

# QUALITY IN AND EQUALITY OF ACCESS TO HEALTHCARE SERVICES

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## Foreword

Poverty and social exclusion continue to be serious challenges across the European Union and for health systems in Member States. People living in poverty or who are at risk of social exclusion are more likely to face health problems and there is evidence that they sometimes do not receive the care that best responds to their needs. There is therefore room for improvement of both health promotion and prevention strategies with these groups in mind, and for more active policies to tackle barriers of access to high-quality care.

This has been recognised at an EU level. Achieving access for all to adequate healthcare and long-term care and tackling inequities in access has now been proposed as a priority objective for the new streamlined EU Open Method of Coordination for social protection and social inclusion to support EU policy coordination.

This document presents the outcome of a study on *Quality in and Equality of Access to Healthcare Services: HealthQUEST* that was commissioned by the European Commission, DG Employment, Social Affairs and Equal Opportunity under the 2002–2006 Community Action Plan on Social Inclusion. The project aims to build knowledge at a European level about barriers to accessing healthcare for people at risk of social exclusion and about effective policy initiatives in Member States to reduce these barriers, in order to contribute to all three strands of the Community Action Programme within the framework of the Open Method of Coordination.

This project was undertaken by a consortium led by the European Health Management Association (EHMA) in Brussels that brought together experts from eight Member States, EuroHealthNet and the European Centre for Social Welfare Policy and Research, Vienna.

The project management team was comprised of Jeni Bremner (EHMA), Manfred Huber (European Centre for Social Welfare Policy and Research) and Nicoline Tamsma (RIVM).



## **Acknowledgments**

This document presents the outcome of the HealthQUEST project. It builds on both draft country studies and findings from the literature, as of the end of August 2007. In-depth country studies cover the situation of the following eight countries: *Finland, Germany, Greece, the Netherlands, Poland, Romania, Spain, and the United Kingdom*, representing different ways of organising and funding healthcare across Europe.

The authors are grateful for the extensive and detailed research that was undertaken by experts in each of the eight countries, and to Clive Needle, Caroline Costongs and Claire Blanchard from EuroHealthNet, who contributed substantial input to the report and project meetings. The report presents extensive material from country studies, not only through the country cases in 'boxes', but also in the main textual analysis. The input from the many national and EU stakeholder representatives is also gratefully acknowledged. We would also like to extend our thanks to those who contributed comments and suggestions on various versions of this report, as well as to Philip Berman, former EHMA Director, for his contributions to the tender document and the design of the study.

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The conclusions and any mistakes in this report, however, are the sole responsibility of the authors.



## Executive summary

### 1.1 Background

Ensuring equitable access to high-quality healthcare constitutes a key challenge for health systems throughout Europe. Despite differences in health system size, structure and financing, evidence suggests that across Europe particular sections of the population are disproportionately affected by barriers to accessing healthcare. Studies have also shown that difficulties in accessing healthcare are compounded by poverty and social exclusion, and that poverty and social exclusion compound difficulties in accessing healthcare.

At an EU level, access to healthcare is also a key issue. Listed as one of the common values for EU Member States agreed in June 2006 (Council of the European Union, 2006b), access for all to adequate healthcare and long-term care and tackling of inequities in access has also been proposed as a priority objective for the new streamlined EU Open Method of Coordination for Social Protection and Social Inclusion. The Social Inclusion Strategy (European Commission, 2006b) also emphasises a strong focus on reducing poverty and social exclusion for EU citizens.

Against this background, the European Commission (DG Employment, Social Affairs and Equal Opportunity) commissioned the European Health Management Association to undertake a study on *Quality in and Equality of Access to Healthcare Services: HealthQUEST*. The study has had two key aims. The first has been to identify and analyse barriers to accessing healthcare, particularly for vulnerable people at risk of social exclusion. The study therefore looks at barriers to access at the supply side, problems experienced in this respect by certain groups of the population (demand side) and also at the interplay between the two. The second aim has been to review policy initiatives taken by Member States to realise the objective of equitable access for all. This has included analysing evidence of the effectiveness of policy initiatives and highlighting good practice.

This study is based on detailed analysis provided by studies on the situation of the following eight countries: *Finland, Germany, Greece, the Netherlands, Poland, Romania, Spain, and the United Kingdom* – countries that represent different ways of organising and funding healthcare across Europe. This was complemented with findings from the literature, in particular from recent European comparative studies.

### 1.2 Structure of the Report

The report falls into three principle parts. The first outlines the policy context and methodology of the project. The second looks at the specific barriers focused

on in the study, including coverage, cost sharing, health literacy and supply-side responsiveness. The third part moves on to analyse the specific problems affecting selected groups at particular risk of social exclusion. In each, underlying factors have been analysed and policy initiatives and good practice identified.

Three groups at particular risk of social exclusion and for which there are important gaps in research (and sometimes also in policy action) were chosen for in-depth study:

- Migrants (including asylum seekers and illegal immigrants);
- Older people with functional limitations;
- People with mental disorders (studied as a special case study under the project)..

For these groups the study looked across the eight countries to find out what issues they face and the interaction between the difficulties they experience. An in-depth review in the form of a case study was undertaken on the access of people with mental health problems to mainstream (somatic) healthcare services.

### 1.3 Key findings and policy responses

This section presents nine key findings from the HealthQUEST report and examples of significant policy responses. These findings relate to both the general barriers faced by vulnerable groups and the experience of the specific groups focused on in the project

***1. Although people at risk of social exclusion benefit from universal healthcare coverage, there are a number of reasons why some groups risk falling through this safety net.***

With a few exceptions, healthcare coverage is universal and mandatory for everybody with a residency status in a European Member State, and basic healthcare coverage is ensured under a public programme irrespective of ability to pay. However, people at risk of poverty and social exclusion, such as migrants and people depending on social assistance, are frequently among those without public health coverage. This includes people with limited capacity to organise and regularly pay for social health insurance in cases where this is an individual responsibility. Lack of public healthcare can seriously worsen their poverty risk.

All countries in the HealthQUEST study had clear policy frameworks to provide coverage for their citizens. Indeed both the Netherlands and Germany have recently changed their systems to provide universal

coverage. However, the study also found gaps in coverage, for example countries mostly excluded illegal migrants from non-emergency care.

**2. Health baskets under public programmes are fairly comprehensive on paper but vulnerable people suffer both from shortages of services in practice and from the financial consequences of remaining gaps in health baskets...**

Limited coverage of dental care and of mental health counselling are among the more serious gaps in the health baskets of the European health systems analysed in this study. In addition, HealthQUEST found that in some countries, a number of services are legally included in the health basket but in practice there is often a gap between policy and reality. The evidence suggests that this is a particular issue for members of vulnerable groups when healthcare systems are in transition.

In Germany, for example, the new policy of universal coverage risks being undermined by low take-up within some groups. Where coverage was increased (e.g. for dental care) this has shown to increase the use of services, especially for disadvantaged groups (Finland).

**3. ...they are also disproportionately affected by the financial burden of cost-sharing arrangements, a burden that is sometimes insufficiently taken into account by existing exemption rules.**

Cost-sharing requirements remain significant in many countries. Some countries use private out-of-pocket payments for financing services or medical goods that are not available in sufficient quantity or quality (such as in a timely manner) under public programmes.

However, private funding is often regressive and can negatively impact on services, in particular for vulnerable people at risk of social exclusion. In addition, in some countries covered by the HealthQUEST report that informal payments are an important issue, which can increase the risk of catastrophic expenditures for vulnerable groups.

The evidence suggests that people at risk of poverty profit more from clauses that provide general exemption rules than from payment ceilings that need paperwork with healthcare administrations or where reimbursement is in retrospect.

Many Member States have made positive policy steps in reducing the burden of cost sharing. Examples include exemptions and reimbursements in Spain, the Netherlands and the UK (amongst others). Poland is notable for its recent moves to reduce informal payments within its health system.

**4. Significant variations in availability of services can worsen social exclusion in deprived regions, especially in rural areas.**

Evidence from this study suggests the existence of significant variation across regions in terms of public budgets, services and health personnel. These variations impact on the utilisation of healthcare services and restrict access to healthcare for groups at risk of social exclusion, especially for elderly people and those with limited mobility. Inequalities are a particular concern for rural areas, which have poorer access to transport infrastructure and healthcare services, lower economic development and higher concentration of elderly people.

Although there remains significant work to be done on this policy area, there are interesting developments, including the Greek KAPI centres for older people in rural areas and the creation of the so-called High Resolution Specialist Centres in Autonomous Communities in Spain.

**5. Organisational barriers can seriously limit access to healthcare for groups at risk of social exclusion.**

Several countries covered by the HealthQUEST report have made progress with policies regulating waiting times (e.g. using waiting-time targets) for elective surgery, a problem that has received significant attention in a number of countries. However, other countries still have important issues with waiting times, and people at risk of poverty usually lack the means to circumvent organisational barriers by accessing the private system. There are other policies that can reduce organisational barriers that are due to other factors, such as putting in place 24-hour walk-in centres. Many Member States have initiated substantial policies in response to concerns about waiting times. Some Member States have also introduced 24-hour healthcare centres to widen access to non-emergency care.

**6. Low health literacy can compound barriers of access to healthcare services, and may delay or prevent uptake of insurance coverage.**

The ability of people to understand how to make sound health and health service choices (including the choice of insurance funds) is crucial for reducing population health inequalities and health-related risks of social exclusion. People from vulnerable groups therefore need special social support, in which local government can play an important role. A number of countries are beginning to address problems of health literacy. In particular, the work in Spain on diabetes and cancer, dealing with care, prevention and self-management provides an interesting and promising approach.

### ***7. Health protection afforded to migrants often does not cover their needs.***

In most countries covered by the HealthQUEST report migrants who have been granted residency status are generally covered under the same terms as other residents. However, those without residency status are often faced with serious access problems and the risk of very high out-of-pocket health expenditures. Where evidence is available, migrants make lower use of specialist inpatient and outpatient care and tend to have greater reliance on emergency services. Although this presents a complex problem, particularly in the case of illegal immigrants, some Member States have taken important steps to improve access. Roma health mediators in several Member States provide an important example of good practice.

### ***8. Older dependent people may receive fewer services than they need and the quality of available service often has deficits.***

The evidence presented in this study suggests that older people often do not access healthcare as frequently as they need. This reasons for this differ, but include: cost of services; problems with mobility; general shortages of preventive and rehabilitative services; health beliefs (low expectations); and gaps in training of geriatricians. Problems of access to and quality of healthcare services can be severe at the interface of health and social services, which often do not work together well. In addition, the limited access to healthcare services of people living in institutions can put older dependent people at great health and safety risk. As older dependent people become an increasing proportion of the population their access to healthcare will become a particular priority. In responding to this challenge Finland, for example, has taken steps to provide comprehensive care assessments for all older dependent people. Some Member States have also increased gerontology training for medical students.

### ***9. People with mental disorders suffer from excess avoidable deaths and somatic co-morbidity, suggesting important access hurdles to somatic healthcare services.***

Many common barriers of access to somatic (mainstream) healthcare have a particular impact on people with mental disorders. In addition, the evidence also suggests that people with mental disorders also face significant stigmatisation and discrimination. However, the HealthQUEST study has found that people with mental health problems are often not on the health policy radar in relation to their somatic health needs. Furthermore, there is evidence that some mental health reforms have not considered their potential impact on somatic healthcare provision, such as lack of access to medical personnel in institutions.

The somatic health needs of people with mental disorders remain a key policy challenge, as do issues around stigmatisation. At present, the UK is the only Member State that has explicitly prioritised general healthcare for people in this group.

## **1.4 Policy Recommendations**

***Vulnerable groups need specific policy attention to overcome the access barriers posed by the ways in which healthcare systems regulate population coverage, the health basket and cost sharing.***

Vulnerable people are particularly at risk from cost sharing for healthcare. Member States may wish to consider putting policies in place –such as exemption or reimbursement rules– to ensure that the organisation of the health system does not unduly disadvantage vulnerable populations.

***Explicitly address health literacy as part of health system reform.***

Member States should ensure that they have clear policies in place to address both supply and demand side health literacy for vulnerable populations. Member States who are changing their healthcare systems should pay particular attention to ensuring that active ongoing measures are in place to support vulnerable populations in effectively using the system.

The European Union should ensure that there is a strong evidence base to support Member States in addressing health literacy.

***Prioritise research on the somatic healthcare needs and access for people with mental disorders.***

The lack of data on access to general healthcare for people with mental disorders is a significant lacuna. This is also evidenced by the fact that, with the exception of UK, no national policies addressing the issue of access to general healthcare for people with mental disorders were identified.

The EU may wish to consider urgently funding research to better understand the somatic healthcare needs of people with mental disorders and what effective interventions can be made to alleviate this problem.

***Address stigmatisation as a major access barrier for people with mental disorders.***

The most significant barrier to healthcare access for people with mental disorders was unanimously felt to

be the stigma and discrimination associated with mental ill health.

Member States need to acknowledge the specific needs of those with mental disorders and centrally target the needs of these groups for mainstream health services in national health inequalities programmes, incentivising providers and performance managing to ensure targets are met. Specific treatment guidelines also need to be developed.

***Give special attention to the high co-morbidity and health risks of people with mental disorders.***

Member States should ensure that health policy explicitly addresses the high rates of co-morbidity of people with mental disorders, particularly when people are inpatients in specialist mental health services.

The EU might wish to consider how good practice examples of targeted health promotion action for people with mental disorders might be disseminated more widely.

***Reassess services for migrants and asylum seekers without papers.***

Member States may wish to consider how to improve the situation of asylum seekers and migrants with no official status. Member States may wish to consider ensuring that healthcare is in place for this group.

***Improve the mix of health and social services in place for older people and their families.***

Member States should improve the mix of services available to older people by fostering access to prevention, rehabilitation and comprehensive care assessment, as well as better care management at the boundary between health and social services.

Evidence suggests that the role of informal carers in supporting older people underpins services to this group in all Member States. Member States may wish to pay particular attention to creating a policy framework to support informal carers and to enable them to stay in employment.

***Improve the access and quality of services of dependent older people in institutions.***

Member States urgently need to ensure that policies are in place to meet the healthcare needs of older

people cared for in institutional settings. The right skill mix of staff in institutions and more seamless cooperation across the social care and health boundary needs special attention.

***Invest in gerontology, better quality assurance mechanisms and care guidelines for dependent older people.***

Member States should invest more in research on improving the knowledge of elderly health and care issues among health and care professions. Member States should consider increasing multidisciplinary research on stigma, anti-discrimination, health promotion, and integrated community-based services.

