

#### SELF-MANAGEMENT AND PATIENT EDUCATION

Self-management and patients' empowerment generally are an integral part of the treatment for patients with chronic diseases. Self-management promotion is often a task of multi-professional teams, operating within DMPs or integrated model of care, which are demanded to give patients and their families the right instruments to manage the disease.

In France, the national plan for improving the quality of life of people with chronic diseases establishes a lot of measures aiming to increase the patients' self-management and self-awareness concerning their own disease; freely accessible health networks offer to patients a wide range of services targeted to improve well-being and good behaviour, such as dietary counselling, weight loss and exercise programmes and provide both patients and their families with training programmes to know and manage chronic diseases.

In Lithuania, patient education is realised at any level through the control of intermediate risk factors. Endocrinology departments in hospitals and outpatient clinics have established teaching centres about food, self-control and pumps for children and parents and for adults. Twice a year they realise seminars for families. The Lithuanian diabetes association provides practical help and advice to chronic patients, organises summer camps for education and produces publications on all aspects of living with diabetes (Proper Diet is Health, Nutrition for Diabetics, Foot care, Insulin, etc.).

Spain and the United Kingdom have developed "Expert Patient Programmes" (EPP) to facilitate autonomy and self-care of patients, promote their active participation, teach them how to take and manage directly responsibilities on disease management and self-care.

In the Netherlands and in Sweden, patient empowerment overcome the simple ability of checking his/her own status. Whenever possible, the patient is involved in the decision-making process concerning his/her pathway of care and is guided to handling his disease, learning to know it and learning how to manage it.

In Denmark, patient education is considered so important that patients themselves, after following self-management programmes, are committed to teach other patients about correct behaviours and self-care.

In Greece, where the role of families is still very important, the system sustains parental care with social programmes and supporting programmes for chronic patients and their relatives.

In Slovenia, hospitals organize workshops for educating patients and their families on the disease and the management of it. Moreover, mental ill patients not only receive acute and long-term treatments, but also follow group therapies and prevention programmes, attend occupational therapies as well as programmes to promote self-independence and social inclusion, generally managed by non governmental organizations.

In Hungary, specialised centers for mental ill people offer therapies in groups and packages of activities that help patients feel useful; moreover, patient education and self-empowerment are encouraged by giving permission to relatives and even pets to stay in hospitals wards and accompany the patient.

#### **NEW ROLES FOR HEALTH PROFESSIONALS**

The spreading of chronic conditions among the population and the evolutions in management of chronic diseases have had impacts on the skills and the organization of the work of healthcare professionals. In particular, the increasing importance of primary care has been requiring nurses to take off some tasks and responsibilities previously reserved to doctors and physicians. Nurse-led clinics are grown in the United Kingdom, the Netherlands and some Scandinavian countries; on the other hand, General Practitioners have also seen increasing their role and duties.

Hungary is strengthening and broadening the competences of GPs to better answer the needs of chronic patients.

In Denmark, the GP is totally responsible for chronic patient, from the diagnosis to the follow-up, moreover he/she takes the responsibility of activating, coordinating and monitoring the multidisciplinary teams.

In the Netherlands, general practitioners and nurse practitioners act as gate-keepers and are continuously responsible for the patient status monitoring and for referral to secondary care; this centralised coordination guarantees good care for patients, reduction in the number of patients who seek medical specialist and general cost containment.

In Slovenia, nursing care at home is offered free of charge after discharge and, together with other long-term services and institutions, helps to improve well-being and quality of life of chronic patients offering high quality and effective care.

In Sweden, nurse-led clinics occupy a fundamental role in the primary care system; in fact all the necessary treatments for chronic patients are offered at the level of primary clinics and nurse-led clinics, which directly depend from primary care centers, encourage self-management, patient education and, if necessary, activate home care and community care.

In the United Kingdom, the figure of consultant nurse is spreading. Often established in nurse-led clinics the consultant nurse operates in the area of hospital care and post-hospitalization services, has advanced clinical practice, held a prescribing role, is responsible for the clinical assessment of patients prior to treatment and develop research and patients' audit in order to evaluate clinical effectiveness.

In France, therapeutic patient education is realized through the involvement of different kinds of professionals, obtaining an effective integration between ambulatory care and hospital providers as well as strengthening the role of general practitioners. Efforts are also addressed to improve the interaction among different professionals, creating providers' networks where information and knowledge on patient status can be exchanged, strengthening coordination, continuity and interdisciplinary of health care provision.

#### PREVENTION AND EARLY DETECTION

The area of prevention is at least as important as having correct patterns of care. This is particularly true in the ambit of chronic diseases, whose spreading and development is greatly influenced by incorrect behaviours and whose improvement can be arrested or restrained thanks to early detection procedures. All countries, at different levels and with different strategies, put in place specific actions of primary prevention, addressed to removing the potential causes of illness, and secondary prevention, aimed at timely identifying the disease so that it can be treated, removed or controlled at an early stage, especially in target populations considered at risk.

In primary prevention, Austria is implementing measures to change people's attitude towards smoking, which is one of the main problems of the country; the government is passing antismoking laws and health organizations, including hospitals and primary care settings, are putting efforts in guaranteeing information to patients and prevention campaigns.

In Finland, primary prevention activities, vaccination, food education and nutrition campaigns address people from the early stages of their life, at home as well as at school; consultation offices for mothers with children are established throughout the country; periodical screenings for diabetes and vascular diseases are offered and in the early stage of illnesses interviews with patients are used to analyze the situation and appropriately define the treatment.

Lithuania explicitly choose to follow a strategy of prevention of modifiable risk factors involving all actors of the system: the government is responsible for primary prevention; municipalities and non-governmental organizations organise campaigns, services and activities to promote healthy behaviours, sport and physical activity. Hospitals through the Lithuanian Health Promoting Hospital Network (LSSLA) take a primary position in educating and actively involving patients in the care pathway. Outpatient cardiology clinics have a

hypertension control service and the Lithuanian Cardiology Association has a web service for assessing the risk level of patients and to deliver information about preventing and dealing with some diseases. On the other hand, to increase the number of people who participate in screening programmes and to promote early diagnoses are the main goals of the Lithuanian Health Care Policy; in particular, primary health care institutions are implementing some preventive programs for cardiovascular diseases, cervical cancer, breast cancer, colorectal cancer and prostate cancer having as target the period 2005-2013.

During the last years, Latvia has concentrated efforts in prevention, especially against cancer. A massive campaign of invitation to screening programmes was organised between 2009 and 2010 and some corrective actions were introduced right afterwards. Today, advertising campaigns aiming at sensitivising the population to cancer threats have been put in place and a systematic research aiming at identifying the elements which hinder population to use screening programmes has started; the target population is addressed through letters having a simple format and written in a very easy and understandable way. At the same time efforts are put in strengthening in the population confidence in the competence and quality of the health structures.

#### ICT INNOVATIONS AND EHEALTH

Information and communication technologies are becoming increasingly important to ensure quality of care to every patient and at the same time facing resource constraints.

Two major kinds of innovations have been developed throughout Europe: eHealth solutions for secure data storage and exchange of information from one site to another via electronic communications; telemedicine, which include the exchange of medical information for the purpose of offering patient consultative, diagnostic or treatment services.

Regarding the first group of ICT solutions, in Denmark, treatments and prescriptions are always recorded and Electronic Patient Records referring to each person are shared between the hospital and the General Practitioner.

In the last years, Portugal has strongly invested in the introduction and implementation of ICT solutions for the management of healthcare and chronic diseases. Today, 90% of Portuguese hospitals use the same network, the surgical waiting lists are managed through a central management system, all information is connected within the IT system and is easily and timely accessible to all the professionals involved in the patient care.

Lithuania has an eHealth strategy aiming to restructure and modernise the healthcare system; one of its main objectives is the integration of the system, and with this scope the SVEIDRA information management system has been designed to deal with state funds and to improve the efficiency of the processes of entering, storing, analysing, reporting and reimbursing services performed by healthcare institutions.

In Estonia, the development of E-health solution has increased the level of awareness about health of Estonian population and is particularly important for patients and doctors that can share health-related information through health portals, encouraging education and opportunities for shared learning; moreover the wide availability of data and information has proved to be an important facilitator for the realization of health and prevention programmes and epidemiological studies.

Greece has well implemented systems for the digitalization of all patients' files and is now working to improve the system interoperability.

Finally, in Spain the different providers involved in a pattern of care are connected in multi-channel health services centres where they can use different technological means to communicate and directly access documents, saving time and costs both for patients and for professionals.

Telemedicine solutions are common as well, they are gaining emphasis and importance since they improve communication between patients and physicians as well as the relation among different physicians, enhance

patients living, help to avoid unnecessary travelling, allow cutting waiting times, repeated exams and extra costs.

In Denmark, telemedicine tools deal with tele-control of measurements and can be used for setting reminders, instructions, self-monitoring, tele-consultation and exchange of data and information, helping patients taking care of themselves while staying at home.

In the United Kingdom, remote electronic monitoring enable patients to adopt a proactive approach, reduces unnecessary travel to the hospital, facilitate education for self-care and early detection of deterioration to optimize medication, preventing and then postponing specialised hospital admission.

In France, telemedicine helps sustaining patient involvement and self-responsibility. The Sophia program for diabetic patients offers efficient web-based tools that help patients' adherence to protocols, their ability to monitor their own conditions, the exchange of information with professionals and the communication with the GP.

In Spain, different typologies of software and programmes of telemedicine are used and experimented also within European funded projects, among those Ykonos allow sharing digital radiological images in the entire region of Castilla la Mancha, Colabor@ allows the patient to be in touch with his referent physicians, sharing documents and information, taking appointments and receiving advices, eliminating the need of travelling to reach every healthcare professional, MEDTING is a web platform where medical professionals can freely share medical images and videos and discuss clinical cases.

Similarly, Estonia is participating in the EU funded project DREAMING. It enables patients to live at home independently through a combination of medical devices and environmental sensors and a powerful Decision Support System which is able to detect risk situations based on the specific profile of the individual user or of the users' category.

#### **RESEARCH**

In relation to what illustrated before, the concept of research can be declined in many different ways, can embrace the economic, managerial, clinical or technological areas and influence all kinds of activities.

In Belgium, research plays a main role, it represents the common thread between prevention, education and multidisciplinarity; it works close to people, supporting local initiatives, because it is considered the better way to find concrete solutions to people's problems.