***Undertake specific impact assessments of major social and health policy changes on the situation of people at risk of social exclusion.***

As Member States change systems for financing healthcare, including cost-sharing regulations, specific attention in routine data collection should be given to vulnerable groups to ensure that policy measures to prevent exclusion are effective. A culture of monitoring and programme evaluation is required to close serious gaps in research and information systems.

Member States need to facilitate systematic research into the reasons why some people fail to obtain a regular insurance status. This should be undertaken for countries where certain vulnerable groups are at risk of exclusion from regular healthcare coverage.

***Give barriers of access for vulnerable groups greater attention in the European Union policy process.***

Among issues of priority for a broader European exchange are affordability of healthcare for vulnerable groups, health literacy and patient empowerment.

***Consider how to address the most pressing questions for further research identified in HealthQUEST.***

The EU may wish to consider whether the most significant questions identified for further research are suitable for funding under the Framework Programme for Research of the European Union.

Priority questions for further research include good practice of tailored prevention and health promotion for people at risk of social exclusion, integrated care models, and the situation of people with mental disorders.

## **Part 1**

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# 1 Introduction

Implementing effective policies to fight poverty and social exclusion is a major challenge for the European Union and its Member States (European Commission, 2006b). Indeed, it is particularly important because the number of people affected by poverty and social exclusion across the Union has continued to grow in many Member States; in 2004, the average at-risk of-poverty rate in the EU was 16% with a gender gap of two percentage points (European Commission, SEC(2007) 329). Moreover, poverty and material deprivation are often compounded by inadequate access to healthcare, in particular for a range of marginalised groups such as migrants, persons with mental health problems or older people with chronic conditions.

The HealthQUEST study aims to find answers to core questions posed by the Commission in this context, particularly looking at the interplay between health access and social inclusion concerns. It aims to provide information both about current evidence, including good practice policy initiatives in the countries studied, and to comment on gaps in evidence and on priority tasks to overcome them.

The study also aims to contribute to mutual learning among Member States, in particular to assist them in ensuring that people at risk of social exclusion have access to healthcare. A particular focus of the project is therefore on systematic policies and social inclusion strategies that integrate approaches between health and other social policy domains, namely for disabled persons, persons with mental health problems and migrants.

## 1.1 The European policy context

The importance of access to healthcare has been recognised at an EU level. Indeed, it forms one of the common objectives for EU Member States, both in the fight against social exclusion and poverty through the Social Inclusion Strategy and through the Open Method of Coordination (OMC) on health and long-term care. It is also among the priority objectives for the new streamlined OMC for social protection and social inclusion (European Commission, 2005a).

It is also important to note that health policy cannot operate in isolation. During its presidency, Finland placed an emphasis on *Health in All Policies* (Stahl et al., 2006), an approach which looks beyond the boundaries of the health sector for solutions to healthcare problems. As *HiAP* observed, social and economic conditions –such as poverty, social exclusion, unemployment and poor housing– are strongly correlated with health status. These determinants point to specific features of the social context that affect health and to the pathways by which social conditions translate into health impacts.

At the November–December 2006 meeting of the Council of the European Union, it was stressed that health is largely determined by factors outside the healthcare delivery system (Council of the European Union, 2006a). As a result it called for broad societal action to deal with broader societal determinants of health, for example the level of education and available economic resources. It concluded that many policies with overlapping health objectives would benefit from inter-sectoral collaboration with common objectives such as employment and social policies. It also called for broader action across policy sectors and for inter-sectoral work to exploit synergies between policy sectors with interrelated objectives.

A second important context for the HealthQUEST project comes from the Open Method of Coordination (OMC). The European Union has decided on a new, streamlined OMC on social protection and social inclusion in order to foster coordination between its different strands: social inclusion, pensions, and health and long-term care (European Commission, 2007, Joint Report). This has been done with a view towards the shared goals of Member States of modernising the European social model, based on the shared values of social justice and the active participation of all citizens in economic and social life. A central role in this respect is played by policies to intensify the fight against poverty and social exclusion and to promote labour market integration of people at risk of social exclusion, including those with health problems and the most vulnerable in this respect.

Without calling into question subsidiarity in these policy fields, the OMC on Social Inclusion has developed into an important instrument and framework for exchange and coordination of policies in the field, in particular with the instrument of shared goals that are now documented in National Action Plans (NAPs) for Inclusion and National Strategy Reports (NSRs) (European Commission, 2006a, c). This includes new ways of involving stakeholders in this ongoing dialogue.

The OMC in the field of social inclusion should also be seen in the light of the strategic objective of the Lisbon European Council of March 2000, which includes both employment goals and the creation of greater social cohesion. For EU-level work, a decisive impact on the eradication of poverty has been called for. The *Joint Reports on Strategies for Social Protection and Social Inclusion, 2007*, for the first time include strategies for health and long-term care as a separate topic for identifying key issues where mutual exchange and learning can take place.

The HealthQUEST study thus contributes to the overarching objectives of the OMC for social protection and social inclusion, particularly in its aim to promote social cohesion and equal opportunities for

all through adequate, accessible, financially sustainable, adaptable and efficient social protection systems and social inclusion policies. At the centre is therefore the question of what impact improved and tailor-made access to healthcare for vulnerable groups of society can have on the eradication or mitigation of poverty and social exclusion, in particular by fighting poverty and exclusion among the most marginalised people and groups.

## 1.2 Previous research initiatives

Initiatives for improving access to healthcare for vulnerable people are part of important strategies that can contribute to reducing inequalities in healthcare. Indeed, the latter is an overarching policy goal that spreads far beyond the healthcare sector and is at the centre of a number of large European research and policy initiatives. It is useful to consider some of these initiatives in order to provide additional context to the HealthQUEST study, and a brief overview of some of the key studies on health inequalities and health access is presented here.

### 1.2.1 Health inequalities across socio-economic groups in Europe

Several studies have attempted to measure inequalities in health and healthcare in European countries, mostly notably under the 'ECuity' project (for more information see Doorslaer and Jones (2004) and the project website at <http://www2.eur.nl/bmg/ecuity>). Using a sample of 13 countries, Doorslaer and Koolman (2004) found that significant inequalities in health favouring the higher income groups emerge in all countries. They also show that health inequality is not merely a reflection of income inequality, but is mainly related to other factors, especially the relative health and income position of retired and disabled people.

Mackenbach (2006) evaluates the evidence on the existence of socio-economic inequalities in health in the EU and its immediate neighbours. This study reviews data on inequalities according to several indicators of health status and chronic diseases, behavioural risk factors, including mortality, self-assessed health and smoking. The main results of this study suggest that there are significant socio-economic inequalities in all three types of indicators. Lower levels of education, occupational status or income are consistently associated with higher rates of morbidity and mortality across countries. Smoking also tends to be higher in lower socio-economic groups, particularly among men.

In addition, inequalities in mortality have also been on the rise in many European countries in recent decades. Mackenbach (2006) argues that this should "warn against unrealistic expectations of a substantial

reduction in these inequalities within a short period of time" and that addressing these issues calls for "new and more powerful approaches to be developed". This reinforces the argument put forward by Judge et al. (2006) that it is important to emphasise the role of the wider determinants of health inequalities, such as the importance of combating social exclusion.

One of the most serious consequences of the existence of health inequalities is the increase in the number of avoidable deaths and in the prevalence of morbidity resulting in loss of years of quality of life. Mackenbach et al. (2007) analyse some of the economic costs resulting from the existence of health inequalities in Europe. They estimate the number of deaths that can be attributed to health inequalities in the European Union in 2004 at around 700 thousand per year. This amounts to a loss of 11.4 million life-years. The number of cases of ill health is estimated at 33 million. Health inequalities also reduce life expectancy at birth by almost two years and the average life expectancy in good health by almost six years.

### 1.2.2 Inequalities in access to and utilisation of healthcare services

Compared to the evidence that has been gathered on the socio-economic inequalities, there is surprisingly little research on the corresponding inequalities in access to healthcare services.

The report by the European Observatory on the Social Situation (2006) considers more specifically some of the issues associated with inequalities in access to healthcare services. The report notes that "differences in access to healthcare services across socio-economic groups may exacerbate existing health inequalities (...) therefore consideration of the extent of inequalities in accessing health care services is essential in understanding the broader goal of health equity" (p. 91).

A study by Doorslaer, Koolman and Jones (2004) has analysed inequality in physician utilisation in 12 EU countries, focusing specifically on general practitioners (GPs) and medical specialist visits. Little evidence was found on income-related inequalities in GP visits in these countries, in fact in some cases there is actually evidence of pro-poor distribution. However, when considering access to specialist medical services there was widespread evidence of pro-rich distribution, meaning that higher socio-economic groups report greater use of specialist services. Their report examines several mechanisms that can contribute to explain this inequality in the use of specialist services. Moreover, the experience of countries that have achieved equality in the use of GP services can be fruitfully extended to new and ascending Members States where perhaps this is still to be achieved.

The links between barriers to healthcare access and social exclusion are complex and there are currently significant gaps in the evidence base to address these issues. Improved survey and data systems for basic reporting on indicators of social inclusion, such as for the Laeken indicators, are now emerging but the statistical study of their link with populating health and health access issues is still in its infancy. As recent studies undertaken by EHMA have argued, progress with the new survey instruments of EU-SILC and the SHARE project are key to improve the situation in this respect.

Large gaps between policy relevance and data availability are also present for other aspects of the interplay of social exclusion and health access that this study addresses. For example, very little is currently known about the state of health literacy and what can be done to improve it to empower people at risk of exclusion. Low educational status, for example, often results in lack of knowledge and information on basic rights and ways in which to access healthcare but, as this study will show, this area is currently very under-researched.

### 1.3 The scope of the study

Social exclusion is a complex subject that affects many different groups and operates in different ways. However, at its heart, social exclusion involves being cut off from the mainstream of society. This includes having access to health services.

The focus for the HealthQUEST project has been the barriers that exclude disadvantaged groups from health services. A number of barriers have been analysed and described in different studies to explain the most important reasons for poor access to healthcare: the HealthACCESS project, for example, suggested six barriers in its assessment of cross-border patient mobility and HealthBASKET looked in detail at the scope of health services available, how these are defined and their costs and prices.

However, two fundamental questions have not been answered in the existing international comparative literature: first, what evidence is there for the health access barriers faced by disadvantaged people, and particularly on how these barriers operate and interact? Second, what are Member States doing about these problems at the policy level? And third, are there any unintended side-effects of wider system reforms on access to healthcare (including access to insurance coverage) for people at risk of social exclusion?

Two approaches were taken to identify the barriers analysed in the project. First, access barriers were identified from a review of the literature (Tamsma and Berman, 2004). This list, in turn, was merged with the list identified and analysed by the HealthACCESS

project: population coverage under public programmes (including mandatory or highly publicly subsidised private programmes); scope of the health package (under public programmes); cost-sharing arrangements; geographical barriers; organisational barriers; and utilisation of accessible services.

In selecting this list of barriers, the project also followed the good practice of countries where more comprehensive research on access problems has been undertaken, namely in the UK (Dixon-Woods et al., 2005). The list was finalised in a meeting with project participants. This gave a list of seven barriers that has been used as the basis of the analysis:

#### BOX 1.1: THE BARRIERS OF ACCESS ANALYSED IN HEALTHQUEST

- Gaps in population coverage under public programmes;
- The scope of the health basket;
- Cost-sharing requirements of health services;
- Geographical barriers of access to health services;
- Organisational barriers;
- Supply-side responsiveness (such as the quality of communication of healthcare staff with clients, or improving access of vulnerable people to services in the community);
- Health literacy, voice and health beliefs<sup>1</sup>.

Within the project we have analysed barriers for three particular groups at risk of poverty and social exclusion: migrants, older people with functional limitations and people with mental disorders.

In all three groups, many people have some risks of exclusion in common. Perhaps most importantly, many will be at risk of poverty. Low overall educational attainment levels and literacy (including language barriers) have been found to be more prevalent among very old people and newly-arriving migrants. Both older people and people with mental disorders often present themselves to the healthcare system with high co-morbidity, for which either medical knowledge or staff training is in many cases not well prepared to adequately respond.

<sup>1</sup> The concept of 'voice' refers to the ability of patients to negotiate with health professions, to express themselves and to explain their health problems. The concept of 'health beliefs' points to the crucial role that traditional beliefs regarding specific health behaviours not only have for individual lifestyles, but also for the expectations vis-à-vis the healthcare sector, influencing the ways services are taken up.

In the project design of HealthQUEST a number of groups at risk have not been included in the detailed analysis as they have been at the focus of much attention by public policy and have been covered by other studies in recent years, namely people at working age who are at risk of exclusion from the labour market because of health problems, and children at risk of poverty, especially those living with lone parents (see European Observatory on the Social Situation, 2006; European Commission, 2007e, 2008).

The focus of this study has been on policy rather than service delivery. This is largely because there is an existing body of evidence looking at different service responses to disadvantaged groups, but little on the policy frameworks that underpin action, and even less on what evidence there is to back up the policies.

From the outset of the HealthQUEST project it was clear that on some of the questions posed about access barriers there was little evidence from research. This is in particular the case for a number of the questions on organisational and geographical (including transport) barriers, which are seldom included in healthcare research, and health information systems are generally ill equipped to answer them (see also the conclusions from HealthACCESS and HealthBASKET).

These studies analysed questions for the whole population, not only for people at risk. It is therefore not surprising that HealthQUEST identified additional gaps in knowledge, such as a general scarcity of impact analysis for health policy on the access to healthcare. We have therefore on some occasions found more gaps than evidence. It is also important to note from the outset that access does not merely encompass the quantity (level of usage), but also the quality of services used. Even groups which are high users of healthcare may thus face access barriers if the care they receive is inappropriate or partial.

The HealthQUEST study has addressed the research questions through a number of tasks. The most important elements of the study are the following:

- I A discussion of the extent to which gaps in access to healthcare can deepen and intensify poverty and social exclusion.
- II The identification of the different supply-side barriers to accessing healthcare faced by vulnerable groups in society, especially those most exposed to social exclusion. Such barriers may stem from health service supply, for example the existence of waiting times for treatment, the location of health services, the cost burden of care, or a lack of sufficient information on available care.
- III The identification of barriers to access to healthcare stemming from health service demand, e.g. relating

to an individual's income, age, gender, knowledge, beliefs, preferences and opportunities. Particular attention has been paid to the situation of the most disadvantaged groups.

- IV An examination of the extent to which the organisation of healthcare systems eases or reinforces such barriers, particularly on the demand side, and how barriers on the demand and supply sides interact with each other.
- V A review of the various policy initiatives taken by the Member States to realise the objective of access for all, including for the most disadvantaged, taking into account differences in the way healthcare systems are organised and the varying institutional contexts.
- VI An examination of the impact of wider health reforms and policy measures on access with respect to the most disadvantaged groups.
- VII A description of the most effective policy measures to ensure access to healthcare for the most disadvantaged groups.

The study looks at inequalities and barriers to access at the supply side, problems experienced in this respect by certain groups of the population (demand side) and at the interplay between the supply and the demand side. Because the study focuses on the interplay between health and social inclusion policies, more general issues of socio-economic inequalities in health and in access to healthcare have only briefly been reviewed and summarised. This general discussion and research strand is now well documented and established and will therefore not be dealt with in any depth under this project (see, e.g. the state of the art documented on the European Health Inequalities Portal, [www.health-inequalities.org](http://www.health-inequalities.org)).

## 1.4 The study methodology

The analysis undertaken in this study draws on evidence collected from existing research and data, and compares and contrasts policy approaches and outcomes in a selection of eight EU Member States. The study takes into account international research and experience in this area as well as the views of stakeholder groups. The analysis has been carried out following three separate but related strands of work:

1. A mapping of the overall state of the art regarding barriers to access, particularly with respect to barriers that are relevant for groups of people at risk of social exclusion;
2. The identification of related national policy approaches taking into account evidence provided by

country studies and the analysis of the National Action Plans for social protection and social inclusion;

3. The analysis of specific needs of the three focus groups at risk of social exclusion, with a view to identify circumstances where access barriers can lead to or aggravate situations of social exclusion, and to provide examples of good practice that are currently in place to prevent this from happening.

The HealthQUEST project has used a variety of sources for the evidence on which the analysis draws:

#### ***1.4.1 The state of the art from the literature and from previous international studies with similar objectives, by drawing on existing research and data***

Literature has been searched via the PubMed online database and via internet searches and lists of relevant European initiatives. Advice from experts, within the project as well as outside, was also taken. Starting from key recent publications, lists of references were used as pointers to other relevant publications that were then checked for relevance. This review complemented earlier work undertaken by project partners and aimed to identify existing or ongoing similar work in order to avoid duplication. There was a special effort to identify grey literature and information sources from the internet. The networks of EHMA and of EuroHealthNet were also approached for this purpose. The literature review of Tamsma and Berman (2004) and the EuroHealthNet "Closing the Gap" web pages were among the most important reference points.

#### ***1.4.2 In-depth country studies***

Based on the issues identified in the project tender and on an initial literature review, a template for in-depth national studies was drafted and discussed with country experts. The elements for system descriptions on health and social systems have also been outlined in the template, together with a short set of indicators. These include elements of background information for the understanding of access, quality of care and social inclusion aspects and information on more specific topics such as cost sharing and population coverage.

#### ***National action plans for social protection and social inclusion (2006-2008)***

The *Guidelines for preparing national reports on strategies or social protection and social inclusion, 2006-2008* (NAPs 2006-2008), invited Member States

to identify how social inclusion policies and the modernisation of health and long-term care interact and can contribute to achieving overarching goals. The European Commission has encouraged Member States to illustrate these points with examples, such as from the fields of the inclusion of migrants and minorities.

The NAPs (2006-2008) for the first time cover healthcare as a separate policy area under the new streamlined Open Method of Coordination. They have therefore been used as an additional source of evidence on recent policy trends. It is important to note that –compared to the NAPs of 2003-2005– the 2006 reports now clearly acknowledge the contribution of good-quality accessible healthcare to the economy. It is also interesting to note the issues that are not covered in NAPs but that are relevant for the policies studied in HealthQUEST and this will be commented in this report.

#### ***Mental health case study***

The HealthQUEST project includes a case study on issues of particular relevance for people with mental health problems. Chapter 6 presents the results from this study.

#### ***Involvement of stakeholders***

As part of the study, core stakeholders were contacted who are concerned with healthcare and its interplay with social inclusion strategies both at European and national levels.

#### ***Statistical information***

Statistical information is taken from country reports, unless other (international) sources are quoted, (such as Eurostat or OECD). Data from these international sources may not correspond exactly to national data.

### **1.5 Overview of the countries included in this study**

The countries analysed in this study form a diverse group in terms of health system organisation. Table 1.1 below provides an overview of the main principles of organisation and financing of their healthcare systems. As it will become clear throughout the report, these organising characteristics can affect the extent of access to healthcare made available to the population, especially for groups at risk of social exclusion.

All the countries operate decentralised provision, with different levels of decentralisation and steering by

**Table 1.1: Main principles for organisation of healthcare systems**

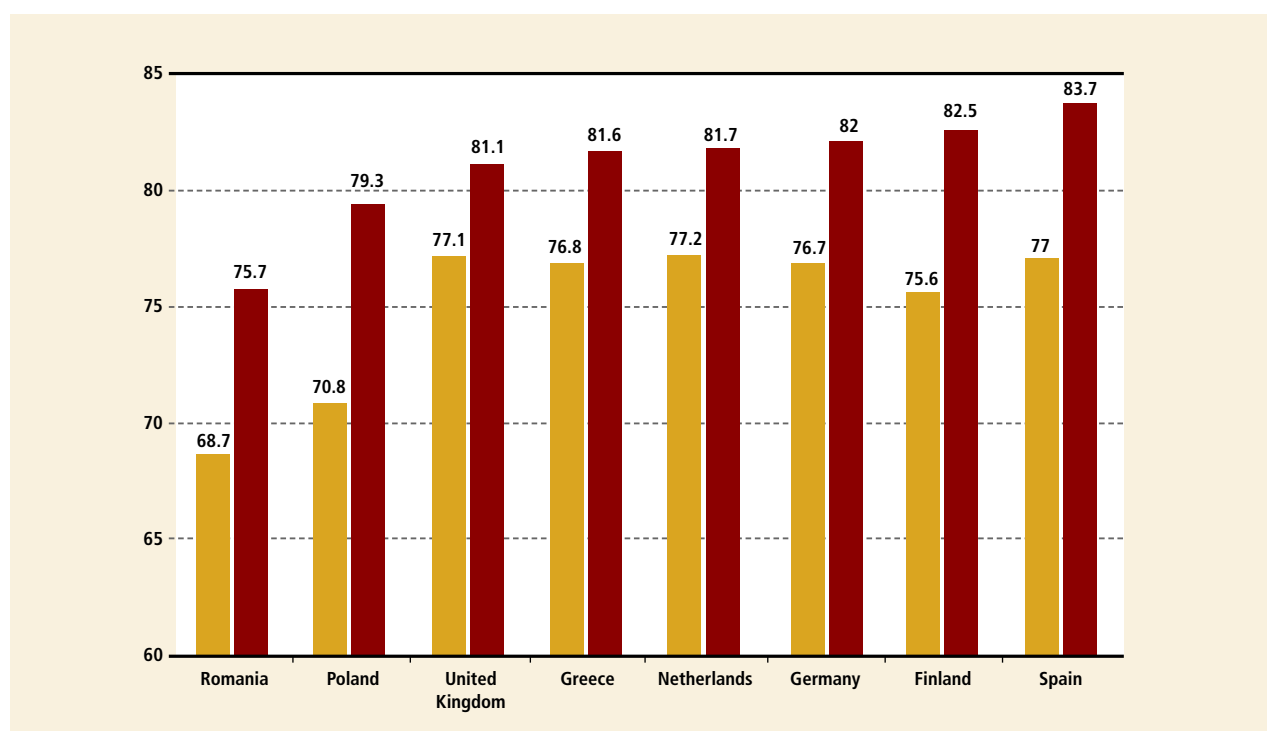
Source: HealthQUEST country reports and National Reports on Strategies for Social Protection and Social Inclusion 2006–2008

	FINLAND	GERMANY	GREECE	NETHERLANDS	POLAND	ROMANIA	SPAIN	UK
<b>Level of decentralisation</b>	Services provided by local authorities (municipalities)	Federal system, provision by sickness funds	Decentralised to regional health units	Decentralised provision supervised by central authority	3 levels: central, regional, communal	Decentralised, regulated by national and district health insurance funds	Decentralised to Autonomous Communities	Responsibility devolved to national administration in Scotland, N Ireland and Wales
<b>Main source of financing</b>	Tax financed	Statutory social health insurance	Mixed tax-based NHS and compulsory social health insurance	Universal compulsory private health insurance	Statutory social health insurance	Statutory social health insurance	Tax financed	Tax financed
<b>Private health insurance</b>	Voluntary, covers 11% population	Covers mainly self-employed, civil servants and employees with high income	Voluntary, covers 8% population	Mandatory and universal	Negligible	n.a.	Voluntary, covers 10% population	Voluntary, covers 12.5% population
<b>Cost sharing and co-payments</b>	Prescription drugs, dental services, hospital care; maximum limits apply	Prescription drugs, dental care; children exempt	Prescription drugs	OTC drugs; children exempt	Prescription drugs	Prescription drugs	Prescription drugs; pensioners, older people in low incomes exempt	Prescription drugs, dental care; children, elderly, low income people exempt
<b>Provision of services</b>	Health centres provide PHC in co-operation with other municipal services; Public district hospitals provide out/inpatient specialist services; Private sector provides mostly specialist care	Sickness funds contract provision with physician (PHC) and hospital (hospital services) associations	PHC centres, public hospital outpatient units provide PHC; Specialist care provided in general and specialised hospitals	Based on private providers: GPs provide supply PHC and act as gatekeepers for out/inpatient hospitals, which provide specialised services	Outpatient clinics and family doctors provide PHC; Specialist outpatient care in private medical practices and inpatient in public hospitals	Independent GPs provide PHC and act as gatekeepers; Out/inpatient mostly provided in public hospitals	Public health centres provide PHC; Outpatient provided in ambulatory centres; Inpatient mostly provided in public hospitals	Purchaser-provider split in England. PCTs responsible for improving general health situation and commissioning services. NHS Trusts manage hospitals, which provide specialist services. GP practices provide PHC
<b>Remuneration of GPs in the public system</b>	Salaries	Fee-for-service with elements of capitation	n.a.	Mix of capitation and consultation fees	Capitation	Mix of capitation (70%) and consultation fees (30%)	Salaries and some capitation	Capitation

**Figure 1.1: Life expectancy at birth in years, by gender (2005)**

Source: Eurostat

■ Males ■ Females



central authorities. In terms of source financing, the public system of coverage is structured in two main models. In Finland, Spain and the UK the main public system is tax financed. Private health insurance in these countries is also at considerable levels, covering around 10%~12% of the population.

On the other hand, coverage in countries such as Germany, Poland and Romania is based on the system of social health insurance. Greece has a mixed system that combines elements of both models, with a tax-based NHS and compulsory social health insurance. The Netherlands is a special case, where major reforms have recently introduced a system of universal and compulsory private health insurance. Out-of-pocket and informal payments are also an important source of revenue in countries like Greece, Poland and Romania.

Patient cost sharing exists in all these countries. All countries charge some level of cost sharing for drugs. In those countries that offer dental health coverage for adult populations this normally entails cost sharing from patients. Most countries have implemented co-payment exemptions providing some level of protection for vulnerable groups; however, these apply mostly to children. Consequently, several other groups of people at risk of social exclusion are still exposed and would benefit from extended protection. Good examples are found in some countries where groups like pensioners, people on low incomes, disabled persons and the chronically ill can also benefit from cost-sharing exemptions.

There is some variation in the organisation of services, but a common model is that health centres provide primary healthcare (PHC), with general practitioners (GPs) sometimes acting as gatekeepers, whilst hospital and outpatient units provide specialised services. In most cases GPs are salaried or remunerated on a capitation basis, that is, they receive a fixed fee for each patient serviced or enrolled with them. However, where capitation is used, a mixed system of capitation and consultation fees is usually in place.

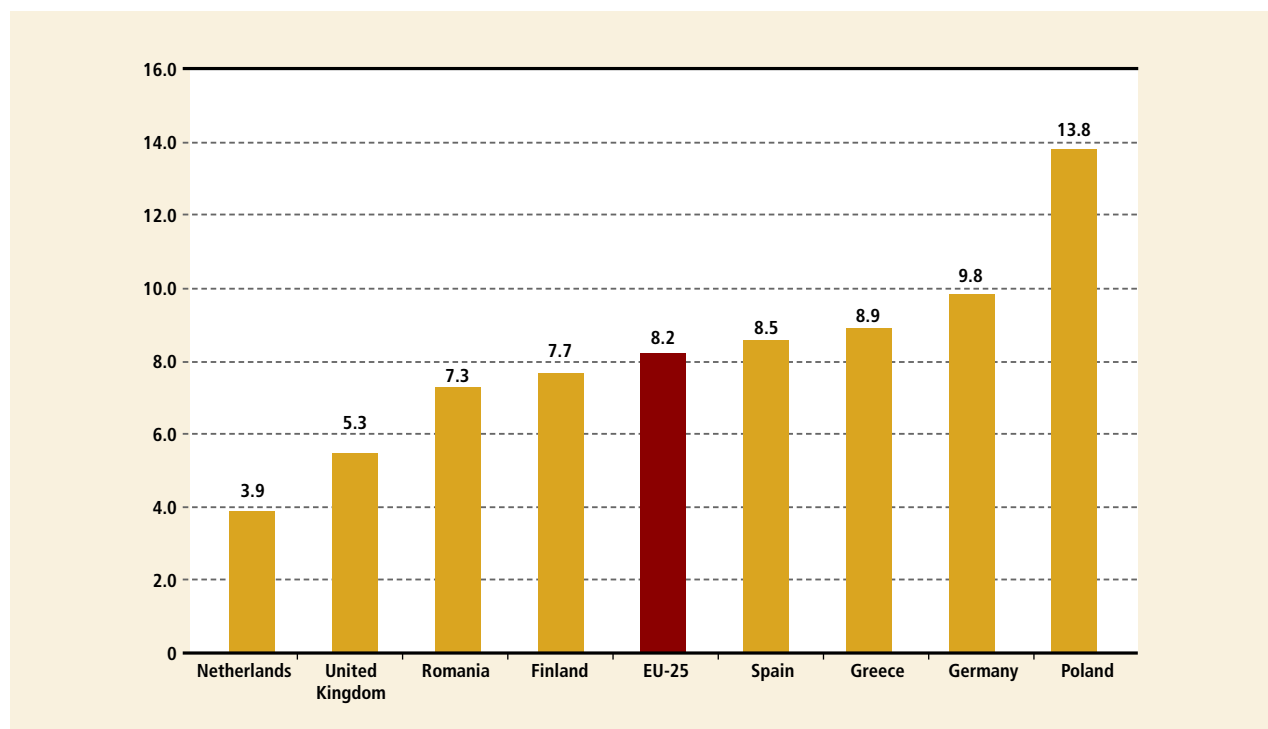
The countries included in this study also differ greatly with respect to many important socio-economic dimensions related to social exclusion, including the at-risk-of-poverty rate, life expectancy at birth, unemployment, socio-economic inequalities in health and in the utilisation of healthcare services. By way of example, the unemployment rate is more than three times as high in Poland than in the Netherlands. There is also an important gap in life expectancy between the EU15 and the new Member States, especially the central-eastern European countries. It is therefore important to bear in mind the different challenges of the eight countries in this study, as well as the differences in the financial resources that public authorities have at hand.