In Lithuania, research plays a central role in the fight against chronic diseases. In 2010 the Ministry of Education & Science has approved the national research programme with the purpose of "determinate morbidity risks and provide theoretical basis for a new health care strategy to develop more sophisticated prevention and diagnosis methods". The research programmes have the specific objective of collecting data about health behaviour and key risk factors of chronic diseases, so that specific therapies can be realised according to people's actual needs. The Lithuanian Government gives direct support to the Biomedical Research Institute, at Kaunas University, which has been participating in different international studies, such as Finbalt health monitor, monitoring health related behaviour and lifestyle in Estonia, Finland, Latvia and Lithuania to promote health and prevent disease, CINDI Programme, monitoring risk factors of non communicable diseases and MONICA project, to determinate risk factors and their prevalence in cardiovascular disease. Finally, the Lithuanian Health Promoting Hospital Network (LSSLA) collaborates at national and international level on WHO Projects and is able whenever opportune to influence National Policy development. Of course, some of the information collected is taken annually to Parliament to develop new policies.

In Hungary, for example, the Budapest University Hospital not only offers a complete high level care to chronic patient, but is also one of the main research centres on Hereditary and Acquired Angioedema and reference centre for all European countries.

# CHAPTER 3 - STRATEGIES AGAINST CHRONIC DISEASES AROUND EUROPE: FINDINGS OF HOPE EXCHANGE PROGRAMME

The following pages briefly summarize the contents of the presentations of HOPE Exchange participants on 16 June 2010. 18 out of 27 European Member States, plus Switzerland, are covered. They are completed with some figures from the WHO Hospital Morbidity Database (HMDB) concerning chronic disease and risk factors. Whenever possible and opportune, the texts have been slightly integrated with external sources indicated in the references. The list of participants for each 'team' is also inserted.



#### **AUSTRIA**

Are we able to influence some chronic diseases by daily life management?

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN AUSTRIA

Matthias Mielke, Germany Ilkka Naukkarinen, Finland Janine Oelmaier, Germany Ane Dragsbaek Poulsen, Denmark Cocky van Splunter, Netherlands

Regular daily smokers aged 15+		27.5 – 23.2	(1990 – 2006)
Incidence	Neoplasm	404.9 – 425.2	(1990 – 2007)
per 100,000 inhabitants	Mental and behavioural Disorders	629.8	(2004)
Diabetes <b>prevalence</b> (percentage values)		4.71	(2006)

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	5.5	19.3	7.6%
Neoplasm	28.9	7.7	37.2%
Diabetes	4.0	11.8	9.6%
Dementia	1.1	29.3	5.5%
Mental and behavioural disorders	14.3	21.6	11.3%
COPD and bronchiectasis	3.4	10.1	8.5%

Daily life management essentially means "to organize our own lives, taking care of our own health and adopting behaviours that respect our well-being".

One of the main problems in Austria is connected to smoking behaviours. About 36% of Austrian population smokes; almost a quarter of populations 15+ are daily smokers.

The main consequence of this situation is the development of heart diseases and lung diseases: Chronic Obstructive Pulmonary Disease (COPD), lung inflammation, lung cancer, which is the first cause of mortality among men and the second one, after breast cancer, among women.

One way to tackle this issue is to reinforce daily life management, which can be done through prevention and empowerment. Different challenges and strategies involve Government, Health Organizations, and individuals.

The Government is enforcing information campaigns and passing antismoking law, such the rule for restaurants to have separated smoking rooms.

The health organizations, including hospitals and primary care, are putting efforts in guaranteeing information to patients, early diagnosis and actions of prevention.

Individuals need to be open to the messages coming from health organizations, should avoid passive smoke and of course change their attitudes towards smoking.

Within the Austrian system a new solution has been found for treating COPD patients: the establishment of weaning centres for graduated and integrated care. These are step-down units with training for patients and relatives and job enlargement/enforcement, providing less intensive care at a lower cost; they are equipped with Intensive Care Unit (ICU), Respiratory Care Unit (RCU) and connected with outpatient services through the Respiratory Monitoring Unit (RMU).

According to the leading Austrian centre of pneumology, the weaning centres are meant to support early discharge, shortening hospital stay and helping to reduce the number of beds needed. The empowerment and training of patients also allows fewer cases of recurrence, improves life quality and reduces hospital costs.









#### **BELGIUM**

From problem-oriented to patient-centred patterns of care

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN BELGIUM

Pascal Dupas, France Helle Yding Kooij, Denmark Véronique Ollion, France Carmen Rodriguez Rodriguez, Spain Evangelia Siozou, Greece

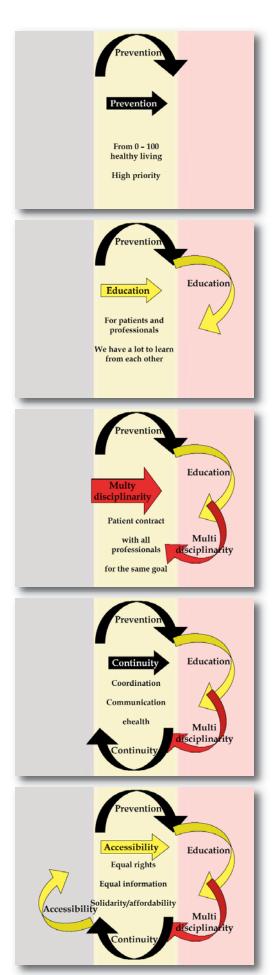
Regular daily smokers aged 15+		32.0 – 22.0	(1990 – 2006)
Incidence	Neoplasm	322.0 – 574.0	(1990 – 2006)
per 100,000 inhabitants	Mental and behavioural disorders	629.8	(2004)
Boundaries	Mental and behavioural disorders	1.07	
Prevalence percentage values	Diabetes	3.5	(2004)
Villacs	COPD and bronchiectasis	5.3	

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	2.7	14.8	4.3%
Neoplasm	11.8	9.3	50.3%
Diabetes	1.9	9.4	6.3%
Dementia	0.2	23.1	3.9%
Mental and behavioural disorders	4.1	10.4	9.3%
COPD and bronchiectasis	2.5	12.1	4.1%

The hospital system in Belgium can be considered quite advanced: there are beautiful and high quality hospitals, experienced doctors, good level researchers, high skilled nurses and social nurses.

However, there is a rather complex financial and organizational system, with many actors responsible for healthcare provision and financing: local communities, insurance companies, primary care and hospitals; and the patients are always free to choose their insurance as well as to access specialized care without referral.

As many other countries, Belgium is facing two main challenges: the increasing patient needs, due to complex chronic condition and in particular multiple chronic diseases; the financial constraints, made worst by the



current financial crisis. Improving the possibilities of "care at home" for chronic patients is considered a means to address both of these issues, yet, it implies a perfect coordination between professionals delivering home treatments and the integration of all level of care.

In concrete terms, Belgium is working to build a coordinate system based on the principles of prevention and education; continuity and multi-disciplinarity; accessibility; and research.

Prevention is a first need and the main priority; it should embrace all periods of life of individuals, from zero to 100 years. Life-long learning and education are important for patients, as well as for professionals: they allow the information exchange and the learning from each other, so that the doctors can give the best answer to patient's needs; moreover, high and continue education allow a high level of self-management, preparing complete-skilled professionals.

The realization of multi-disciplinary teams, which might be able to work together effectively, lies on the high level education. These teams are composed by different professionals, working towards the same goal, hence patient-oriented and well-integrated, able to meet and communicate timely and switch competencies and information properly, guaranteeing appropriate and efficient continuity of care also using the supports of the most advanced technology (e-health).

Research plays a main role in this new and integrated pattern of care, representing the common thread between prevention, education and multi-disciplinarity. Research needs to support local initiatives, because it has to be close to people so that it can better work to find a solution to their problems.

Belgium has been working hard in putting together all of these elements and in this way it is winning the challenge of offering the highest quality of care to everyone, changing the pattern of service delivering from 'problem-oriented cure' to 'patient-centred integrated care' for everyone with one or more chronic diseases.





#### **DENMARK**

Intersectorial integration and self-management as examples of excellence

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN DENMARK

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Regular daily smokers aged 15+		37.0 – 24.0	(1994 – 2007)
Incidence	Neoplasm	535.8 – 595.3	(1990 – 2007)
per 100,000 inhabitants	Mental and behavioural disorders	143.0 – 484.1	(1990 – 2008)
	Neoplasm	3.26 – 3.73	(1990 – 2007)
Prevalence percentage values	Mental and behavioural disorders	0.13 – 0.97	(1990 – 2008)
tuides	Diabetes	2.40 – 4.40	(1990 – 2007)

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	3.4	8.9	10.0%
Neoplasm	14.1	6.5	25.5%
Diabetes	1.6	6.9	10.0%
Dementia	0.2	11.1	8.8%
Mental and behavioural disorders	2.1	4.9	28.1%
COPD and bronchiectasis	3.0	5.9	10.9%

In Denmark<sup>1</sup>, as in many other countries, the main threats for the health of citizens are tobacco and alcohol consumption, obesity and unhealthy diet. A huge number of health problems are associated to incorrect 'lifestyle', among those, the Acute Coronary Syndrome and the Cardiac Arteriosclerosis. The treatment received by patients affected by these kinds of problems can be used as a good example to describe the 'journey' within the Danish healthcare system of patients affected by multiple chronic diseases.

<sup>1</sup> See also: Schiøtz M, Frølich A, Krasnik A (2008). Denmark. In: Knai C, Nolte E, McKee M (eds). Managing chronic conditions: Experience in eight countries. Copenhagen, WHO Regional Office for Europe, on behalf of the European Observatory on Health Systems and Policies: 15–28.

The first contact with the system happens through the General Practitioner, who acts as gate-keeper and has the task of diagnosing the disease. In relation to the severity of the disease, the GP can refer the patient to a specialized hospital, where the acute symptoms are treated. The patient is discharged in a short period of time. Meanwhile, all of his/her problems, treatments and prescriptions will have been recorded: 'Electronic Patient Records' are shared between the hospital and the General Practitioner.

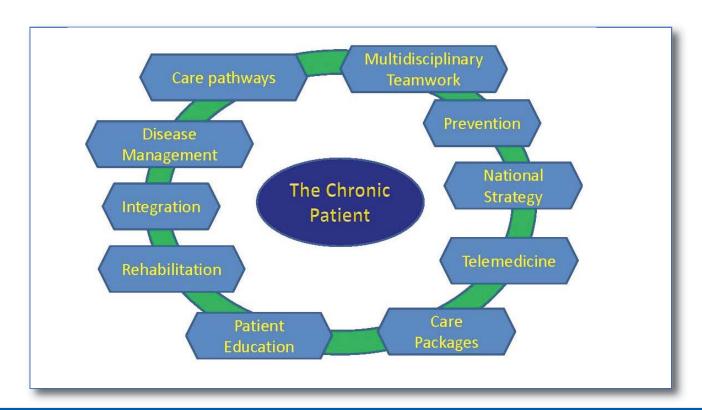
At this stage a lot needs still to be done: the patient must change his/her habits and lifestyle, so that the risk of acute episodes decreases. The GP is responsible of follow up the patient, assess the lifestyle changes and the eventual progression of the disease; he/she can refer the patient to healthcare centres – providing a range of services from primary prevention to rehabilitation - self-management support programmes, disease-specific education classes and/or educational sessions; in any case the GP will activate a multidisciplinary team and will be responsible of coordinating and monitoring all treatments.

The multidisciplinary team realizes a 10-week programme, during which the patient learns how to take care of himself by meeting several specialists: specialist nurse, cardiologist, psychologist, physiotherapist and dietician. At the same time the patient starts a personalized programme of rehabilitation at the hospital, based on his own characteristics and on the severity of the disease.

Finally, the patient should be able to understand his/her problems and follow the advices received by the multi-professional team: stop smoking, follow a healthy diet, doing some sport and not least, checking his status (self-management).

A new tool can also help the patient taking care of him/herself staying at home but also being monitored and controlled: telemedicine solutions dealing with tele-control of measurements can be used for setting reminder, instructions, but above all for self-monitoring, tele-consultation and for exchanging data and information. The GP always remains responsible of periodically checking the health status of his patient and, in case there is something wrong, he will again refer him to secondary care. Depending on the real needs and problems occurred, the patient can now join the quit-smoking group at the pharmacy, follow rehabilitation courses at the municipality and finally join the patient association to share his successful experience with other people.

In conclusion, the Danish healthcare system has structured coordinated pathways of care based on a clear national strategy which stresses the importance of both multidisciplinary team-working and self-management (through patient education) to guarantee a complete and efficient disease management based on standards of quality.





#### **ESTONIA**

Coordination and patient-centred care

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN ESTONIA

Kate Glass, United Kingdom Miguel Angel Polo Ostáriz, Spain

Regular daily smokers aged 15+		28.2 – 26.2	(1990 – 2008)
Incidence	Neoplasm	315.6 – 497.2	(1990 – 2006)
per 100,000 inhabitants	Mental and behavioural disorders	189.3 – 208.0	(1990 – 2007)
	Neoplasm	1.60 – 2.77	(1990 – 2003)
Prevalence percentage values	Mental and behavioural disorders	3.59 – 8.75	(1990 – 2007)
Tenace and the second s	Diabetes	2.91	(2006)

In Estonia healthcare is publicly funded through mandatory health insurance. Health expenses represent 5% of the GDP, still below the European Union average.

The Estonian healthcare system has undergone several changes since 1991, when the country gained independence, and started pursuing gradual changes to join the European Union in 2004. Actors in the health system are:

- the Estonian health Insurance Fund (EHIF), which purchases services based on patient needs;
- the Ministry of Social Affairs, responsible for the entire system administration, optimizing hospital services and increasing emphasis on primary care;
- the Hospital Association, representing hospital care providers, that highlights an increasing demand on specialist services;
- the Family Doctor Association, which increase emphasis on prevention and wellbeing.

Social care service providers are playing an increasing role, because of their strong relationship with all other levels of care and because of population ageing. Some clinical and managerial challenges can be identified which affect the entire system as well as the care of chronic diseases: the need to increase public health awareness and patient adherence; the necessity to clarify the distribution of roles and responsibilities, the need of strengthening the gate-keeping system and integrate the different levels of care; the opportunity to recruit more family nurses and to develop the voluntary sector even if facing resource constraints.

To face the new challenges of chronic diseases, the Estonian healthcare system is implementing three strategies: development of patient-centred patterns of care; strengthening of models of good practice between different levels of healthcare; development of E-health solutions.

The concept of patient-centred care really put the focus on patients and their needs, helping to strengthen the relation between EHIF, providers and 'clients': the EHIF purchases healthcare services based on patients' needs, reviewing patients' preferences and carrying out annual surveys to determine quality of services and areas of improvement, moreover it has a health care provider's complaint system; health care providers carry out surveys to collect information on patient/carer views and experiences as well as patient complaints/suggestions procedures.

The Ministry of Health is working to strengthen models of good practices through the "on-going" development of clinical and referral guidelines between the different levels of healthcare. These guidelines support a strong communication and coordination between long term care, home nursing and family doctors, enabling patients with chronic conditions to be managed in the most appropriate care setting.

The development of eHealth solutions has the first effect of increasing the level of awareness of health of Estonian population. It is particularly important for patients and doctors, since they can share health-related information through health portals, encouraging education and opportunities for shared learning. The wide availability of data and information is an important facilitator for the realization of health and prevention programmes and epidemiological studies.

Telemedicine solutions are also being tested. They assist patients with chronic conditions, permit patient independence and are able to early detect the deterioration of health status, in this way improving quality of life of patient and health outcomes.

An example of telemedicine tool applied in Estonia is the EU funded DREAMING Project (elDeRly friEndly Alarm handling and MonitorING), which enables patients to live independently at home through a combination of medical devices and environmental sensors and a powerful Decision Support System which is able to detect risk situations based on the specific profile of the individual user or of the users category.

#### Social Care

- Social care services are playing an increasing role
- Developing social care services since healthcare reform
- · Increasing need by aging population
- Strong relationships between different levels of health care

#### Interest Groups

- EHIF Purchasing services based on patient need
- Ministry of Social Affairs Public interest, optimizing hospital services and increasing emphasis on primary care
- Hospital Association Creating a voice for hospital care providers. Evidencing increasing demand on specialist services
- Family Doctor Association Increasing emphasis on prevention and wellbeing

#### Patient-centred care

EHIF purchase healthcare services based on client need

- Reviews patient preferences on information sources
- · Has a health care provider's complaint system
- Carry out annual surveys to determine quality of services and areas for improvement
- Health care providers carry out surveys to collect information on patient/carer views and experiences
- Patient complaints/ suggestions procedures

#### E-Health in Estonia

Increase the level of awareness of health of Estonian population

Patients can share health-related information through health portals.

#### Medical professionals

- Sharing information amongst health professionals, encouraging education and opportunities for shared learning
- To enable development of health and prevention programmes and epidemiological studies

#### E-Health in Estonia

DREAMING — elDeRly friEndly Alarm handling and MonitorING

- EU funded DREAMING Project
- · Enables patients to live at home independently

Telemedicine assists in the management of

Patients with chronic conditions by

- improving quality of life
- enabling patient independence
- early detection of deterioration of health and improved health outcomes.



#### **FINLAND**

Continuity of care from prevention to home treatments

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN FINLAND

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Regular daily smokers aged 15+		26.0 – 20.4	(1990 – 2008)
Incidence	Neoplasm	355.8 – 494.3	(1990 – 2007)
per 100,000 inhabitants	Mental and behavioural disorders	96.0 – 99.7	(1990 – 2008)
	Neoplasm	1.90 – 3.89	(1990 – 2007)
Prevalence	Mental and behavioural disorders	1.33 – 1.80	(1990 – 2008)
percentage values	Diabetes	2.15 – 4.21	(1990 – 2008)
	COPD and bronchiectasis	2.01 – 3.72	(1990 – 2008)

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	5.5	39.5	2.9%
Neoplasm	17.3	9.1	22.2%
Diabetes	2.2	13.8	4.8%
Dementia	2.4	123.1	1.4%
Mental and behavioural disorders	15.6	44.1	4.9%
COPD and bronchiectasis	1.7	11.6	4.0%

During the 1990s, Finland faced a deep recession and addressed huge challenges in the allocation of resources to health care. Today, Finland has one of the lowest costs of state funded health care and one of the highest rates of people satisfaction regarding healthcare.

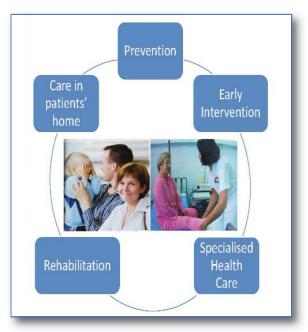
The main challenges in Finland are represented by diabetes, alcohol consumption, depression, obesity and related cardiovascular diseases. The increasing proportion of elderly people throughout the country is likely to raise more and more the problem of multiple chronic diseases. There is often a lack of professionally qualified

staff, especially when considering the most isolated areas and the countryside. This brings to the necessity of effectively organizing caring for patients living in rural areas, away from the big urban centres, and to carefully plan the allocation of resources.

In facing all of these changes, Finland is trying to find the balance between different aspects of delivering health and social care. The care for chronic diseases is organized throughout a coordinated flow, which runs from prevention and early intervention, to specialized health care, rehabilitation and home care, and which is able to guarantee an efficient use of professional and financial resources.

Prevention is offered from the early stages of people's life. Almost all children is vaccinated; maternity care is offered for the whole family and both parents receive parental checks. At school as well as at home people take care of food education and nutrition, on average children are healthy and the rate of obesity among youngsters is still below the European average. Consultation bureau for mothers with their children are established throughout the country and the importance of rural living and outdoor life is emphasized.

Early intervention is considered fundamental. All employers are required to offer occupational health services, larger companies provide their own, smaller ones often buy the services from private companies. They provide quick and convenient access for workers to health assessment, advice and treatment and help to reduce the pressure on public health centres and personal practitioners. Periodical screenings for diabetes and vascular diseases are offered. Easy access to primary care allows a rapid intervention and



interviews with patients are planned in the early stage of illnesses to better analyze the situation and appropriately define the treatment..

The integration between primary care, specialized health care and social care is realized effectively. If someone requires medical help, he/she phones and speaks to a nurse who triages him/her into a classification from A to E and directs him/her to the right service. For most relevant cases university hospitals support the entire district, but the short stay in acute beds is always incentivized. A good specialized care is granted by the important role played by primary care and nurse triage but also by the coordination among healthcare and social care, both under the responsibility of municipalities. This means that the expensive and expert resources are more targeted at those patients that really require them, allowing improving cost effectiveness.

Patients are referred to rehabilitation clinics as soon as possible and are eligible to vocational training when they are facing 'retirement' to support return to work. Physiotherapy or other treatments can continue at home, with the support of telemedicine and group homes with a normal house setting for elderly. In parts of Finland they are also supporting home care for a range of different ages and case groups, including neurological patients, and patients with heart and respiratory diseases, with 24/7 care with nurse and breathing apparatus. Exercise programmes for elderly people are widespread.