## 1.6 Overview of the report

The report is organised into four parts, comprising seven main chapters.

**Figure 1.2: Unemployment rates (2006)**

Source: Labour Force Survey, Eurostat



**Part II (chapters 2 and 3)**, focus on the specific barriers analysed in the project. The first group of barriers analysed in **chapter 2** refers to limitations in the design of public healthcare programmes and includes three specific barriers: population coverage under public programmes, the scope of the health basket and cost-sharing regulations. These three barriers have to be analysed together, since effective access to healthcare available to the population is to a large extent determined by the interaction between them.

The next group of barriers analysed in **chapter 3** encompass broader and more complex issues which impact on access to healthcare. These include geographical and organisational barriers, supply-side responsiveness and health literacy.

A central feature emphasised in both chapters is the interaction between barriers. Indeed it is a key argument of the report that barriers affecting vulnerable groups often compound each other and can therefore seriously restrict access to healthcare.

Having analysed each barrier in turn, **part III (chapters 4 to 6)**, presents the results of in-depth explorations into the experience of three groups at risk of social exclusion in accessing healthcare. The groups considered are migrants, asylum seekers and illegal immigrants (chapter 4), older people with functional limitations (chapter 5) and people with mental health problems (chapter 6).

These groups were selected on the basis of their very specific and multifaceted healthcare needs and their particular risk of social exclusion. Dependent older people, for instance, often need a complex mix of health and social care services and are therefore vulnerable to access hurdles, including lower health literacy and higher risk of poverty of very old persons. Migrants, on the other hand, are frequently exposed to a high risk of poverty and to the consequences of unmet health needs aggravated by restricted access to healthcare services. Similar problems of interaction between ill health and deprivation also affect people with mental health problems, and are further compounded by stigma and discrimination, which can in some compromise integration into the labour market. It is crucial to draw particular attention to the problems affecting these three groups as the current policy debate frequently focuses on other vulnerable groups, whilst the needs of migrants, older people with functional limitations and people with mental health problems are often left behind.

All the chapters present evidence from country studies and are complemented by an extensive literature review. The chapters also draw on the results of a study carried out by EuroHealthNet that focused on the potential of health promotion interventions to prevent social exclusion.

**Part IV (chapter 7)**, which concludes the report, presents overall conclusions.

## **Part 2**

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## 2 Barriers of Access to Healthcare

### 2.1 Introduction

The following two chapters provide an in-depth analysis of barriers to accessing healthcare (including deficits in the quality of services related to them). They consider not only barriers on the supply side (system characteristics), but also look at demand-side barriers, such as health literacy and help-seeking behaviours, with an emphasis on their interplay.

For the purposes of the analysis, the barriers have been divided into two groups.

Chapter 2: Coverage and cost barriers:

Gaps in population coverage; the scope of the health basket; and cost-sharing requirements.

Chapter 3: Broader system/demand-side barriers:

Geographical barriers of access; organisational barriers; supply-side responsiveness; health literacy, voice and health beliefs.

However, it is also important to note that it is a key argument of this chapter that all the barriers considered by the project interact, and wherever possible these linkages are established and developed.

As this chapter will also argue, the evidence on many of these intersections and corresponding questions is currently underdeveloped in both national and EU-level research. As we will see, no country has done research on all of the key questions, and the evidence on some questions is overall too mixed to provide a clear answer. This is not surprising. As previous work on health access has argued (see HealthACCESS final report, Wismar et al., (eds.), 2009, forthcoming), the available evidence on the barriers (other than coverage, health basket, and cost sharing) is currently rather limited for studying their impact on the population in general. The available evidence is in many cases even more limited for the more specific questions on how these particularly affect people at risk of social exclusion.

#### 2.1.1 Exploring barriers to access through the lens of vulnerable groups

To explore the barriers identified by the project in greater detail three groups at risk of social exclusion and with particular health needs were also identified:

1. Migrants;
2. Older people with functional limitations; and
3. People with mental disorders.

The experience of each of these groups in accessing health services is explored in detail in chapters 4 to 6.

A graphical overview on how supply side system characteristics (barriers at the supply side) interact with group characteristics (demand side) of people at risk of social exclusion is given in Figure 2.1. As Figure 2.1 illustrates, all group characteristics raise specific research questions about their potential interactions with barriers on the health system level. The questions raised at the corresponding intersections in this graph are illustrative for typical and important questions about access problems potentially faced by vulnerable groups in the population. They are far from being a complete list. Moreover, evidence is in many cases limited to a few or only one country studied in detail in HealthQUEST, often due to limited specialised research available.

The questions listed in Figure 2.1 can also be read as illustration of the fact that the supply-side barriers (system characteristics) do not act independently of each other. For example, different sub-systems of public systems may differ in the health basket they offer. Very high cost sharing may effectively limit the health basket that some people can afford. It is also important to note that some of the questions in Figure 2.1 (and of the longer list studied in this chapter) have been studied and have been a concern of intense policy discussion in a number of countries, for example waiting lists, whereas others are rarely prominent on policy agendas, such as the need to address health literacy, voice and health beliefs. As a result, there is more evidence about policy initiatives and good practice examples for some of the challenges suggested at the intersections in Figure 2.1 and its example questions than for others.

Before looking at the interrelation of a number of access barriers in more detail, this section closes with an overview of self-reported access problems among European Union countries. Recent data from the European Union Statistics on Income and Living Conditions (EU-SILC) provide information on the lack of access to medical attention for different age and income groups in several European countries. We illustrate this below in Figure 2.2 and Figure 2.3, which depict the proportion of people reporting unmet needs for medical examination due to problems of access (because the person could not afford the examination; because there was a long waiting list, or the place was too far to travel). Data is presented for 14 countries for the year 2005, by income quintiles and age groups, respectively.

These figures suggest a considerable association between lack of access to healthcare, age and income. Moreover, there is significant variation across countries in terms of the proportion of people with unmet needs. In some countries, such as Denmark, Slovenia,

**Figure 2.1: Barriers to healthcare studied in HealthQUEST and their relevance for people at risk of social exclusion**

		Group characteristics			
		Age, gender, migrants, mental health, dependency	Specific health problems and high health care demand	Low income, high poverty risk	Health literacy, voice & health beliefs (Chap3.5)
System characteristics					
Chap.2.2.1	Population coverage	More likely to be excluded from coverage?	Do people not covered delay or forego care they would need due to high cost?		Effects of obligations for individual contracting and choice?
Chap.2.2.2	Health basket	More affected by cost of services not covered?			Knowledge about right of supportive services?
Chap.2.2.3	Cost-sharing	Do exemptions and ceilings take these characteristics into account?		Additional financial burden? Consequences for service uptake?	Bureaucratic hurdles of exemption rules?
Chap.3.2	Transport, geography, regional variations etc	Do regional disparities limits access to services?		Do access problems worsen social exclusion in rural areas?	Difficulties to find information on providers, transport services?
Chap.3.3	Organisational barriers	More affected by waiting lists?		By-passing waiting lists with private money not affordable?	Difficulties to negotiate with providers?
Chap.3.4	Supply-side responsiveness	Risk of discrimination and stigma?	Are services tailored to needs? Gaps in medical & social services know how?		Difficulties to negotiate with healthcare professional their way through the system?

Austria, Luxembourg, the Netherlands and Belgium, only a very small proportion of the overall population (below 1%) have reported any unmet needs for medical examination. On the other hand, in Estonia, Lithuania, Germany, Poland and Latvia more than 5% of the population have reported unmet needs. In Latvia almost 20% of the overall population have reported such access problems.

As shown in Figure 2.2, there are also marked differences in terms of unmet needs across the income distribution. In all countries the proportion of people who reported unmet needs in the lowest quintile of income distribution is always higher than among those in the highest quintiles. Whilst the UK reports the smallest difference between the two quintiles in proportional terms, Belgium reports the highest difference. Nevertheless, although the proportional difference is the highest in Belgium, the overall level is less elevated.

Figure 2.3 reports a similar situation, this time with respect to differences across age groups. Overall there is a tendency for more pronounced access problems among people in the older age groups. The exceptions are Greece, Ireland, Iceland, Norway, Sweden and the United Kingdom, where the incidence of access problems is relatively more common among the younger age groups.

Although this data does not control for other potentially significant variables, they seem to suggest an association between self-reported lack of access to medical care and socio-economic indicators. More

specifically, there are elements to suggest that people on low incomes and the elderly are more likely to face limitations to access medical care in case of need. The following sections will explore this in more detail, mainly based on information from country studies.

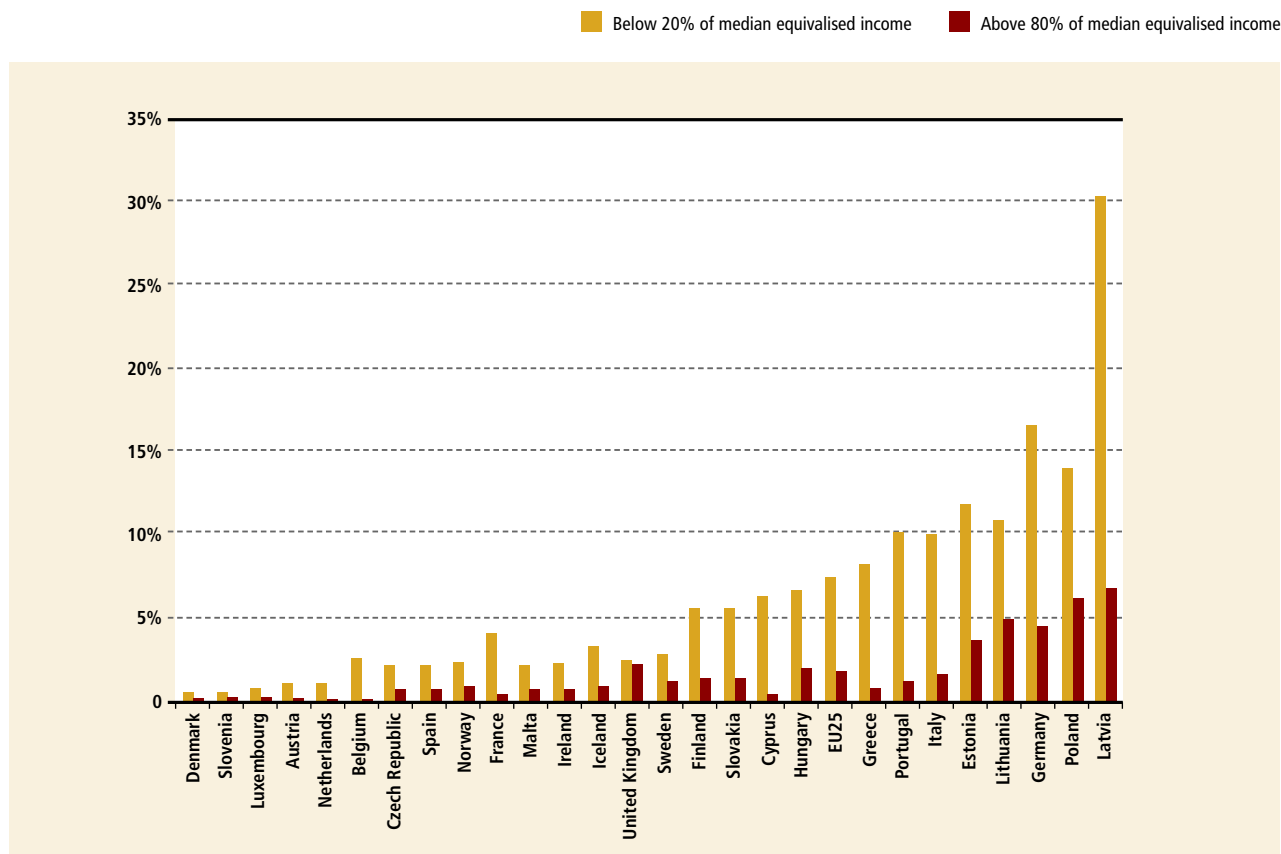
## 2.2 Coverage and cost-sharing barriers

The list of barriers analysed in this section has been studied in previous research as a sequence of access hurdles (or subsequent ‘filters’) that people have to master one after another. The questions asked are then: first, am I covered under a public programme (coverage)? If I am covered, are the services I need in the basket of goods and services covered by the public programme to which I adhere (health basket)? If this is the case, what cost sharing am I expected to pay for these services? For all three of these barriers, recent research has gathered a relatively solid evidence base from a European comparative perspective, for which updates are presented in this study.

The research of HealthQUEST on the specific ways these first three barriers affect people at risk of social exclusion has, however, shown that these barriers are very much interrelated. For example, many people in the vulnerable groups studied in HealthQUEST are at risk of poverty, which means that the cost sharing requested may lead to delays or non-take-up of services, therefore effectively limiting the health basket that they will access.