It is evident in Finland an effective model of coordination between primary, secondary and rehabilitation/long-term care which ensure continuity of treatments and is integrated with home care. The strength of the Finnish approach is that it recognises that the solution to the challenge of chronic diseases needs action in more than one aspect of healthcare and that it should not be addressed by increasing the number of hospital beds.

Future goals of Finnish health system are:

- to improve and extend the use of technology, in particular realizing the benefits of the electronic patient record systems;
- to further develop the integration of the system, experimenting the joint delivery and management of health and social care and linking the planning of specialized care to the rest of the health care system.



#### **FRANCE**

A national plan for improving the quality of life of people with chronic disease

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN FRANCE

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Regular daily smokers aged 15+	29.0 – 25.4	(1991 – 2003)
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	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	2.2	11.3	3.5%
Neoplasm	12.6	7.6	40.5%
Diabetes	1.9	7.2	22.6%
Dementia	0.5	6.1	27.0%
Mental and behavioural disorders	3.9	13.6	40.3%
COPD and bronchiectasis	0.9	9.0	18.7%

According to its historical fame of being a country of order and planning, the French system<sup>2</sup> has been facing the issue of chronic diseases in a systematic way since the beginning of the 20th century. In France, most common chronic diseases are asthma, chronic bronchitis and diabetes.

The main issues addressed in the recent years concern the improvement of coordination and integration within the system, in particular among primary care, hospital care and ambulatory care, and the improvement of patient involvement and self-management.

In France, the Government is responsible for determining the health policies; according to this system it passed in 2004 a Public Health Law, which paved the way for the approval of a national public health plan for people with chronic illnesses.

The Public Health Law defined 5 major health plans, 104 public health priorities and 22 categories of individual target indicators, of which 11 concerned chronic conditions or diseases, for the period 2005–2009. One of the health plans foreseen by this law specifically targeted chronic condition: the 'national public health plan for improving the quality of life of people with chronic illness' was published in 2007 and covered the period 2007-2011; it established 15 measures and a total investment of 726.7 millions € for tackling chronic conditions.

<sup>&</sup>lt;sup>2</sup> See also: Karlberg I (2008). Sweden. In: Knai C, Nolte E, McKee M (eds). Managing chronic conditions: Experience in eight countries. Copenhagen, WHO Regional Office for Europe, on behalf of the European Observatory on Health Systems and Policies: 115–130.

The importance of this national plan lies in its purposes and in the main measures foreseen:

- to help patients to understand and to manage their disease. Therapeutic patient education is realized through the involvement of different kinds of professionals, realizing an effective integration between ambulatory care and hospital providers as well as strengthening the role of general practitioners;
- to include diseases prevention in medical practice. Active spaces and freely accessible health networks allow patients to receive a wide range of services targeted to improve well-being and good behaviour, among those dietary counselling, weight loss and exercise programmes;
- to facilitate the every-day life of the patient. This can only be achieved through the involvement of patients, the implementation of self-management, home-care and the involvement of families. Within the already mentioned health networks some services encouraging patients' empowerment and training relatives to care patients are provided; these services always follow evidence-based protocols and they are particularly developed for diabetic people, for which they normally consist in information and training sessions on insulin injections, diet, foot care or exercise;
- to know better the consequences of the disease on the quality of life, improving the knowledge about the needs of patients.

Yet, efforts in the French system are addressed to improve the interaction among different professionals, creating providers' networks where information and knowledge on patient status can be exchanged, strengthening the still weak coordination, continuity and inter-disciplinarity of health care provision.

The role of telemedicine is gaining emphasis. eHealth helps sustaining patient involvement and self-responsibility and the Sophia program for diabetic patients is worth to be mentioned: it offers efficient web-based tools that help patients' adherence to protocols, their ability to monitor their own conditions, the exchange of information with professionals and the communication with the GP. The program aims to improve health status and quality of life of diabetic patients, reduce complications and co-morbidity frequency and at the same time allows avoiding redundant examinations and consultations, optimizing health care expenditure.

The French structure is going to focus on organization of care rather than on inputs, which means to adapt the entire package of treatments offered to the patient to his/her specific needs as well as to rethink and adapt the current ways of the financing administration.

# Why a national plan is important?

- To <u>help patient to understand</u> and to manage their disease
- To include <u>diseases prevention</u> in medical practice
- · To facilitate the every-day life of the patient
- To know better the consequences of the disease on the quality of life



#### **GERMANY**

Towards an integrated model of care

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN GERMANY

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Regular daily smokers aged 15+	33.9	(2003)
Neoplasm incidence per 100,000 inhabitants	417.9 – 529.1	(1990 – 2008)
COPD and bronchiectasis prevalence percentage values	0.24 – 0.32	(1993 – 2007)

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	5.1	16.5	2.7%
Neoplasm	24.1	10.3	2.8%
Diabetes	2.8	13.4	1.3%
Dementia	0.3	-	-
Mental and behavioural disorders	14.8	24.5	5.8%
COPD and bronchiectasis	2.5	12.3	0.8%

As in many parts of the world diabetes is spreading in Germany<sup>3</sup> among all people regardless of age, average income or education. 8 million official diabetic patients are accounted in Germany and every year 47,300 new people are diagnosed; moreover, no less than 20% of the cost of medical treatment in Germany is proved to be diabetes-related.

Several steps to overcome the problems linked to chronic diseases have been taken since the early '90s. From the early 2000 the German system has implemented Disease Management Programmes (DMPs) for people affected by chronic diseases like diabetes, coronary heart disease, asthma and COPD.

DMPs are offered by Social health Insurance funds, which per each chronic condition negotiate DMPs' contracts at a regional level with the associations of doctors and other actors, such as the regional association

<sup>&</sup>lt;sup>3</sup> See also: Siering U (2008). Germany. In: Knai C, Nolte E, McKee, M (eds). Managing chronic conditions: Experience in eight countries. Copenhagen, WHO Regional Office for Europe, on behalf of the European Observatory on Health Systems and Policies:75–96.

of hospitals. DMPs are based on evidence based guidelines; they are managed by family doctors but they also introduce an intersectoral approach and aim to promote self-management.

When these programmes are proved to be effective, they are linked to care and treatment of chronic diseases. Hence, after being diagnosed and be eventually referred to DMPs, the patients normally have to be in contact with several professionals: of course the family doctor and then chiropodist, ophthalmologist, pharmacist, dietician, as well as hospital professionals.

The major weaknesses of the German system concern the policies of prevention and the effectiveness of communication among professionals: patients in Germany are still not fully aware of the risks and consequences of unhealthy behaviours and they are even not able to recognize severe symptoms of serious conditions, so that often the access to the system happens through hospitalization due to acute care needs.

On the other hand, once the chronic patient is in the system, there is not always an effective communication among the different healthcare professionals involved in his/her care pathway, and their activity is not always optimally coordinated, it is often the patient him/herself who is responsible for all contacts.

Insurance companies and government should increasingly support risk-management and prevention creating mechanisms to incentivize physicians for preventive work. The role of coordination and integration of family doctors should be further specified and strengthened. Incentives for cooperation might be set out.

Finally, a further source of difficulties for patients is the frequent change of drugs and prescriptions, due to the fact that every German insurance company quarterly negotiates drug-prices with pharmaceutical companies, with the risk and the possibility to change people's therapies four times a year. It results confusion for patients and strategies to avoid this situation might be studied by government, companies and insurance funds.



#### **GREECE**

The chronic patient, Sysiphean challenge?

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN GREECE

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Prevalence percentage values	Diabetes	0.17 – 0.15	(1990 – 2006)
	COPD and bronchiectasis	0.26 – 0.27	(1990 – 2005)

Sisyphus is a character of the Greek mythology who dared to withstand Zeus. His punishment was a pointless and endless activity.

Can the treatment of chronic diseases be seen as a Sisyphean task?

For sure Greece is going to face this issue for a long time in the coming years. The Greek chronic patient is mainly affected by mental disorders or physical diseases/disabilities being long-lasting and recurrent or characterized by long suffering.

Major problems within the system are: the increasing number of patients; the escalating costs of the system; the huge waiting lists, mainly due to the absence of a gate-keeping system and of a developed primary care system, in fact patients can directly access hospitals.

Different organizations are dealing with the care of chronic conditions: hospitals and community health centres (CHCs), centres for children and adults with physical and/or mental disabilities, hostel for people with mental disabilities and/or psychiatric disorders, rehabilitation programs, organizations for people with addiction problems, day-care and social care services. The main issue is linked to the lack of coordination among these parties.

In the climate of the current financial crisis, it is even more difficult to invest in any area of healthcare and health promotion. Nevertheless, this offers an opportunity to rethink the system, promote structural changes and propose a new paradigm which overcomes traditional views.

There are on-going discussions within the Greece government regarding the establishment of a primary care system, the merger of different hospitals and/or CHCs, the improvement of public-private relationships and the development of logistical solutions, such as afternoon schedule, to face the issue of long waiting lists, the establishment of financial 'targets' for doctors as well as for patients.

Some effective solutions for chronic patients relief have also been developed:

- information technology and empowerment of eHealth, digital systems and telemedicine have brought to the digitalization of all patients files, the effort to be made now is to allow the system interoperability;
- the role of the families is vey important, and the system sustains it with social programmes and supporting programmes.

In conclusion, the effort to respond to the problem of people with chronic disease might be an 'interminable' activity in the Greek system, but for sure it is not unveiling. The struggle itself and the results it is obtaining are enough to be satisfied and go on.

## To the top of the mountain...

Establish primary care system



Merge different hospitals and/or CHCs

Relationship private vs. public

Financial 'targets' doctors (and patients)

#### Other solutions:

- Information technology and empowerment (E-health, digital systems, telemedicine)
- Logistical solutions (e.g. afternoon schedule)



#### **HUNGARY**

A proper rehabilitation leads to a higher quality of life

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN HUNGARY

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Regular daily smokers aged 1	5+	44.0 – 30.4	(1992 – 2003)
Incidence per 100,000 inhabitants	Neoplasm	270.9 – 846.7	(1990 – 2008)
	Mental and behavioural disorders	440.7 – 343.6	
Prevalence percentage values	Mental and behavioural disorders	2.07 – 1.84	(1990 – 2006)
	COPD and bronchiectasis	0.36 – 1.25	(1770 – 2000)

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	9.6	8.9	-
Neoplasm	26.5	6.2	0.4%
Diabetes	4.0	7.2	-
Dementia - mental and behavioural disorders	12.7	23.9	0.4%
COPD and bronchiectasis	3.2	9.8	-

Hungary has a population of almost 10 million inhabitants and almost 176 hospitals. Between 2005 and 2008, the number of chronic patients has overcome the number of acute patients and the number of chronic beds has overcome the number of acute beds. After falling down of socialist era, the Hungarian health system has had to adapt to other European countries and has put in practice different reforms in a short period of time, but not all of them have resulted in long-term benefits.