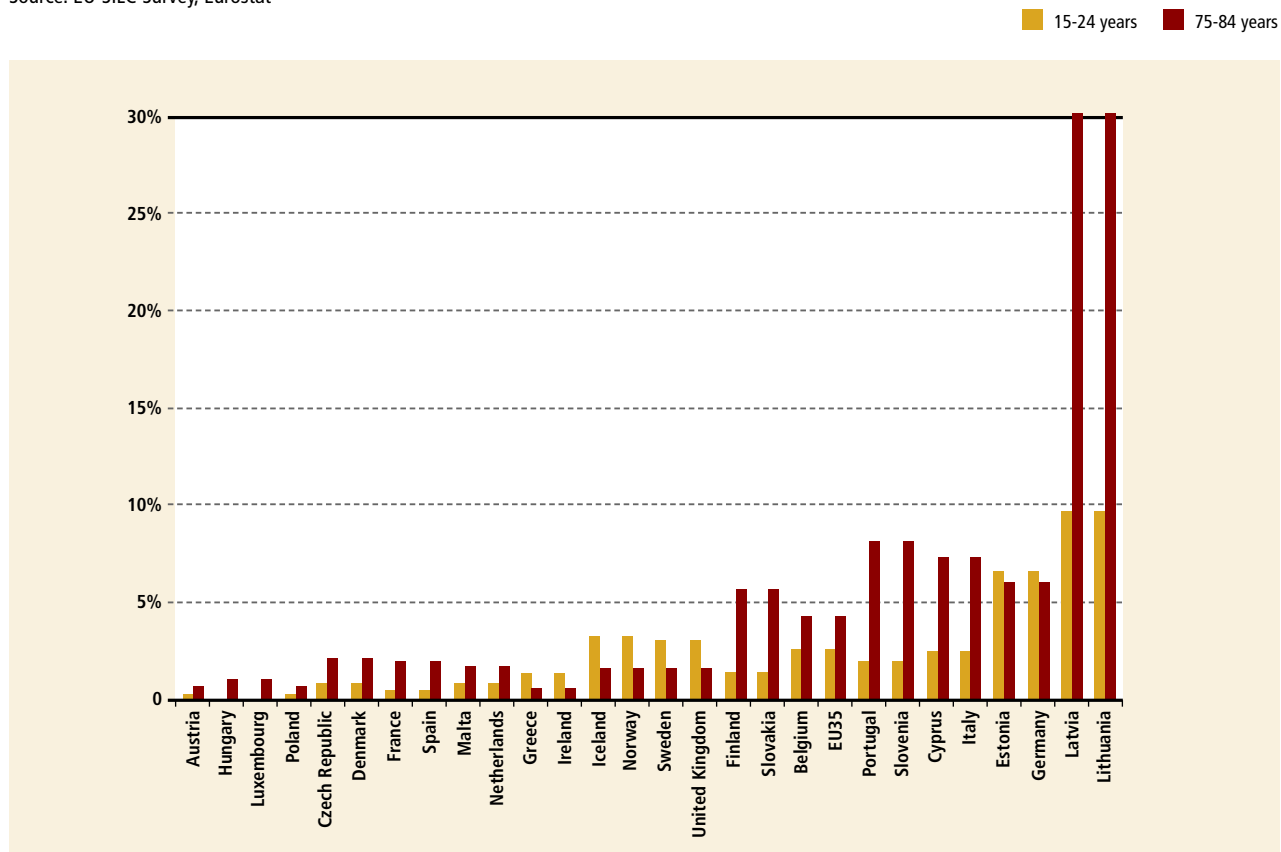
**Figure 2.2: People with unmet needs for medical examination, by income quintiles (2005)**

Source: EU-SILC Survey, Eurostat



**Figure 2.3: People with unmet needs for medical examination, by age groups (2005)**

Source: EU-SILC Survey, Eurostat



## 2.2.1 Population coverage for healthcare under public programmes

Most countries in the EU have mandatory systems with universal coverage. This coverage often extends to asylum seekers and legal immigrants with a residence status. Like other European Union Member States, the eight countries studied in HealthQUEST all offer either universal or near-universal coverage against basic health risks under public programmes to all people with a documented residence status.

As we demonstrate in the following examples, situations where registration with a healthcare administration or making regular insurance payments is a personal responsibility can, however, pose problems of access in practice. In **Germany**, **Netherlands** and **Romania**, people who are obliged to register with an insurance fund but do not comply with this requirement are faced with fines and/or retrospect contribution payments when they request healthcare without being able to prove that they are insured.

Because models of regulated insurance markets as core instruments of healthcare coverage as well as models of 'consumer choice' are spreading in health and social care in the EU, the lessons from these countries on how people at risk of social exclusion might be affected is of special relevance for health policy. This section has therefore a focus on these systems and their recent reforms.

### 2.2.1.1 Main system of coverage

Coverage under the main public programme is uniform for people of all groups in the population in **Spain** and the **UK** as well as the coverage of a broad basic package of services, which is mainly free of charge (see also sections 2.3 and 2.4 for more detail).

In **Finland**, all residents are covered by municipal healthcare. In addition, the National Health Insurance provides partial reimbursement for privately paid services and for prescription drugs. People not covered under public programmes are asylum seekers without a residency permit, illegal immigrants and temporary foreign workers. Moreover, many people profit from collectively arranged so-called occupational healthcare, which can include basic healthcare services, such as a GP: a much more comprehensive idea than 'occupational health' as understood in other countries.

The public health sector in **Greece** is a combination of two systems: a compulsory social health insurance and a tax financed National Health Service (NHS). However, in order to access high-quality services, substantial informal payments may be expected (see 2.4 for more detail). Coverage is also nominally near-universal in

**Poland**, but shortage of available services and high cost (including informal payments) can pose serious access barriers.

Two countries (**Germany** and the **Netherlands**) have recently moved to a more universal system with a general obligation for all residents to contract or register with an insurance fund. There are, however, important differences between these two systems following the recent reform. Whereas the Dutch reform has introduced a mandatory private system for healthcare coverage, Germany retains a system where social insurance and private insurance provide main coverage for the two segments of the population.

In **Germany**, the 2007 reform aimed to reduce the risk of people being uninsured and often having to rely on social assistance as healthcare funding of last resort. This risk of being uninsured was greatest for self-employed people with small incomes often with irregular working life careers, divorced or widowed women who were not working and not contracted with an insurance fund, and people on social assistance.

In the **Netherlands**, the reforms were designed with the aim of achieving a more efficient system, both in terms of costs and in terms of quality, through the introduction of a regulated private health insurance market, with service providers, health insurers –or local authority commissioners– and patients as main players (see Box 2.1). The sections below will study in more detail the (expected) impact for people at risk of social exclusion.

### 2.2.1.2 People not covered directly by any healthcare system

Although the rules vary among the countries, the main gap in coverage is for illegal immigrants and asylum seekers without residency permits. As mentioned above, such groups are normally entitled to emergency services only.

There are also some specific circumstances that apply to residents and country citizens. For instance, in **Spain** 0.5% of the population are self-employed high-earners who opt out of the public system and contract private health insurance. According to the Polish country report, only a small number of residents seem to be without insurance status in **Poland** and these are more likely to be people from vulnerable groups.

There is, however, often a difference between the coverage set out in policy and the reality of healthcare access. In **Germany**, the number of uninsured is estimated to have increased in recent years from an estimated 0.2% in 2003 (around 188,000 residents) to

## BOX 2.1: THE CASE OF THE NEW MANDATORY PRIVATE INSURANCE SYSTEM IN THE NETHERLANDS

In the **Netherlands**, population coverage of medical costs has been subject to fundamental change under the health system reforms of 2006. Under the previous social health insurance law adults and children living in higher income bracket households were exempt from public coverage. Instead, they were expected –but not obliged– to take out substitutive voluntary health insurance (VHI) instead. This situation applied to approximately 30% of the Dutch population.

A single, mandatory scheme of private health insurance was created in 2006. Under the new Health Insurance Act (Zorgverzekeringswet, Zvw) this scheme now provides coverage for a standard service basket. All Dutch residents are now obliged to take out health insurance on a privatised health insurance market. The legal obligation to take out health insurance applies to all Dutch residents and to non-residents paying income tax in the Netherlands. Health insurers have to accept everyone applying for coverage of the basic package.

Source: Netherlands country study

almost 0.4% (or 300,000) in 2005, following the tightening of some social benefits (to which health insurance was automatically linked). Those not covered included some self-employed people with low incomes who had until 2007 no obligation to contract for health insurance and people who were reclassified in their unemployment status (to the so-called type II), meaning they lost their automatic right to health insurance coverage. In addition, people, such as divorced spouses, who were previously jointly covered as spouse of another family member, sometimes remained uninsured – at least for some time.

It is reported that for many of these people the loss of health insurance cover was due to lack of knowledge and understanding of the need to individually register with a social health insurance fund within three months of losing their coverage. This non-uptake issue due to limited health literacy –or health administration literacy– seems to be a common issue for health and social programmes that rely on individual initiative, such as for contracting with administrations and insurance funds and requesting reimbursements (see also the discussion on health literacy under 4.4).

In the **Netherlands**, the new system means people at risk of social exclusion are no longer automatically covered for healthcare costs. Instead, they have to take active steps to ensure coverage with a private insurer. In May 2006, 1.5% of the population were

uninsured: approximately 241,000 Dutch residents, including 40,000 children. People without legal residence status are not included in these numbers. Among people relying on some form of social benefit, the proportion of uninsured is relatively low: 0.7%.

To a lesser extent, this is also the case for people on income support (1% of whom do not have standard insurance cover). It is not clear to what extent this may be due to the role of local authorities as collective health insurance purchasers.

### 2.2.1.3 Initiatives to improve coverage under public programmes

In terms of the options available to improve accessibility to healthcare a series of common key issues can be identified across the eight countries, as highlighted by country studies and NAPs. Most countries present high population coverage under the public system.

However, **private health expenditures** remain stubbornly high in some countries, posing significant challenges for socially excluded groups. This is the case in particular for **Greece, Poland, Romania and Spain**.

It is important to note, however, that countries differ as to why this is the case: informal payments are an important component of private spending in Greece, Poland and Romania, whereas informal payments are not an issue in Spain.

In **Finland**, private expenditures have decreased with the introduction of ceilings to reduce patient burden, but are still high. Under the 2007 reforms, **Germany** now for the first time has a system of universal coverage with general obligation for all currently uninsured people to register with an insurance fund (public or private).

Because most uninsured persons are expected to be at risk of poverty but not eligible to social assistance (Rabbata, 2005), the new rules may substantially benefit these people. Choice of insurance funds is, however, limited. Those who were privately insured before they lost their healthcare coverage are not allowed back in the social insurance system, even in cases where the reason for loss of private insurance cover is, for example, the divorce from an (automatically) privately covered state official.

Although private insurance is obliged to offer a standard contract that is not risk-rated in such cases, the cost of insurance can be as high as the most expensive contract under the social insurance system, and access to care is reported to be in many cases hindered by the bureaucratic hurdles of the private insurance system

## BOX 2.2: POLICY EXAMPLE: LOCAL GOVERNMENT FACILITATING ACCESS FOR PEOPLE ON INCOME SUPPORT THROUGH COLLECTIVE CONTRACTING

Local authorities are responsible for managing elements of the national social benefits package in the **Netherlands**. In 2006, an estimated 325 local authorities entered the market on behalf of their clients on social income support and negotiated collective contracts that often included complementary coverage. Some local authorities will subtract the insurance premium from the benefit allowance, but other authorities may not do so. In the latter case the client will still need to make regular insurance payments themselves. Approximately 80% of all people on social income support were covered through this type of collective contract. This percentage is much higher compared to other lower-income groups, including older people or people with a disability allowance. For their clients, there may be many advantages to this:

- Coverage will be cheaper (as discounts tend to apply for collective contracts);
- They do not have to enter complex choice processes;
- They may have broader coverage as their collectively arranged package may also include services that would normally be part of complementary packages;
- Depending on whether their premium is directly subtracted from their allowance, they do not have to budget in advance for premium payment, fill in forms to apply for the Healthcare Allowance, cannot neglect their payment duties and thus do not risk their right to coverage.

Source: Netherlands country study

Local authorities in the **Netherlands** provide an excellent example of local initiatives to improve coverage (Box 2.2).

### 2.2.2 The scope of the health basket

This section reviews coverage of healthcare services under public programmes by analysing specific gaps in services and the question of how these can affect vulnerable groups.

The definition of the term 'health basket' used in this study is provided in Box 2.3 below. It is important to note that limitations in the extent of the health basket can exist either because some services are not covered in the benefit basket, or because they might be covered but are not made available to the population. The latter case consists of deficiencies in the enforcement of legal regulations and usually results from budgetary pressures.

As described in Box 2.3 above, there is significant variation with respect to the precision of health baskets in different countries. However, Busse and van Ginneken (2009b, forthcoming) argue that there is a trend across EU Member States towards increasing explicitness in the definition of benefit packages, in particular with regard to which services are excluded, which may be of relevance for people at risk of social exclusion who often find it more difficult to negotiate with healthcare professionals.

The decision criteria for inclusion are often based on need, appropriateness, effectiveness and cost-effectiveness. However, "a true formalisation of the process is still lacking for many healthcare categories and is often restricted to one or few sectors of the healthcare system, e.g. pharmaceuticals or medical devices, and are not generalisable to all products or services. Transparency is still lacking concerning the interpretation, operationalisation and application of the criteria in the process of decision-making" (Busse and van Ginneken, 2009a, p. 166, forthcoming).

In some countries the inclusion of specific services is likely to be determined through cost-effectiveness criteria. For example, the services in the standard package in the **Netherlands** are tested for efficacy, cost effectiveness and for the need for collective financing (Busse and van Ginneken, 2009b, forthcoming).

The remainder of this section falls into two parts. First, the next subsection reviews some of the evidence from country studies regarding the main gaps in the scope of health baskets. The cases of dental and mental health services are reviewed. Second, 2.2.2.2 considers examples of policy initiatives to improve health baskets, with specific emphasis on the benefits for groups at risk of social exclusion.

#### 2.2.2.1 Evidence from country studies on gaps in the health basket

Overall public programmes in the countries surveyed provide very comprehensive coverage of preventive health, primary care services (including home visits by general practitioner), hospital services and maternity services. These services are normally available free of charge to all the eligible population.

Some of the main gaps in coverage include non-prescription drugs, plastic surgery for purely cosmetic purposes, smoking cessation and sex reassignment surgery (the latter is provided in some Autonomous Regions in **Spain**). Moral and bio-ethical considerations are frequently behind some of the exclusion of specific services in some European countries, such as in the case of fertility treatments, abortion and euthanasia (Busse and van Ginneken, 2009b, forthcoming).

### BOX 2.3: WAYS OF DEFINING HEALTH BENEFIT BASKETS AND TYPICAL EXCLUSIONS

Busse and van Ginneken (2009a, forthcoming) define the term 'health benefit basket' as the totality of services, activities and goods reimbursed or directly provided by a public healthcare programme.

Benefit baskets may consist of one or more 'benefit catalogues' which are the document(s) that state the different components of the benefit basket in detail, i.e. which enumerate the services, activities or goods in a more detailed way, even listing single interventions (such as specific technologies). In the absence of explicit benefit catalogues, inpatient and outpatient remuneration schemes have the character of (less explicit) benefit catalogues.

The level of explicitness of the benefit basket varies significantly. The NHS in **England** has overall the least precise definition, which requires that the Secretary of State for Health should provide services "to such an extent as he considers necessary to meet all reasonable requirements" (Mason and Smith, 2005). On the other hand, the NHS in **Spain** has a benefit basket that is structured in a more systematic way and defines several categories and subcategories of services (Puig-Junoy et al., 2006).