The main challenges Hungarian government faces today deal with efficiency and effectiveness of services, equity and sustainability. In fact, the hospital system carries a burden of inefficiencies due to an inheritance of unnecessary service delivery. The decentralized access to the services creates gaps in quality and effectiveness of care received, whereas the disparity and inconsistency of infrastructures poses problems of inequality of healthcare supply throughout the country. Besides all of other problems, the lack of financial resources the system is facing, together with the increasing demand of services, poses serious problems of sustainability. A lot of health sector programmes are in place today to overcome the mentioned problems and to answer the needs of chronic patients. They comprise the strengthening and broadening of the roles and competences of general practitioner, the modernization and development of specialized outpatient care, the upgrading of

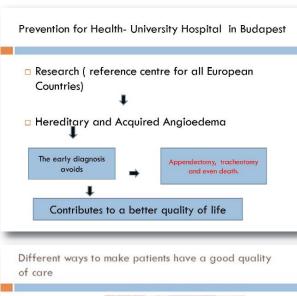
emergency care and ambulance services and the empowerment of information technology systems. However, in the majority of cases, chronic patients receive good quality and high level services. Both primary health care and hospitals take into account health prevention, promotion and education trying to change unhealthy life style, which is the main risk factor for most chronic diseases.

The University Hospital in Budapest is one of the main research centres on Hereditary and Acquired Angioedema and reference centre for all European countries. Here a complete high level care is offered with the aim of contributing to a better quality of life of people concerned. The centre offers the early diagnosis, which avoids appendectomy, tracheotomy and even death and offers a complete package of care from counselling and continue education, to treatment in mild and acute events, as well as follow up and continuous monitoring.

Among the services provided to physical disabled patients there are special units and special rehabilitation centres where patients can exercise with the main purpose of strengthen their muscles. For people with mental disorders specialized centres offer therapies in groups where patients can attend a package of activities - gardening, hand-made crafts, farming, embroidery and find a way to be and feel themselves useful (e.g. Psychiatric Rehabilitation Centre, Doba). Specialized centres for people affected by heart disease aim to accompanying people back to ordinary life, helping them to lose the fear of moving; patients exercise and do all the activities they are going to do at home, such as swimming, walking and dancing, being continuously under control. Their movements are closely monitored and when they are discharged they know the kind of exercise they have to do (e.g. National Rehabilitation Institute, Budapest).

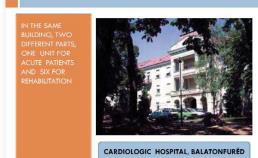
Particularly relevant is the high level of education for healthcare professionals. Patients are treated by high level and broadly experienced staff, and rehabilitation is not considered totally separated from acute care, but there is continuity between acute phase of healthcare and the rehabilitation phase which can coexist in the same institute; human aspects, such as empathy are emphasized, since they have a strong influence on rehabilitation, the fact that patients and staff share the same dining room make them stronger (e.g. Cardiologic Hospital, Balatonfurëd).

Moreover, a wide range of solutions to let patients feel comfortable and facilitate rehabilitation are offered: often relatives are allowed to stay with patients all time and they can even collaborate in care; pets are also allowed to stay in hospital with patients, since they help them smile and being positive.











PETS ARE
ALLOWED TO
STAY IN
HOSPITAL
WITH
PATIENTS



HOPE - Chronic diseases October 2010



#### **LATVIA**

Spotlight on breast cancer

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN LATVIA

Johannes Menner, Austria Stavros Karakolidis, Greece

Regular daily smokers aged 1	5+	30.3 – 30.4	(1994 – 2006)
Incidence per 100,000 inhabitants	Neoplasm	283.7 – 416.5	(1990 – 2008)
	Mental and behavioural disorders	509.0 – 228.9	
Prevalence percentage values	Neoplasm	1.43 – 2.67	
	Mental and behavioural disorders	2.82 – 2.90	(1990 – 2008)
	Diabetes	1.13 – 2.80	

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	8.6	11.0	1.6%
Neoplasm	19.4	9.3	2.1%
Diabetes	2.0	9.1	2.8%
Dementia - Mental and behavioural disorders	14.8	24.6	2.0%
COPD and bronchiectasis	1.8	9.4	1.1%

In Latvia, 86% of deaths are caused by chronic disease. The most common chronic diseases are cardiovascular diseases, neuro-psychiatric conditions and cancer.

The most frequent kind of neoplasm among women is breast cancer; in 2009 it had an incidence of more than 19%, affected about 80 women per 100,000 females and in the last five years it registered a rate of late diagnoses encompassed between 31% and 44%.

The Latvian government has decided to expressly address the problem of cancer by means of specific strategies encompassing activities of prevention, screening, early diagnosis, treatment and aftercare.

In 2006, the "Procedure for Organization and Financing of Health Care" (regulation No.1046 of the Cabinet of Ministers) stated that "the State organizes cancer screening". On this legal basis different kinds of screening where organized:

- Cervical cancer screening cytological smear for females, 25–70 years old, once in 3 years
- Breast cancer screening mammography for females, 50–69 years old, once in 2 years
- Intestinal cancer screening occult fecal blood test for all patients since 50 years, once a year

Between January 2009 and February 2010 in the framework of the breast cancer screening programme more than 90,000 letters of invitation (referrals) were sent, however the women examined were a little less than 21,000, which indicates a rate of response by 23%. This response was rather low, the reason has been found in socio-economical as well as structural elements: 40% of the population is of Russian origin, which can cause problems in understanding the language. The letters were written in official wording, not familiar, and hence not clear to the majority of the whole population. Most certified mammography institutes are located in the big, main cities, often far away from people's settings, which means extra costs just for reaching the screening

place. Finally, the general fear to have extra expenses often prevent people from "accepting the invitation", since actually only the screening procedure is free, while any other expenditure that would be necessary should be paid directly by the patient.

In response to this situation the government decided to put in place a package of corrective action both to increase the population sensitiveness toward this issue and to improve the ability to answer people's needs. Systematic research aiming at identifying the elements which hinder the population to use screening programme has started. Advertising campaigns addressed to make the population sensible to cancer threats has been put in place. The format of the letters, and in general the communication strategies, have been simplified, so that the population is now informed in an understandable way. Common link between all of these action is the effort to strengthen the confidence in the competence and quality of the health structures.

As observed, the fight against cancer has a prominent position in the health programme of the present government and is a part of the countrywide political agenda. Future strategies in this direction aim in particular to reduce cancer mortality and incidence of some cancers as well as improving the quality of life of cancer patients promoting the effectiveness of cancer diagnosis and therapy.t

#### Probable Reasons of Little Response

- Socioeconomical
- Misunderstanding of language(40% of the population is of Russian origin)
- Far distances to the Certified Mammografy institutes
- Fear to have extra expenses
- Letters are written in official wording

#### How to increase the response rate?

- Using advertising methods to make the population sensible to cancer
- Inform the population in an understandable way
- Strenghten the confidence in the competence and quality of the health structures
- Searching for obstacles which hinder the population to use this useful method

#### Aims for the Future

- Reduction of cancer mortality and incidence of some cancers
- Promotion of effectiveness of cancer diagnosis and therapy
- Improvement of the quality of life of cancer patients
- Fighting cancer must become a part of countrywide political agenda



#### **LITHUANIA**

Strengthening research and prevention to reduce chronic diseases

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN LITHUANIA

Araceli Fernández-Corada, Spain Antonio López Álvarez, Spain

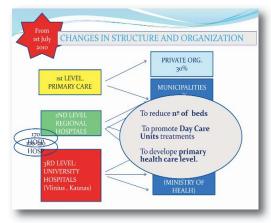
Regular daily smokers aged 15+		30.0 – 26.5	(1992 – 2006)
Incidence per 100,000 inhabitants	Neoplasm	270.1 – 479.9	(1990 – 2008)
	Mental and behavioural disorders	463.6 – 259.0	(1990 – 2008)
Prevalence percentage values	Neoplasm	1.13 – 1.99	(1990 – 2006)
	Mental and behavioural disorders	4.30 – 4.94	(1990 – 2008)
	Diabetes	0.97 – 2.02	(1990 – 2008)
	COPD and bronchiectasis	2.35 – 3.20	(1990 – 2008)

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	11.5	22.5	0.9%
Neoplasm	17.6	10.2	17.2%
Diabetes	2.3	11.3	0.7%
Dementia - Mental and behavioural disorders	11.5	24.6	1.1%
COPD and bronchiectasis	2.9	12.5	0.3%

In Lithuania, there are about 3.4 million people, the life expectancy at birth is 66 years for men and 77 years for women, the main causes of death are cardiovascular diseases (55%) and cancer (20%). The delivery of care is organized in three levels: primary care, managed by private organizations and municipalities; regional hospitals and university hospitals, which belong to the counties or to the ministry of health.

The healthcare system policy model set out by the government promotes active health policies emphasizing two priorities: health protection and disease prevention. The strategy for reducing the burden of chronic diseases encompasses four points: collecting data & information through research & e-health; developing preventive programmes for chronic diseases; patient education and support of patients with chronic diseases. Research has a central role in the Lithuanian fight against chronic diseases.

The Ministry of Education and Science has approved the national research programme "chronic non-infectious diseases (2010-2014)", whose purpose is 'to determinate morbidity risks and provide theoretical basis for a new health care strategy, to develop more sophisticated prevention and diagnosis methods'. The research programmes have the specific objective of collecting data about health behaviour and key risk factors of chronic diseases, so that specific therapies can be realised according to people's actual needs. Moreover, the Government gives direct support to the Biomedical Research Institute, at Kaunas University. It participated in different international studies, such as Finbalt health monitor, monitoring health related behaviour and lifestyle in Estonia, Finland, Latvia and Lithuania to promote health and prevent disease; CINDI Programme, monitoring risk



factors of non communicable diseases; MONICA project, which determinates risk factors and their prevalence in cardiovascular disease.