With regard to social health insurance systems, **Poland** has a very explicit benefit basket. This is defined in the list of procedures of the national health fund and addresses a vast range of healthcare categories. **Germany**, on the other

hand, has a less precise framework for the benefit basket (the Social Code Book) but at the same time a wide number of catalogues which –all together– contribute to a quite detailed definition of the items included.

In several EU countries, some of the typical gaps in health baskets include limited coverage for dental and ophthalmic services, and limited access to specialised services, which frequently require going through a GP gatekeeper. According to Busse and van Ginneken (2009a, forthcoming), several countries also typically exclude services such as cosmetic surgery, medical certificates, vaccination for travelling purposes and non-conventional treatments, such as acupuncture.

Still, according to Busse and van Ginneken (2009b, forthcoming), some treatments are constrained or prohibited in certain countries based on moral and bio-ethical grounds, e.g. fertility treatments, abortion and euthanasia. As a consequence, it is frequently the case that patients choose to go abroad to receive such treatments. In the case of fertility treatments, in some cases women "travel to countries where donor anonymity is guaranteed for sperm and egg donations" (p. 17). Estimates suggest that 50% of women receiving fertility treatment in **Spain** come from other EU Member States; the numbers coming from the **UK** have increased considerably after changes on anonymity laws.

Source: Busse and van Ginneken (2009a, forthcoming)

There is a strong relationship in the way that health basket regulations interact with issues of coverage under public programmes and cost sharing to determine the access. For instance, although the coverage for prescription drugs is quite extensive, cost-sharing requirements can restrict access to drugs, in particular for vulnerable groups. These issues are addressed in more detail in section 3.4.

#### *Access to dental services and mental healthcare*

Another area with incomplete coverage is the provision of dental services. In some countries there is wide coverage, sometimes conditional on professional evaluation. In general, however, full coverage is limited to young people (normally below 16 or 18 years), while those above this threshold are liable to co-payments. Problems in accessing dental treatment are also related to high costs of private treatment (see section 3.4 on cost sharing).

The situation with respect to dentistry services is particularly precarious in **Romania**, as described in Box 2.4.

### BOX 2.4: DENTAL SERVICES IN ROMANIA

At present there are around 12,000 working dentists in **Romania**. Most of them started their own clinics after 1990, following the collapse of the communist regime.

Around 95% of the dental services in Romania are provided in private practices, which collect fees from the patients. Precarious economic conditions in rural areas mean that most dentists are working in the larger cities. Consequently many areas face a total lack of dental services. The public system includes only the school clinics and those serving some special ministries with internal networks.

Overall there are very significant barriers of access to dental services in Romania. The concentration of dentists in the cities severely limits access in rural areas. Moreover, payments required for private treatment impose major barriers of access for low-income groups, including the elderly population dependent on pensions.

Source: Romania country report

In **Spain**, many Autonomous Communities provide complete and free dental care for infants. However, dental healthcare for the adult population is covered mainly by the private sector, as public sector services are limited to diagnosis and extraction. This means that financial capacity to pay for services is what determines access. Several studies have shown that this introduces a pattern of inequity in the use of dental services. The use of dental services is lower among groups with lower socio-economic status (Rodríguez-Sanz et al., 2006; Borrell, 2006; Borrell et al., 2001; Palanca Sánchez I., 2002). Rodríguez-Sanz et al. (2006) estimate that the prevalence of use of dental services in Spain in 2003 was 16% among individuals (men and women) from lower social class and between 21% (men) and 29% (women) among those from higher social class. According to a 2005 *Living Conditions Survey* 46% of people who were unable to have dental treatment stated finances as the primary reason.

In the **UK**, complex changes in the organisation of the dental services have resulted in many dentists shifting increasingly into private practice. Consequently, a growing number of people find it difficult to access dentists who will accept them for NHS treatment rather than treating them privately (Gibson, 2003). The latest round of payment reforms (April 2006) guarantees dentists a minimum income which, in conjunction with shifting the responsibilities for dental services to Primary Care Trusts (PCTs), was meant to address this problem of access (Oliver, 2006). However, there are still reports of problems in specific geographical areas. PCTs have a duty to find a dentist willing to treat NHS patients for people unable to access one for themselves, but some geographical areas are under-served which makes it necessary to travel long distances. This has resulted in higher use of private care and private dental insurance which may work against those unable to afford this as an alternative.

Unfortunately, similar problems also apply to mental health services. In many cases these are covered only to a certain extent and there are non-financial constraints that limit access. In some countries such as in **Finland**, the **Netherlands** and the **UK**, access to treatment and/or reimbursement of treatment costs is conditional on assessment of the need by a physician. As Box 2.5 describes, **Germany** has introduced some more flexible regulations, which aim to counterbalance potential access limitations resulting from the need to have physician referral for mental health treatment. However, significant inequalities remain across socio-economic groups.

In the **UK**, the NHS provides free services to those in hospital and for community services on recommendation of the GP. However, waiting lists mean that some people choose to use private healthcare, as waits can be many months. In the **Netherlands**, counselling and psychotherapy services from psychologists working

within primary care settings are covered up to a maximum of eight sessions and require an out-of-pocket payment of €10 per session.

### *Gaps remain in practice despite legal equality*

It should be noted that formal legal entitlements do not necessarily imply that health is in reality delivered on equal terms or that barriers do not exist. Indeed it is a key argument of this report that it is still common that existing legal regulations establish that public systems should provide an extensive range of services, whilst in reality intervening factors mean that this does not happen.

In **Greece**, for example, the NHS provides a range of healthcare services, including preventive services, family planning, and maternal and dental services. In principle, this should guarantee that access is provided on equal terms for clients of both the NHS and the insurance funds. However, this is not the case in practice since there are significant inequalities in the volume and the funding of the services provided (see Geitona, 2001; Kyriopoulos and Levett, 1999; Petsetaki and Geitona, 1999; Yfantopoulos, 1999). For instance, despite the fact that populations in need are eligible for medication, significant variations exist in the provision and utilisation of drugs among the various social funds. In 2004, when the average per capita pharmaceutical expenditure was about €210, it was €100 for the self-employed fund, €190 for the IKA fund, and €265 for the public servants fund (Greece country report).

#### **BOX 2.5: MENTAL HEALTH COUNSELLING IN GERMANY**

In **Germany**, mental health counselling by psychologists affiliated to the social health insurance scheme does not require a prescription but may be accessed directly. Clients see a physician for a somatic check-up after the sessions. This regulation was introduced in 1999 to avoid excess somatic-orientation leading physicians to under-recognise mental disorders and under-provide mental health services.

Treatment may be performed in groups or on a one-to-one basis. It is usually limited to 12 or 30 sessions. Though data are not available, the requirement of certified 'treatability' and 'treatment prognosis' based on the therapist's judgment tends to prioritise younger adults with light disorders, little co-morbidity and high educational status, while mentally retarded people, people with severe mental health problems, severe somatic co-morbidity, the elderly and people with low educational status tend to be disadvantaged (Bundesverband Psychiatrie-Erfahren, 2007; Melchinger et al., 2003).

Source: Germany country report

## BOX 2.6: POLICY EXAMPLE: EXPANDING COVERAGE OF DENTAL SERVICES IN FINLAND

In order to improve adults' access to dental care and to lower cost barriers to the use of dental services in **Finland**, the age limits restricting access for adults to public dental services were removed in 2001–2002 and reimbursement for private dental care was expanded to cover all age groups. The implementation of the reform was pushed forward by legislation ensuring access to public healthcare in 2005, defining a maximum waiting time of six months for non-urgent dental care (Ministry of Social Affairs and Health, 2004).

According to national statistics the use of public dental services increased and the number of persons receiving reimbursement for the cost of private care doubled. Due to the reforms, improvements were seen in the supply of emergency dental services in the public dental services across the country. In 2000, 22% of adults used public dental services and in 2004 the user rate was 24%. The percentage of those aged 0–17 years who visited the public dental services remained at the same level (76%) over time. In 2000–2004, the proportion of adults receiving reimbursements for private oral healthcare increased from 12% to 25%. At the same time, the total running costs of dental care in Finland increased by 19% (Widström, 2006).

A survey evaluating the effects of the reform reported that self-reported oral health improved and perceived need for dental care decreased in the period 2001–2004 (Kiiskinen et al., 2005). Simultaneously, the proportion of persons visiting dental care during the previous 12 months increased from 57% to 61%. The utilisation of the public dental services increased slightly, but the total number of private patients remained at the same level as before the reform. The increase in the use of services was especially clear for people with middle level education. An increase was also seen in those with a low level of education, but their use of services remained at a lower level compared with that of persons with a middle or high level of education. Thus, the dental care reform contributed to the goal of achieving greater equity in access to dental care.

In the public dental services, the cost share between patients (20%) and municipalities (80%) did not change. In the private sector the NHI financed a bigger part of the costs (in 2000, 15%; in 2004, 26%) and the patients' out-of-pocket costs decreased from 85% to 74%.

Source: Finland country report

**Poland** has legal regulations that establish the health basket in very explicit terms. However, in reality there are several objective barriers acting to limit access. Some of the main barriers collected from the literature and mentioned in the Polish country report have an organisational character and have been shown to restrict the scope of services that patients can access and to affect vulnerable groups in particular (CSIOZ, 2007). These include:

- Patients have to wait in the waiting room for long periods of time before being admitted to the physician's office (more information is provided in section 3.6 on organisational barriers);
- Geographical barriers if a specific specialty physician is not available in a village or small town and receiving care requires travel to a bigger town, which may cause both physical and financial difficulties;
- Other barriers are caused by the provision of only a limited range of services resulting in long waiting lists.

The situation described in the last point above has been shown to induce patients to opt for private treatment, most often involving out-of-pocket payments. This is often the case for dental treatment. This can result in significant problems for people at risk of social exclusion, who face financial barriers that prevent them from using private care.

### 2.2.2.2 Initiatives to improve health baskets that are also beneficial to groups at risk

The country studies provide some important examples of policy initiatives that are currently in place in EU Member States to extend the coverage of services and improve the basket of benefits. Some of these examples are particularly relevant for HealthQUEST because of the potentially beneficial impact for vulnerable groups at risk of social exclusion.

In recent years one of the main initiatives in terms of expanding health baskets has been the expansion of public dental care for all in **Finland**. Box 2.6 describes this case in detail.

In **Poland**, regulations have been put in place to provide specific treatment for certain conditions even if patients are not covered by the insurance system. This applies, for instance, to specific communicable diseases, mental health, and drugs and alcohol abuse problems. Under this regulation, for example, patients are entitled to receive alcohol abuse therapy even if they are not insured.

The model of collective contracting in the **Netherlands** also provides an example of how to extend the basket of services made available to groups at risk of social exclusion (see section 2.2 on coverage for more information). Under this system clients can decide to join

a collective arrangement, in which case the collective will negotiate a total package for them and will therefore also make these decisions on the behalf of its members. For example, local authorities can establish collective contracts with health insurers on behalf of people on income benefits. In another example, stakeholder groups can form similar contracts on behalf of people with chronic diseases. This can lead to broader coverage as the collectively arranged packages may also include services that would normally be part of complementary packages.

### **2.2.3 Cost-sharing requirements as a barrier to access**

Private expenditure –on private health insurance, occupational healthcare, and out-of-pocket expenditure –plays an important role in funding healthcare in EU Member States. Indeed out-of-pocket expenditure usually accounts for the largest share of private spending. Out-of-pocket expenditure comprises cost sharing in the funding of the publicly provided healthcare basket, expenditure for ‘over-the-counter’ goods, expenditure for services not covered under public programmes, and informal payments.

This part of the study analyses the barriers to access caused by cost-sharing regulations, the groups of the population most affected, and policy examples on how some countries have designed cost sharing in ways that minimise their impact on vulnerable or disadvantaged groups of the population.

As this review, (based on country reports under HealthQUEST and latest evidence from the literature) will show, groups at risk of social exclusion are disproportionately affected by the financial burden of healthcare costs. Where policies have tried to address this, this is often done in a way that is interrelated with other social benefits, such as social assistance or tax breaks, or shifting cost to other programmes.

There are, however, limitations to the analysis that is currently possible because changes in cost-sharing regulations have in many cases not been evaluated regarding their impact on equity in healthcare services and in particular on effects such as deferred visits to physicians, or other threats to access to healthcare. Indeed in many cases, the basic data systems (e.g. surveys) to do so are not in place.

#### **2.2.3.1 Overall trends in private cost sharing**

Co-payments are generally required for a range of goods and services, including prescription drugs, dental services (including dental prostheses), physiotherapy, hearing aids and glasses.

Over the last 15 years, private expenditure has increased as a share of total expenditure on health in the EU15 on average (Figure 2.4) and this is partially due to increasing private cost sharing in several countries. There is, however, evidence that cost sharing (private spending without private insurance and other private spending) has stabilised or decreased as part of overall spending in a majority of the countries studied under HealthQUEST, with the notable exception of **Germany, Greece** and the **United Kingdom** (Figure 2.5).

These trends from the international health accounting data collection of OECD-WHO-Eurostat are complemented below by the more detailed information from country studies under HealthQUEST.

Over the last 15 years, public healthcare customer fees have increased in **Finland**, which reportedly has worsened access barriers for disadvantaged and low-income households (Kapiainen and Klavus, 2007). The evidence suggests that low-income households are much more affected by cost sharing than other households: the percentage of households that spend high percentages of their income on out-of-pocket payments is considerably higher in the lowest income classes (see Figure 2.6 below). There has also been a change in the overall trend: in the 1990s, funding of Finnish healthcare was progressive, but in 2001 the progression was lost, mainly due to the increase in out-of-pocket payments for public health services (Kapiainen and Klavus, 2007).

A similar situation has been reported in **Greece**. Private expenditure, including informal payments, has continuously increased, currently standing at over 50% of total health expenditure (Kyriopoulos, Tsalikis, 1993; Kyriopoulos et al., 1998; Liapopoulos et al., 1998; Mossialos et al., 2005). Public health expenditure has decreased, but private insurance has been reinforced through tax deductions. This is further complicated by elevated health expenditure as a proportion of GDP (see Figure 2.4). Despite being in the low- to mid-range in terms of national income, **Greece** has one of the highest levels of health expenditures relative to GDP in Europe. The fact that a substantial proportion of this is financed out-of-pocket suggests that households have to cope with excessive financial strain to guarantee access to healthcare.