The eHealth strategy aims at restructuring, modernising and integrating the healthcare system. A SVEIDRA information management system has been designed to deal with state funds and to make more efficient the processes of entering, storing, analysing, reporting and reimbursing services performed by healthcare institutions. Prevention of modifiable risk factors is a strategy that needs the cooperation of all actors involved: the government is responsible for primary prevention; the municipalities as well as the non-governmental organizations organise campaigns, services and activities to promote healthy behaviours, sport and physical activity; hospitals, through the Lithuanian Health Promoting Hospital Network (LSSLA), promote health and prevention.



Screening and early diagnoses have been established as the main goals of the Lithuanian Health Care Policy and can be declined in two objectives: to ensure early detection and effective treatment and to reduce morbidity. Primary health care institutions are implementing some preventive programs for cardiovascular diseases, cervical cancer, breast cancer, colorectal cancer and prostate cancer having as target the period 2005-2013.

The government is putting in place a five-action strategy to strengthen primary care: provision of additional payments to GPs for promoting health services to patients; development of private offices of GPs working pursuant to agreements with territorial patients' funds; reimbursement of medication for primary prevention of cardiovascular disease; coordination with hospitals and outpatients clinics for high risk patients.

Finally, patient education is realised through the control of intermediate risk factors and every single actor of the system cooperates to this goal. Within hospitals and outpatient clinics endocrinology departments have established teaching centres for children & parents and for adults about food, self-control and pumps and

realise seminars for family twice a year. Outpatient cardiology clinics have a hypertension control service. The Lithuanian Cardiology Association has a web service for assessing patient about their risk level and delivering information about preventing and dealing with some diseases. The Lithuanian diabetes association provides practical help and advice, organises summer camps for education and produces some publications on all aspects of living with diabetes (Proper Diet is Health, Nutrition for Diabetics, Foot care, Insulin, etc.).





#### **MALTA**

Management and education for a system wide approach

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN MALTA

Susanne Hoffmann Lauritzen, Denmark David Muñoz Ortega, Spain Evija Palceja, Latvia

Regular daily smokers aged 15+		28.0 – 20.4	(1992 – 2008)
Incidence	Neoplasm	308.9 – 524.6	(1990 – 2007)
per 100,000 inhabitants	Mental and behavioural disorders	104.1	(2008)
Prevalence percentage	Diabetes	5.20 – 6.40	(1990 – 2008)
values	COPD and bronchiectasis	0.09	(2008)

Malta is a small country composed of two islands and hosting 400,000 people. The main disadvantages of this situation are the high costs and limited resources, connected to the need of offering all services to the citizens; moreover the country is facing a steady migration of healthcare professionals. However, the short distances, the concentration of technology and the possibility of building good relationships and effective managerial pathways make it easier to put up multidisciplinary teams and to organise the care delivered to citizens and patient with chronic conditions.

The main challenges for chronic patients per each phase of care can be summarised as following:

- in primary health care the cure offered is effective, but there is lack of prevention;
- after diagnosed and eventually admitted to acute hospital patient discharge become problematic;
- rehabilitation hospital needs more support for community services;
- mental health care services need to invest more strongly and explicitly in the enhancement of patients' independent life in the community;
- community services need a change of culture;
- elderly residences need to improve services aimed to support patients' independent living.

The Maltese government has put in place a comprehensive strategy to optimally tackle the burden of chronic conditions from the clinical and managerial perspectives. The strategy for the period 2010-2020 has as "policy direction to add health to life by increasing years lived free from ill-health", this will be done by strengthening prevention and control of non-communicable diseases, enforcing rehabilitation and preparing management to competently address the core needs of the chronic patient emphasizing the multidisciplinary approach.

In particular, efforts in management and leadership training are aimed to address and prepare health professionals to the new and more extensive role they are progressively taking. In fact, the Maltese system is now not simply promoting management and leadership skills, but it is actively investing time, energy and resources in introducing new pathways and new skills for new professionals and for those already working in

the hospital. The new training and the life-long learning courses incorporate concepts of corporate governance where people who will become manager and those who already are managers get the opportunity to learn how to manage differently people, resources, finances, equipments and time, respecting patient needs, delivering effective care and ensuring safe services.

Finally, one area of excellence in Malta is rehabilitation. At the admission at the rehabilitation hospital each patient meets a multidisciplinary team of specialists composed by nurse speech language, pathologist, social workers, occupational therapist and physiotherapist that will be integrated with a podiatry and a psychology. All of the components of these professional teams share the same vision, and build a patient-centred pattern of care which is concise and describes the objective they are going to achieve during the care; to ensure the maximum level of care, quality and effectiveness, outcomes and results are constantly monitored and evaluation measures are periodically set up.











#### **NETHERLANDS**

A new role for the patient

#### PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN THE NETHERLANDS

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Regular daily smokers aged 15+		36.7 – 29.1	(1990 – 2007)
Neplasm incidence per 100,000 inhabitants		407.4 – 563.9	(1990 – 2006)
Prevalence Diabetes		1.90 – 3.75	(1990 – 2003)
percentage values	COPD and bronchiectasis	1.40 – 1.51	(1990 – 2007)

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	1.9	12.6	4.9%
Neoplasm	10.0	8.5	49.4%
Diabetes	0.7	11.3	24.9%
Mental and behavioural disorders	1.4	22.8	88.3%
COPD and bronchiectasis	1.3	11.2	7.7%

As in many other countries, the changes affecting the Dutch health system mainly deal with demographic evolution: the increasing number of elderly inhabitants means more chronically ill people and more people having multiple conditions. While it would cause exploding costs for primary and hospital care, the country is actually facing budget constraints and it is going towards a future lack of healthcare workers.



The main strategy adopted by the Netherlands to face these issues foresees a shift from hospital care to community care, exploding the potential of primary care system, strengthening the coordination between hospitals and General Practitioners and promoting patient education and self management.

In practice, the Netherlands has created disease management programmes based on early detection, self management and patient empowerment, multidisciplinary care and continuous evaluation, decreasing the role of hospitals and reducing the rate of admissions and the length of stay in secondary care settings.

The access to GPs in the Netherlands is free and quite easy, this allows people to be always monitored and to receive an early detection of their diseases. Furthermore screening programmes are in place for some of the most common diseases (e.g. heart failure, COPD, diabetes).

After being diagnosed chronic patients are likely to be treated by the GP, if necessary they will visit hospitals just for specific analysis as well as in case of acute episodes.

GPs, or nurse practitioners, which have attended a two years course to be able to handle some of the tasks that GPs traditionally used to do, activate and coordinate a multidisciplinary team of professionals who will take care of the chronic patient, including physiotherapist, cardiologist, dietician, ophthalmologist, podiatrist, community nurse, depending from the disease and patient condition. To facilitate the interaction among these professionals clinical pathways are established also for primary care. The financing system of chronic care in the primary sector rewards the professionals who work in multidisciplinary teams and thereby provide patient centred care, instead of centring on each specialization.

The most important role of GP or nurse practitioner is patient education. In fact, whenever possible the patient is involved in the decision-making process concerning his/her pathway of care and is guided to handling his disease, learning to know it and learning how to manage it, so to be able to continue living the daily life. Patients are given a lot of information material, and structured education programmes are organized. Staying at home is incentivised, in fact thanks to the use of telecommunication tools patients check every day their status and send the analysis to the hospital, where a nurse practitioner controls them. When she notices, that there is a problem, she calls the patient, refers him to secondary care or simply sends advices about diet or exercises.

Key performance indicators concerning average length of stay in hospitals or the type of complications related to any specific program are being implemented to evaluate the effects of the treatment and improve clinical pathways.

The system put in place in the Netherlands, introducing self-management and centralizing the coordination role on GPs guarantees good care for patients, and cost containment. Self management through telecommunication helps to keep costs down, because it reduces the number of patients who seek medical specialist, reduces hospitalization, and improve effectiveness, since the general practitioner or the nurse practitioner continuously monitor the situation, evaluating eventual complications, discovering co-morbidities and acting as gate-keepers towards hospitals.













## **PORTUGAL**

Holistic initiatives against chronic diseases

## PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN PORTUGAL

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Regular daily smokers aged 15+	28.0 – 20.9	(1990 – 2006)

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	3.0	10.4	1.6%
Neoplasm	7.6	10.5	17.4%
Diabetes	1.1	10.5	4.9%
Mental and behavioural disorders	1.4	16.4	1.3%
COPD and bronchiectasis	1.0	10.1	0.7%

Portugal has a population of 10,6 million inhabitants, of which 4.2% immigrants. The majority of the population lives in urban coastal areas, but there is a high level of income inequality.

The main needs of chronic patients in Portugal not only concern the continuous need for therapy and follow-up, but also the feelings of social isolation, uncertainty about the future and difficulties in interpersonal relations. The main challenges are also connected to integration and communication to patients, which often experience a lack of explanation and understanding of their problems.

The most recent innovation in the Portuguese healthcare system is represented by the National Health Plan 2004-2010, which introduced reforms in the ambits of primary & hospital care, maternity and emergency, established a new model of hospital organization based on Public and Private Partnerships and centralised health care units and proposed national guidelines for chronic patients.

The best practices for chronic patients are the care centre for children with development disorders, the Information Technology System and the day hospital management. In particular, during the last years Portugal has strongly invested in the introduction and implementation of ICT solutions for the management of healthcare and chronic diseases.

Today, 90% of Portuguese hospitals use the same network and the surgical waiting lists are managed through a central management system that also allow a systematic and efficient management of waiting lists of all hospitals. In the management of chronic diseases, the IT systems have a central role to connect all information and make it easily and timely accessible to all the professionals involved in the patient care. Moreover, telemedicine solutions allow patients to stay at home and being always connect to the hospital and their care-givers.

The management of chronic patient is built around the day-hospital care and the activation of a multidisciplinary team that puts together healthcare professionals working in direct contact with the patient, like neuro-pediatrician, development paediatrician, adult neurologist, hospital nurse, therapists, technicians (for diagnosis) and social workers, such as family doctors, community nurses, educational system and voluntary organizations. Relatives are directly involved in the pattern of care, since the multidisciplinary teams develop a holistic view of chronic patients and their families.

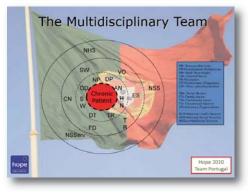
The day hospital model and the presence of a multidisciplinary team allow to support and motivate patients' self-management and to cover the different phases of patient care, offering a wide range of adequate and opportunely coordinated services, from education, rehabilitation and social care, to home care, telemedicine and palliative care.