There is research evidence for Greece that the population groups who are disproportionately affected by the financial burden of health costs include older people, legal and illegal immigrants, asylum seekers and the disabled and low-income and socially disadvantaged groups more generally (Geitona and Boukoura, 2004). Informal payments play an important role for many people, as the percentage of these payments as a percentage of GDP has increased from an estimated 0.3% in 1974 to 1.4% in 2006.

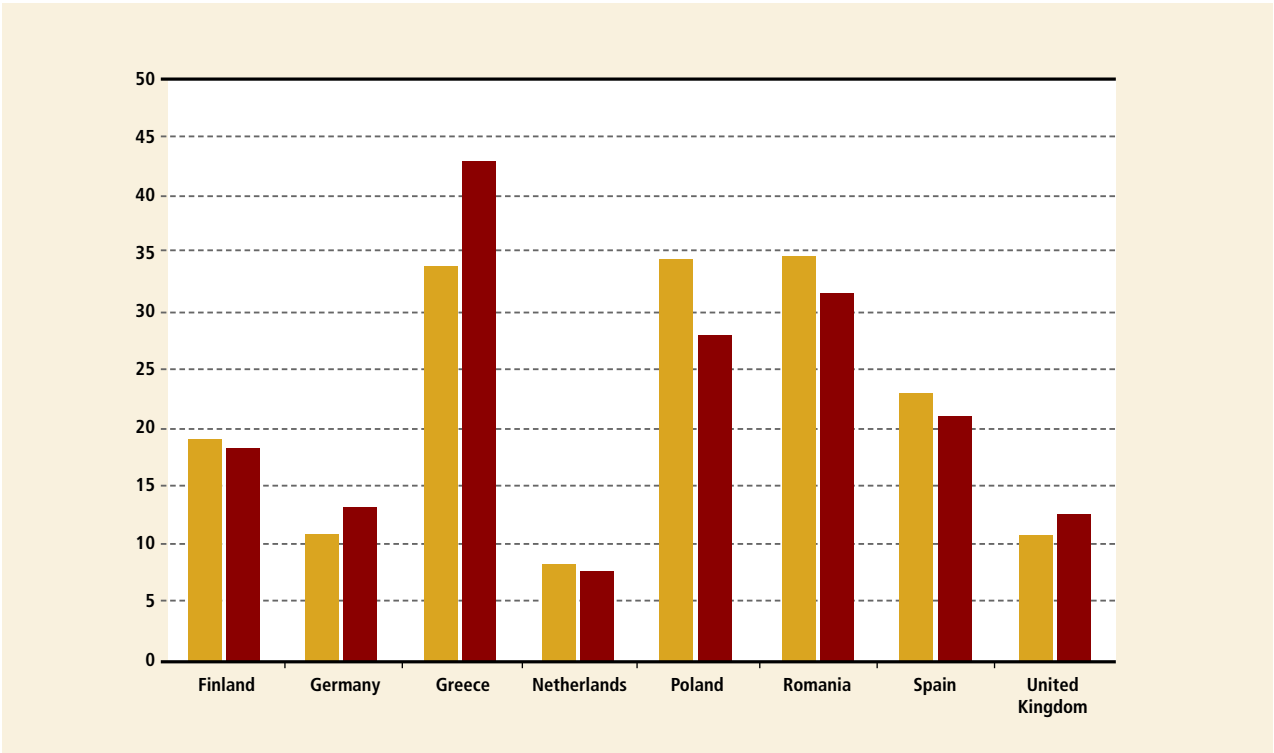
**Figure 2.4: Private spending as % of total health expenditure, 1990–2004**

Source: OECD Health Data 2007; HFA Database/WHO Europe



**Figure 2.5: Private households’ out-of-pocket payments (% of total health expenditure), 1998 and 2004**

Source: OECD Health Data 2007; HFA Database/WHO Europe (Romania)



By contrast, **Germany** has the highest level of health expenditures as a share of GDP among the countries surveyed. However, more extensive financing from government and private health insurance guarantees relatively low levels of out-of-pocket expenditures, although these have increased in recent years (Figure 2.5).

For Germany, there is some evidence that co-payments affect the chronically ill and people with expensive medication needs disproportionately (GEK, 2006).

As a result of the recent increase (and modification of rules) governing co-payment on pharmaceuticals, the share of prescriptions that are exempt from cost sharing has decreased from 48% in 2003 to 29% in 2004 (Busse, Riesberg, 2004).

In **Poland**, household out-of-pocket expenses have also increased since the early 1990s.

Although there has been a reduction in recent years, out-of-pocket expenses are currently estimated to average 35% of total health expenditures, up from 10% in the early 1990s.

### 2.2.3.2 Differences in cost sharing for healthcare services and medical goods

For countries where detailed information is available (Orosz and Morgan, OECD, 2004), the biggest out-of-pocket spending item is pharmaceuticals, including private cost sharing for prescription drugs, followed by spending on ambulatory and outpatient services and medical goods (such as spectacles, hearing aids and medical non-durables). Private cost sharing is less important for hospital inpatient and emergency services (see, however, the examples of **Poland** and **Greece** below).

#### Prescription drugs

Cost-sharing requirements for prescription drugs are common in EU Member States and for the eight countries studied in HealthQUEST (Table 2.1). From the eight countries studied, only the **Netherlands** and the **UK** provide pharmaceuticals free of charge for a basic package of prescription drugs. In other countries, co-insurance can be high but may be reduced for pharmaceuticals (often generics) with prices within a

**Table 2.1: Cost sharing for prescription drugs**

Source: HealthQUEST country reports and MISSOC 2007

	COST SHARING	EXEMPTIONS AND LIMITS
<b>Finland</b>	58% co-insurance; €3 per item in case of serious and chronic diseases; (MISSOC)	Maximum limit for the co-payment is €627 per calendar year (2006)
<b>Germany</b>	10% co-insurance (at least €5 with a maximum of €10) €0 if price is at least 30% below the reference price 100% for amount beyond the reference price	Children are fully exempt; there are a number of exemptions for people with low income and certain other groups
<b>Greece</b>	25% co-insurance; 10% for chronic diseases; 0% in cases of severe diseases	No charges payable in the event of an occupational accident, during pregnancy and for chronic illnesses (cancer, diabetes)
<b>Netherlands</b>	No cost-sharing for basic package of prescription drugs with reference pricing; 100% for over-the-counter drugs and homeopathic remedies; co-payment may apply above reference price level	
<b>Poland</b>	2.5 PLN (€0.65) Basic medicines are reimbursed up to a fixed cost; complementary drugs are reimbursed at 70% or 50% of the drug price	Limit of a maximum of 0.5% of lowest salary (as determined by the Minister of Health)
<b>Romania</b>	n.a.	n.a.
<b>Spain</b>	40% coinsurance; There is a 90% reduction of the price for certain special medicaments, with a maximum limit of €2.64	Exempt are pensioners, residents over 65 years of age with low income, and for victims of employment injuries and occupational diseases
<b>UK (England)</b>	85% of prescriptions are dispensed without charge the charge in England is fixed (£6.85 / €9.9) and there are 4-month and 12-month pre-payment options available to those for whom it would be cheaper to pay this way (as a result, 50% of the population are entitled to free prescriptions)	Exempt are children under 16; those in education aged 16–19; people over 60; pregnant women and 12 months after birth; war pensioners; people with certain special conditions and people with low income

**Table 2.2: Cost sharing for services of general practitioners**

Source: HealthQUEST country reports and MISSOC 2007

	<b>COST SHARING</b>	<b>EXEMPTIONS AND LIMITS</b>
<b>Finland</b>	Health centres may charge a single or annual payment for doctors' appointments. The maximum single payment is €11, which can be charged for a maximum of three appointments. (Extra fees up to €15 for house calls at night or weekend)	The maximum annual payment for physician services is €22 per calendar year; visits are free for children below 18
<b>Germany</b>	€10 for the first visit per quarter and doctor; referrals free; children exempted. Patients' participation for aids (e.g. massages, baths or physiotherapy) which are part of the medical treatment is 10% and €10 per prescription	No co-payment for children. Exemption of participation for expenses above 2% (1% in case of chronic diseases) of the gross income. Reduction of co-payment for early-detection measures and bonus models
<b>Greece</b>	No official cost-sharing for contracted GPs under the NHS	Does not apply
<b>Netherlands</b>	No charges under the Health Insurance Act; no claim waived	Does not apply
<b>Poland</b>	No official cost-sharing under the public benefit-in-kind system	Does not apply
<b>Romania</b>	n.a.	n.a.
<b>Spain</b>	Patients receive free medical care at the point of delivery	Does not apply
<b>UK (England)</b>	Residents do not have to pay fees for services provided by the National Health Service	Does not apply

certain limit defined under a reference price system. Exemptions from these co-payments often include a broad range of groups of the population, defined either by healthcare needs (such as groups with chronic or severe illness) or within age or income limits. Exemptions apply to all older people in **Spain** and in the **UK**, for example.

### *Services of general practitioners*

In most countries there are no formal co-payments for visiting a general practitioner, who plays an important gate-keeping role in many instances. Exceptions for cost-sharing requirements are **Finland** and **Germany** (see Table 2.2). There is evidence from research that the introduction of this cost-sharing requirement has reduced the number of GP visits in Germany. However, there is also evidence that this was to a large extent a temporary effect, which the German country report suggests may point to the fact that many people needed some time to learn how to apply for exemptions and reimbursements. There are, however, studies from surveys that indicate that the new co-payments initially impacted disproportionately upon the care-seeking behaviour in low-income groups (Zok, 2005; Braun et al., 2006). Data from Berlin show that the utilisation of emergency units decreased in areas where a high proportion of recipients of social assistance lived (Meißler, 2005). A survey among insured persons found that shortly after introduction

of the new co-payment 11.7% reported that they had avoided or delayed ambulatory visits. This share was substantially higher among insured people with lower income (19%) and for unemployed persons (21%).

The situation is complex in **Finland**, because different cost sharing is required depending whether the patient sees a physician at a health centre, in the context of the occupational healthcare system, as a hospital outpatient, or in the private sector. For example, much higher cost sharing is usually requested in the private sector (see the Finnish report for more detail). As a consequence an inequality index that compares demand factors (age, gender, long-term morbidity and self-rated health status) with actual service consumption, finds that inequality to access is substantially higher for private services and the occupational health system compared with the core public system of health centres (Figure 2.7).

### *Dental healthcare including dentures*

Dental care (including dental prosthesis) is in many cases only partially covered under public programmes, which poses important financial risks for many people, in particular when they need a dental prosthesis. In many cases there is a distinction between basic services on the one hand and orthodontic and prosthesis work on the other, with the latter being only partially

**Table 2.3: Cost sharing for dental prostheses**

Source: HealthQUEST country reports and MISSOC 2007

	<b>COST SHARING</b>	<b>EXEMPTIONS AND LIMITS</b>
<b>Finland</b>	Not covered by health centres (MISSOC).	(Dental prostheses are free for war veterans).
<b>Germany</b>	50% of fixed subsidies for ca. 30 defined diagnosis-related standard treatments. Claims in excess of this: 100% Concomitant diagnostic and conservative treatment: 0% Repair: 0% if within the 2-year liability period of the dentist.	Full exemption for children; for very low-income persons (with limited choice of providers); general 'hardship' exemptions; bonus for regular preventive visits: co-payment decreases 30% (5 years) or 20% (10 years)
<b>Greece</b>	Charge of 25% for dental prosthesis source.	n.a.
<b>Netherlands</b>	Free for prostheses that are included in the standard health basket (same as for dental services).	
<b>Poland</b>	Officially there is no co-payment in the system.	
<b>Romania</b>	n.a.	n.a.
<b>Spain</b>	Dental prostheses are not included in the health basket.	Certain financial aids for dental prostheses are available.
<b>UK (England)</b>	(Same as for dental services.)	(Same as for dental services.)

**Table 2.4: Cost sharing for dental health services**

Source: HealthQUEST country reports and MISSOC 2007

	<b>COST SHARING</b>	<b>EXEMPTIONS AND LIMITS</b>
<b>Finland</b>	The basic fee for dental care is a maximum of €7; on top of this, a fee can be charged for the treatment administered (€5–130)	Persons under 18 years of age do not have to pay for health centre ambulatory services, such as an appointment with a doctor or dentist
<b>Germany</b>	Dental preventive, conservative, surgical care: practice fee of €10 at the first visit per quarter and at any further non-referred visit in this quarter; orthodontic care: 20% (10% from the second child onwards)	Full exemption for children; hardship exemptions
<b>Greece</b>	(Very restricted coverage in the standard health basket)	n.a.
<b>Netherlands</b>	Treatment fully covered until 18; 18 and over: specialised dental treatment only	
<b>Poland</b>	Basic treatment is free of charge under public programme (but informal payments may apply)	
<b>Romania</b>	n.a.	
<b>Spain</b>	Fully covered under public health basket	
<b>UK (England)</b>	Payment falls into one of three charge bands depending on the type of treatment received: the minimum amount is £15.90; the maximum amount was reduced in 2006 as part of a revision of the dental payment system and fell from £378 per course of treatment to its current level of £194	Exemptions are those aged under 18, those under 19 in full-time education, pregnant women and those who have given birth in last 12 months. Patients in receipt of various social security benefits or with a low income are entitled to partial or completely free treatment.

reimbursed under public programmes (Table 2.3 and Table 2.4). Dental prostheses are not reimbursed under the main public programme in Finland and Spain.

### Medical aids and appliances

Countries also differ substantially in the cost sharing required for medical aids and appliances. This can affect older people in particular, as they are heavy users of a number of the medical goods reviewed in Table 2.5 (such as spectacles, hearing aids, incontinence material and wheelchairs).

### Services of specialists and inpatient hospital services

In most countries there are no formal co-payments for specialist visits, for hospital outpatient attendances or for hospital inpatient services. Exceptions are **Greece**

with €3 co-payment for hospital and outpatient attendances and **Finland** (maximum of €22 for outpatient visits and €72 for outpatient surgery).

In addition, hospital inpatient care usually does not require co-payments, again with the exception of **Finland** where there is a daily charge, and **Germany** (€10 per hospital day). Although there are no official cost-sharing charges in **Greece, Poland** and **Romania**, patients may be informally requested to contribute substantially to the cost of their stay in a hospital. For example in **Poland**, patients may be requested to privately pay for pharmaceuticals that are needed for their treatment. In **Romania**, patients' contributions are requested to upgrade the quality of services. Privately funded upgrading of accommodation and amenities of hospital inpatient stays will usually be available in all countries for patients who can afford these, such as for people who have contracts with supplementary private health insurance.