The main benefits obtained through this system are a decrease in hospital admissions and length of stay, a reduction in emergency visits and hospital infections as well as in costs of chronic patients care.













#### **SLOVENIA**

The Slovenian inclusive strategy for fighting chronic diseases

## PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN SLOVENIA

Josefa Lario de Oñate, Spain Fernando Jorge Vieira de Sousa, Portugal

Regular daily smokers aged 15+	34.0 – 18.9	(1988 – 2006)
Neoplasm incidence (per 100,000 inhabitants)	318.6 – 549.8	(1990 – 2006)
Neoplasm prevalence (percentage values)	1.60 – 3.37	(1990 – 2006)

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	2.3	17.2	1.0%
Neoplasm	17.7	7.9	12.8%
Diabetes	1.2	9.2	21.7%
Dementia - Mental and behavioural disorders	6.0	37.5	7.2%
COPD and bronchiectasis	1.3	10.1	2.2%

Slovenia has a little more than 2 million inhabitants, with 79 years life expectancy and 70 years of expected healthy life. Chronic conditions are responsible for about 87% of deaths, most of them due to diseases of circulatory system (39%) and neoplasm (40%).

Healthcare is organized on three levels, with Health care centres, hospitals and specialized clinics which can all refer patient to rehabilitation settings in the communities and are supported by public health programmes of prevention. Treatments for chronic patients foresee different steps from primary care to community care. Prevention, made through public health programs, is in principle addressed to cardiovascular diseases, tobacco and alcohol consumption, and consists in cancer screening programs, nutritional advices and HIV prevention.

At the primary level general practitioners, gynaecologists, paediatricians, specialists of school of medicine and dentists act as gate-keepers. GPs are responsible for the detection of the chronic condition and for the implementation of public health programmes of prevention. They can refer patients to specialized hospitals. At the secondary and tertiary level of care outpatient services and the main inpatient clinical treatments are received; in particular, hospitals organize workshops for educating patients and their families on the disease and the management of it.

After discharge patient can access the community care services: nursing care at home, offered free of charge, and home care. A number of long-term services and institutions aiming at improving well being and quality of life of chronic patients complete the healthcare provision: elderly houses, home in the community, effective home/family/self-help groups and daily centres for treatment and rehabilitation. In general, they offer high quality and effective care, nonetheless they are still difficult to appropriately access countrywide because of the isolation of some patients. The places in houses for the elderly are not sufficient to answer the demand of supply, requiring longer stays in hospitals while waiting for elderly accommodations, home services are still too expensive for some patients.

In general, the care of GPs, who can also handle home visits, the workshops held in hospitals for patients and relatives, the strong home care nursing provided free of charge and the social care for people with low conditions are effective elements of the Slovenian healthcare system; conversely the system faces challenges linked to the lack of physicians at primary level and of middle-term institutions.

One particular chronic condition affecting Slovenian population is mental illness. Slovenia has one of the highest EU degrees of mortality due to diseases caused by the abuse of alcohol and, linked to that, one of the world's highest rates of suicides.

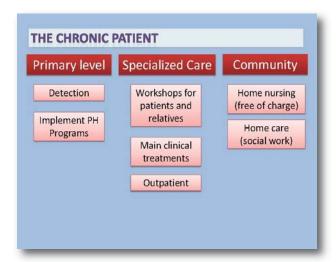
Mental illness is treated at primary level by psychiatrists and home nurses: psychiatrists act as gate-keepers, without the need for referral from family doctor; home nurses represent the connection of the patient with hospital and community care, they take care of the follow-up of patient condition and medications, of the communication with families and with social workers.

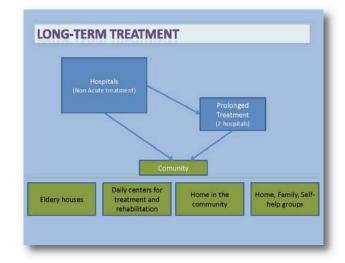
At the secondary and tertiary level mental ill patients receive acute and long-term treatments, follow group therapies and prevention programmes and attend occupational therapies as well as programmes to promote self-independence and social inclusion; programs for continue treatment in the community are also developed within hospital settings.

In the ambit of mental health also non governmental organizations (NGOs) play an important role. They organize several programmes aimed at promoting inclusion and reintegration, such as:

- psycho-social rehabilitation programme, including daily centers and housing groups, where people with similar problems live together supervised by a coordinator;
- programmes for de-stigmatization and information to public;
- employment and vocational training programmes;
- programmes of advocating human rights.

In general, in Slovenia there is a comprehensive strategy to care and prevent mental illness that encompasses prevention programs, workshops and group activities in hospital, detailed program prepared in hospital after discharge and strong work of NGO's. Yet some problems, such as the stigma among society and family and the late detection of depression, remain unsolved, and some challenges within the system, such as the lack of psychiatrists and the low integration between hospitals and primary care, need to be carefully considered when planning services for the coming years.







#### **SPAIN**

The Spanish integrated model of care

## PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN SPAIN

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Regular daily smokers aged 15+	32.1 – 26.4	(1993 – 2006)
Diabetes prevalence (percentage values)	5.0 – 5.1	(2003 – 2006)

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	1.9	11.9	0.4%
Neoplasm	7.7	10.7	29.6%
Diabetes	0.7	9.7	10.9%
Dementia - Mental and behavioural disorders	1.8	15.0	22.8%
COPD and bronchiectasis	2.1	9.3	5.8%

As many other European countries, Spain is facing the problem of ageing population and the connected spread of chronic diseases: 60% of Spanish inpatients and 80% of outpatients suffer from chronic diseases; 70% of the Spanish health system expenditure are used for chronic patients and on average each person aged 65+ has 2.8 chronic diseases, while each person aged 75+ has 3.2 chronic diseases.

Examples of pluri-pathologic and poly-medicated coexistence of diabetes, cardiovascular disease and hypertension are quite common in Spain; people affected need a complex package of care, from prevention, medication and rehabilitation, to psychological and social care. Older people affected by multiple chronic diseases, living alone in villages far away from main cities and from their families are increasing faster and faster.

The Spanish model of healthcare is generally structured around two levels: primary monitoring provided in healthcare centres and specialist care provided in specialist care centres and in hospitals, emergency access is a third level of entrance in the system. This framework is incomplete especially in relation to the needs of chronic patient with multiple conditions, who need an easier access to health care system, effective coordination between different levels of healthcare, efficient sharing of information between healthcare providers and human and economic support to home care.

During the last years, Spain has been implementing a model of integrated care for people with multiple chronic diseases in order to avoid unnecessary visits to the doctor and false medications, reduce costs of care and give patients a better quality of life. The elements of this model include Multi-channel Health Services Centres, Multidisciplinary teams, IT Programs to share information (Digital networks like Ykonos, clinical history), Telemedicine, Support programme for poly-medicated patients, Units for highly complex patients (UPP), Post-hospitalisation care, "Expert Patient Programme" (EPP).

Multi-channel Health Services Centers connect patients and different providers, which can communicate through different technological means, from e-mails and telephone to SMS and direct access to documents. This allows reducing emergency visits, saving time and costs, since exams and investigation do not need to be repeated by different professionals. Multidisciplinary teams, supported by technological instruments and patient records, put together a complex number of healthcare and social workers from different specialties: physicians, psychologists, therapists, nutritionists, auxiliary nurses, pharmacists, administration officers, home care, IT-specialists and social workers. They act under specific protocols in all phases of hospitalization, guaranteeing a quicker and expert diagnosis and a better coordination for personalized, integrated & continuous care, improving patient's safety & quality of life.

IT programmes and telemedicine improve communication between patient and physician as well as the relation among different physicians, enhance patients living, help to avoid unnecessary travelling, allow cutting waiting times, repeated exams and extra costs. Example of software and programmes of telemedicine are:

- Ykonos is a Regional digital network of medical images and report in Castilla la Mancha. It is a co-funded European project that allows to share digital radiological images in the entire region. This means that any healthcare professional, wherever located in the region, can access the digital radiography, independently from the centre where it has been done avoiding repeating exams and waiting times due to delivery of non-digital images by mail.
- Colabor@ is a video-conference tool that allows specialists to exchange documents and patients information.

Support programmes for poly-medicated patients have been implemented firstly through information campaigns and advertising and then offering specific supporting services at the healthcare community centers: 'Medicacion controlada' (Medication under supervision) is a personalized doses system that makes easier for elderly chronic patients on multiple medication the administration of medicines in compliance with the prescription they have.

Units for highly complex patients (UPP) can be defined as organizations of healthcare professionals which provides multidisciplinary care by means of a wide range of caring services to frail, highly complex pluripatological and pluri-medicated patients with multiple chronic conditions, with frequent use of emergency services and hospitalization. UPP aim to increase patients' quality of life and to reduce costs and medical contacts, the development of this kind of units is one of the most important challenges for the Spanish healthcare system. They may be incorporated within any other healthcare service with a broader service portfolio but need to include close cooperation between the manager specialist doctor of the unit and the doctors from the primary healthcare attention system and the existence of a whole range of healthcare systems that quarantee patients' attention in the most appropriate time and place.

Post-hospitalization interventions have been planned to complete care and monitoring chronic patients, reducing the permanency in hospital and at the same time ensuring continuity of care. The service for care and information to patient (Servicio de atención e información al paciente) implementing a protocol of post-hospitalization control, phones patients to ensure that medical treatment, nursing care, medication, psychological assistance, rehabilitation are continuing, inform patients and their families about patient's rights, obligations and documentation for last wills, realises evaluation and analysis of satisfaction.

Finally, among the service aimed to facilitate autonomy and self-care of patients the Expert Patient Programme (EPP) promotes the active participation of patients, which learn how to take and manage directly responsibilities on disease management and self-care.

In conclusion, Spain is successfully managing to create an integrated model of care for multiple chronic patients activating three leverages: enforcement of relationship between professionals involved and between those and the patients; enhancement of long-term care and self-management, also involving patients' families; and implementation of advanced technologies, especially at a regional level.





#### **SWEDEN**

The Swedish chain of care

## PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN SWEDEN

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Regular daily smokers aged 15+	25.8 – 13.8	(1990 – 2007)
Neoplasm incidence (per 100,000 inhabitants)	474.3 – 547.6	(1990 – 2007)

In Sweden<sup>4</sup>, there is a tax-financed, decentralised system, with two levels of responsibility in healthcare:

- county council/region, which provides health care and promotes health in the entire population;
- municipalities, which are responsible for elderly care, social services and support for disabled.

The role of the State is to establish principles/guidelines, distribute responsibilities and supervise the system.

In Sweden, the life expectancy is very high, people aged 65+ are sharply increasing, hence the rate of elder people with multiple chronic conditions, such as diabetes, hypertension and obesity is increasing, as well as quite common is the condition of elder chronic patients living faraway from their families and relatives.

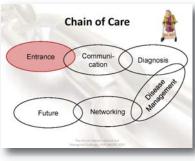
Care for chronic patients is organized through the chain of care, which tries to link in the best possible way primary care, hospital care and community care.

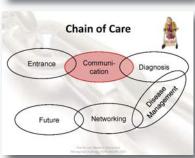


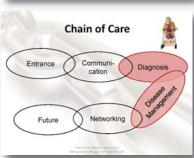
The access points of the system are normally the primary care centres, of which fundamental elements are the nurse-led clinics. Even if the Swedish system tries to minimize the patient access and permanence in hospital, inevitably in the most serious cases the entrance can also happen through the hospital emergency units.

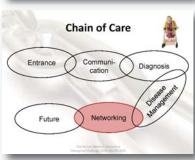
Once accessed the hospital or the primary care centre, one of the main problems for a correct diagnosis is represented by the difficulties to communicate with the patient, which is not able and to report appropriately his/her anamnesis and to clearly

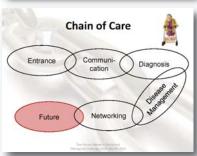
<sup>&</sup>lt;sup>4</sup> See also: Karlberg I (2008). Sweden. In: Knai C, Nolte E, McKee M (eds). Managing chronic conditions: Experience in eight countries. Copenhagen, WHO Regional Office for Europe, on behalf of the European Observatory on Health Systems and Policies: 115–130.











communicate his/her symptoms. The access to correct information at the right time is however made difficult by a lack of interoperability between the IT systems in the communities, counties, hospitals and primary health centers. Some pilot projects to implement compatible IT solutions, to develop telemedicine and to extract information from patients' records at all provider levels are being implemented.

After diagnosis, the patient become the central actor in the realization of his/her pattern of care and is always consulted, at every stage of the therapy and decision, to establish a correct disease management programme. Normally, the patient will not stay in hospital for a long time, and all the necessary treatments will be offered at the level of primary clinics. The return to specialized care happens only once or twice a year, for checking the health status. Within the nurse-led clinics, which directly depend from primary care centres, self-management is encouraged and, if necessary, home care and community care are activated.

At this stage coordination and networking between all health professionals involved become crucial to reach cost-effective pathways of care and multi-professional agreements and the extreme decentralization of the Swedish system could create problems. For this reason the Swedish healthcare institutions are developing check-lists and guidelines for cooperation and for treatments of specific diseases, are implementing multi-professional team-meetings, medicine management and social care and self-care management.

Further challenges that the Swedish system is facing in relation to chronic diseases are:

- the necessity to avoid readmission, maintaining optimal health of patients and making them as independent as possible, avoiding cognitive decline and understanding their actual needs;
- the necessity to better identify chronic patients and find patterns of care for ageing population.

Hence, Sweden is improving health education and promotion, models of temporary housing, alert systems and mechanisms to systematically involve patient families, models of cohesive multi-professional team approach, is looking for best practice, creating risk registers in primary care and ways to ensure flexibility of services.

# **Future for Anna**

## · Challenges:

- avoid readmission,
- maintain optimal health,
- not yet fully independent,
- cannot self-medicate/ cognitive decline,
- understanding what Anna needs.

#### • Solutions:

- cohesive multi-professional team approach,
- health education/promotion,
- temporary housing,
- asking Anna and her family,
- flexibility,
- alert system,
- recall and review.



## **SWITZERLAND**

A Swiss pathway to create quality of life for people with chronic diseases

## PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN SWITZERLAND

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Regular daily smokers aged 1	5+	28.2 – 20.0	(1992 – 2007)
Incidence	Neoplasm	1273.6 – 1239.3	(2003 – 2007)
per 100,000 inhabitants	Mental and behavioural disorders	556.9 – 497.7	(2003 – 2007)
	Neoplasm	1.29 – 1.26	
Prevalence percentage values	Mental and behavioural disorders	0.33 – 0.38	(2003 – 2007)
13.53	COPD and bronchiectasis	0.17 – 0.17	

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	2.1	14.8	0.7%
Neoplasm	11.0	10.7	12.8%
Diabetes	0.6	12.6	2.5%
Dementia - Mental and behavioural disorders	1.2	32.7	36.5%
COPD and bronchiectasis	12.0	12.6	2.1%

Switzerland accounts 7.7 millions citizens with an average life expectancy at birth of 82 years. The Health Care System is financed through a complicated mix of insurances and tax paid contributions from the state.

There are 318 Hospitals and Clinics per 40,000 beds, with a mix of public and private ownership. The average length of stay for all hospitals is 10.7 days, while it is 7.7 days for general acute care

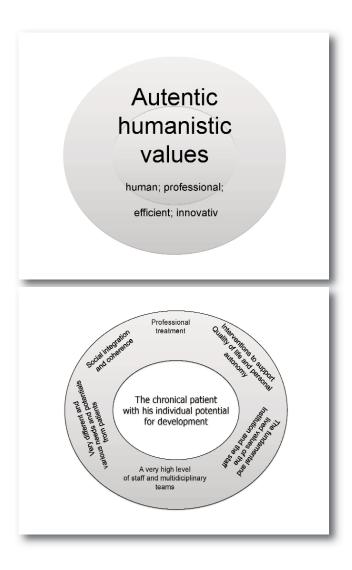
An estimate concerning the total population 15+ (2007) indicates that the most common diagnoses for chronic patients are hypertension ( $\sim$ 15%), allergies ( $\sim$ 14%), arthroses/rheumatoid arthritis ( $\sim$ 11%) and depressions ( $\sim$ 8%).

All of the 26 Swiss cantons are able to offer a wide range of highly specialized hospital and institutional services for chronic patients; a notable example is the Health Care Centre Spiez in the canton Bern.

The Spiez Health Care Centre is a complementary Centre for Chronic Patients, with extended possibilities for medical and therapeutical treatments, specialized care and different types of living possibilities. With 180 beds, 66 senior-flats, a multidisciplinary staff of 330 professionals, 30-40 students and about 70 charity workers it provides a wide range of services: primary and secondary prevention, therapeutic treatments, specialized palliative care, psychological interventions. In particular, it offers physical therapy on prescription or by the medical specialist in the house, weight training for improving general well-being or for specifically strengthening of the cardiovascular system and the respiratory system, dietary long-term, sustainable weight reduction and group training.

The philosophy of the centre consists in promoting "worry-free living and well-being" through an open-minded and integrated approach. For this reason, the centre is not isolated, but integrated in the city atmosphere. Promoting authentic humanistic values, the Spiez healthcare centre receives a wide range of different chronic patients with very various diagnosis and very different types of needs, the multi-professional staff work with patients to enhance each person's individual potential for development ensuring high professional treatments and interventions that support quality of life and personal autonomy.

The Spiez Health Care Centre is an example of effective integration of services and complete care of the chronic patients. It suggests a new model that benefits complex chronic patients and innovative and human ways to cross managerial boarders.





#### UNITED KINGDOM

Working together to make life better

## PARTICIPANTS HOPE EXCHANGE PROGRAMME 2010 IN THE UNITED KINGDOM

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Regular daily smokers aged 15+	30.0 – 21.0	(1990 – 2007)
Neoplasm incidence (per 100,000 inhabitants)	480.5 – 485.3	(1990 – 2006)
Diabetes prevalence (percentage values)	3.2 – 3.8	(2005 – 2008)

	Admission rate per 1,000	ALOS	Day-cases to all admissions
Cerebrovascular diseases	2.0	23.8	5.8%
Neoplasm	9.4	8.9	69.4%
Diabetes	0.7	8.8	38.3%
Dementia - Mental and behavioural disorders	3.0	51.8	20.0%
COPD and bronchiectasis	2.3	8.9	10.4%

The national healthcare systems of the four countries that compose the United Kingdom<sup>5</sup> are facing the same challenges: financial constraints and demographic changes, the need of increasing coordination of care and to improve the skills and knowledge within the system.

They are addressing the issue of chronic diseases through the empowerment of primary and community care, hospital care and specialist hospital and research services. Moreover, new services, role and activities have been put in place throughout the country.

<sup>5</sup> See also: Singh D, Fahey D (2008). England. In: Knai C, Nolte E, McKee M (eds). Managing chronic conditions: Experience in eight countries. Copenhagen, WHO Regional Office for Europe, on behalf of the European Observatory on Health Systems and Policies: 29–54.



The role of community care is being strengthened; interdisciplinary teams composed by general practitioners, specialized nurses, psychologists, physio and occupational therapists, social workers, support workers and palliative care workers provide education for self-care and support patients to stay at home with the best possible quality of care.

Both Scotland and England are putting efforts in the implementation of self-management and patients' empowerment. In particular, England is implementing the 'Patient Expert Programme' that aims at improving the self-management of long-term conditions and allow patients to learn new skills, meet others and share similar experiences and develop more effective relationships with healthcare professionals. In Scotland, a new service for health information and self care advice, named 'NHS24', has been introduced. It provides complete information about all health programmes in Scotland, access to the emergency care summary and self-care advices.

In the areas of hospital care and post-hospitalization services the role of consultant nurses is increasing at a very rapid pace. Consultant nurses, often established in nurse-led clinics, have advanced clinical practice, held a prescribing role, are responsible for the clinical assessment of patients prior to treatment and develop research and patients' audit in order to evaluate clinical effectiveness. The introduction of this new figure and service should allow reducing hospital admissions, increasing support to patients and liberate physicians from some ordinary tasks.

Finally, the implementation of instruments of tele-monitoring is acquiring a fundamental role in the optimization of specialist hospital care. Remote electronic monitoring enable patient to adopt a proactive approach, reduce unnecessary travel to hospital, facilitate education for self-care and early detection of deterioration to optimize medication, preventing and then postponing specialised hospital admission. The further areas in which the healthcare system of the United Kingdom is investing for the near future are prevention, coordination of care, life style improvement, research in new treatments and information & communication technology.



As long as we have HOPE,
we have direction,
the energy to move,
and the map to move by.
We have a hundred alternatives,
a thousand paths and infinity of dreams.
HOPE-ful, we are halfway to where to want to go;
HOPE-less, we are lost forever.

-- Hong Kong Proverb --





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