**Table 2.5: Cost sharing for medical aids and appliances**

Source: HealthQUEST country reports and MISSOC 2007

	COST SHARING	EXEMPTIONS AND LIMITS
<b>Finland</b>	Medical aids such as wheelchairs and other mobility aids and prostheses are free of charge	Glasses for children <18 years are free as well as for adults with defined serious impairment or for therapeutic vision aids in injury or eye disease
<b>Germany</b>	100% co-insurance for spectacles; 10% for hearing aids, prostheses, orthopaedic aids and other durables medical aids with at least €5, max. €10 per item  If fixed amount prices have been set for an aid: 100% of any cost beyond the fixed amount.  10% for non-durable medical aids (incontinence pads etc.) with a max. of €10	
<b>Greece</b>	Maximum of 25% co-insurance (MISSOC)	
<b>Netherlands</b>	The standard health basket includes medical assistance / devices	
<b>Poland</b>	There exists a list of all medical appliances, which are available for free.  Prosthetic devices, hygienically materials are fully or partly publicly financed.  30–50% co-insurance for spectacle frames and lenses	
<b>Romania</b>	n.a.	n.a.
<b>Spain</b>	40% co-insurance with a maximum of €30; Hearing aids, glasses and incontinence pads are partially reimbursed.	
<b>UK (England)</b>	Partial cost-sharing for glasses is available for those on low incomes, children and those aged up to 19 still in full time education.  NHS hearing aids are free.  Publicly-funded wheelchairs are provided for free. Vouchers are available in some parts of the country, which allow people to top up the amount that an NHS wheelchair would cost and to purchase one privately of higher specification than the basic NHS model.	Sight tests are free for those receiving hospital eye services; people over 60; children; those in fulltime education aged 16–19; people on a low income; those at high risk of developing eye disease; blind people; partially sighted and those with complex conditions

Co-payments for maternity services are even less common, and some countries (e.g. the **Netherlands**) also make these services available for illegal immigrants.

Cost sharing can also be very substantial for a range of services that mental health patients would greatly benefit from, such as individual psychotherapy in ambulatory care. While some countries impose no formal co-payments for mental counselling, there are other non-financial mechanisms that potentially limit access to treatment.

In **England**, the NHS provides free services on the recommendation of the GP. However, long waiting times suggest that many people may have to pay for private treatment in order to get timely access to services. In the **Netherlands**, as of 2008 the initial eight sessions will be covered under the Zvw and an out-of-pocket payment of €10 per session will be required.

### 2.2.3.3 Recent policy changes in cost-sharing arrangements

Changes in cost sharing may pose threats to accessing healthcare services and have important equity implications. In **Finland**, for example, there are suggestions that individual healthcare contributions (co-payments and premiums) may have affected the utilisation of services, with a strong bearing on people in lower income strata (Kapiainen and Klavus, 2007).

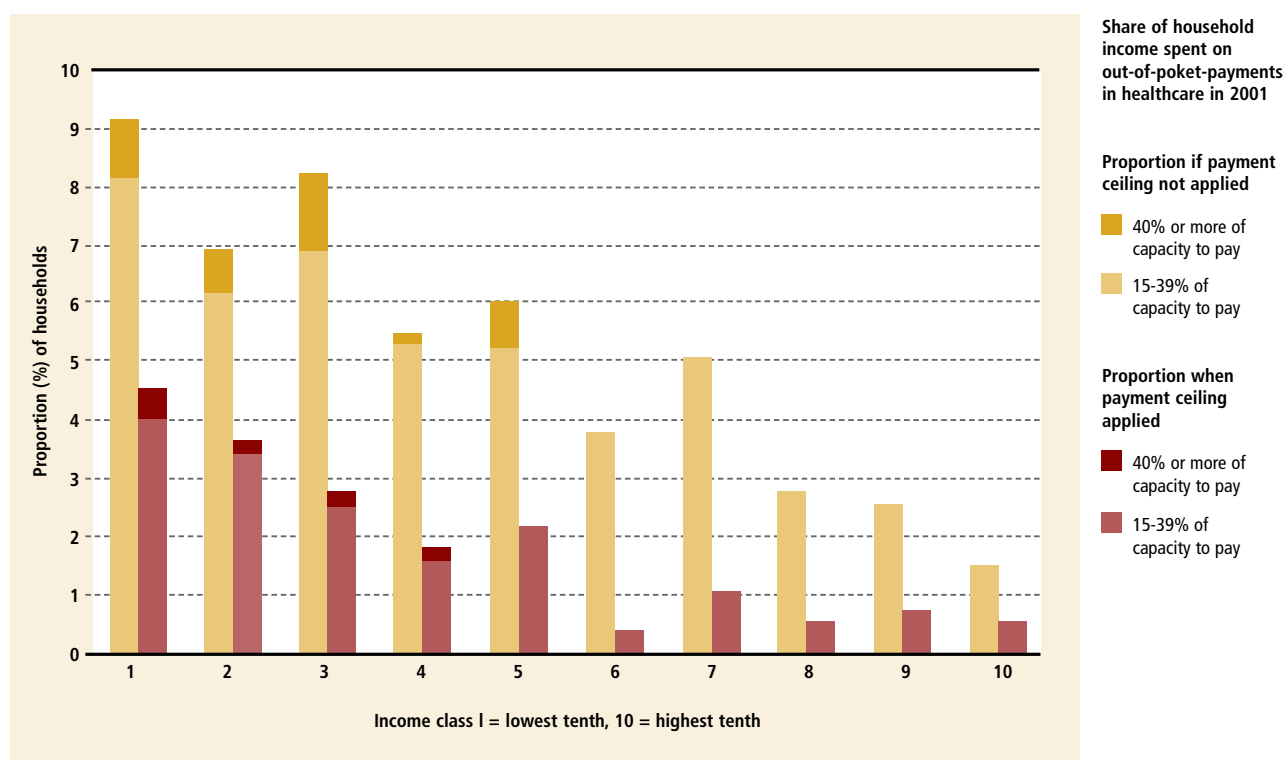
As Figure 2.6 shows, the proportion of households that spend a considerable percentage of their income on cost sharing is elevated for lower income strata. This figure also illustrates the protective effect of payment ceilings that have been put in place, as well as showing a simulated number for the percentages of highly affected households in cases where payment ceilings would not have been in place.

In **Finland** in particular, patient fees have become a more important source of income for public health services, and the burden of these fees is disproportionately affecting low-income households. Moreover, users are not charged for services in the occupational health system. Within the occupational healthcare, coverage of services varies between socio-economic groups and some groups, such as people working with short-term contracts or in very small companies, have been reported to have poorer access to services (Pirainen et al., 2005).

Although an inequality index for access to physician services that has been estimated for Finland (Figure 2.7) has somewhat decreased over time for different types of providers, there are significant differences in the inequality index for services delivered by different providers. Not surprisingly, inequality is lower for municipal services, and relatively high for hospital outpatient and private services. As the authors conclude, the low level of reimbursement for private health services is an access barrier to private health services for people in the lower economic segments (Häkkinen and Alha, 2006).

**Figure 2.6: Effects of cost-sharing ceilings, the case of Finland**

Source: Kapiainen and Klavus, 2007



In the **Netherlands**, there is evidence from research that uptake of home care decreased after co-payments were raised (Baanders, 2004) and uptake of physiotherapy decreased when this was excluded from the standard social health insurance package –except for specific groups of patients– in 2004 (Swinkels and Van den Ende, 2004). It is also clear that people with lower levels of education (a strong predictor of income) use significantly less dental services (Westert and Verkleij (eds.), 2006). Both physiotherapy and dental services are sparsely covered in the current standard package. Covering costs for physiotherapy and/or dental care were important reasons to take out complementary insurance (De Jong et al., 2006). There are also suggestions that the no-claim bonus might have induced deferred visits to physicians.

**2.2.3.4 Informal payments**

As discussed in 2.2.1, in some countries informal payments are an important issue. In **Greece**, for instance, there is a substantial difference between public sector reimbursement rates and the effective prices charged by providers, implying that users often have to bear the additional cost. According to the existing literature 2.4% of Greek households face catastrophic health expenditures related to their disposable income (Kyriopoulos et al., (eds.), 2003).

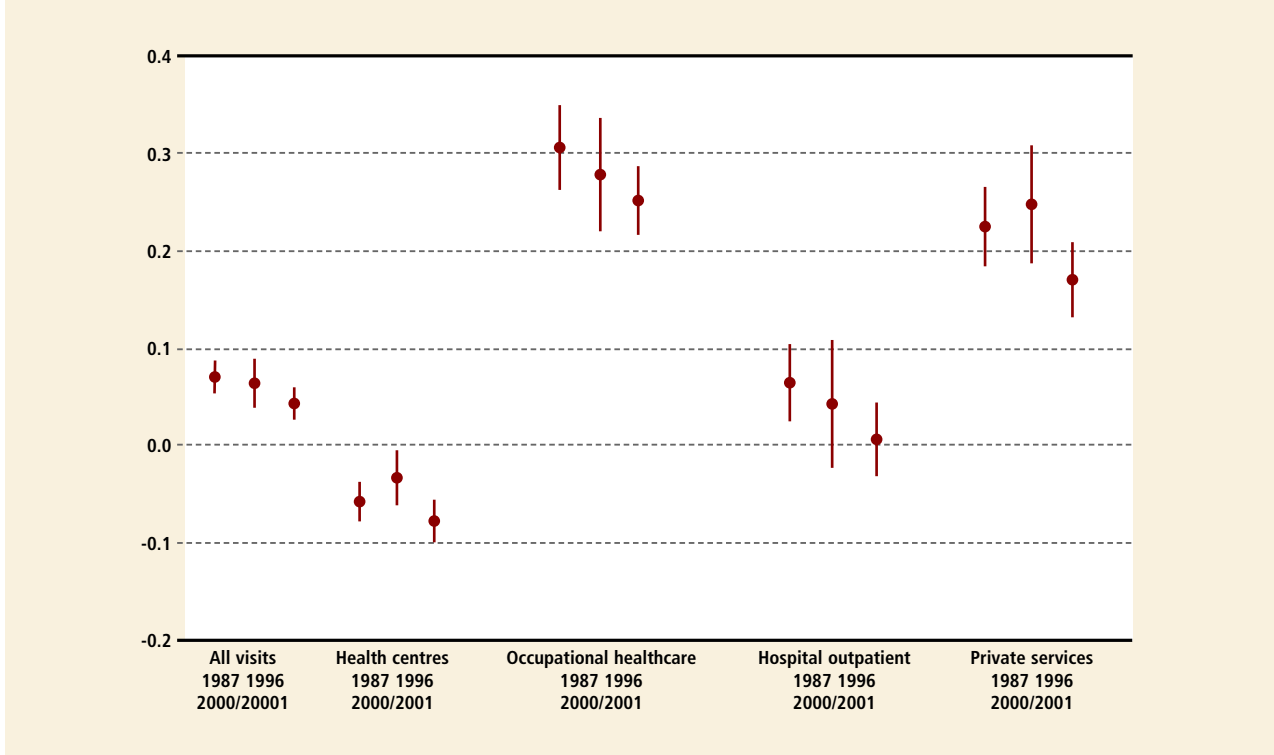
Officially, health services in **Poland** are almost fully free of charge. In practice, however, informal payments are widespread, and patients and their families co-pay in various forms. Patients make various kinds of donations to hospitals and cover part of the cost of services, most frequently in nursing care and accommodation. They also purchase hygienic materials and medicines necessary during hospital stay. Hospital management welcomes this kind of support, despite the fact that officially public finances should cover all hospital care, since it allows them to continue core functions, such as new admissions and continuity of care. It is also common that patients reward informally professionals like physicians, nurses and physiotherapists.

For **Romania** there is evidence on informal payments from patient surveys on their experience with informal payments. One in 10 patients reported that medical staff directly asked for extra payment for certain services during their last hospital stay, but a third declared corresponding suggestions were raised more indirectly. Payments are usually given to different staff including physicians, nurses and guards. Moreover, payments are reported to be high enough to require using personal savings or taking out a loan for around half of all respondents.

Informal payments are not a recognised problem in other countries, and evidence on gratitude payments or donations in kind is largely anecdotal.

**Figure 2.7: Inequality index for access to physicians by type of provider in Finland, 1997–2000/2001**

Source: Häkkinen and Alha, 2006



### 2.2.3.5 Policy options to mitigate barriers of access to disadvantaged groups by protecting people from cost sharing

Several countries provide examples of provisions to protect people on low income against income losses of cost participation. For instance, in **Greece** these groups normally enjoy exemption from co-payments for primary and hospital care, and there is evidence that they receive care free of charge through municipalities. However, this might change with projected reforms of the voluntary health insurance system, which do not take into account the situation of these groups. There are also concerns about the system of tax deductions or rebates. It is believed that these provide insignificant protection because they are based on official reimbursement rates, which are much lower than the actual prices that providers charge.

In the **UK**, there are cost-sharing exemptions largely based on income, with special provisions for families with children, pensioners and benefit recipients (see Table 2.1 to Table 2.5 for more detail).

In the **Netherlands**, the 'Healthcare Allowance' (Zorgtoeslag) is an essential instrument to compensate lower-income strata for their increased healthcare costs as a result of the system reforms. This is done by providing tax compensation for those with low income to allow them to afford insurance premiums. In **Spain**, chronically ill people, pensioners over 65 years and people with disabilities enjoy reduced rates of cost participation and are entitled to free medications.

There are also some special clauses to protect people on low incomes. The **Finnish** system imposes payment ceilings to avoid catastrophic expenses (defined as exceeding 40% of household income), which affect mostly elderly and low-income households. Finland is also an example for the complexity that these regulations can take. In Finland, there are in fact currently three independent payment ceilings in place:

1. For customer fees in public healthcare;
2. For prescribed drugs; and
3. For travel expenses.

These have been important to compensate for the increase in user fees and to avoid catastrophic expenditures (Kapiainen Satu and Jan Klavus, 2007). Municipalities also hand out a basic sum of money as a last resort to be used by low-income households that do not have enough funds to pay out-of-pocket expenses. There are problems with payment delays, however.

Some countries have guidelines with respect to the utilisation of generic drugs. In **Romania**, for instance, drug suppliers must offer the cheapest medicine first

and supply the more expensive medicine only if patient explicitly asks. In **England** and **Spain** the prescription of generics is compulsory. Pharmacists are obliged to dispense generic medicines or, if supplies run out, a medicine with the same composition that does not exceed the maximum price.

Spending caps and exemptions under cost-sharing regulations have been combined in some cases with other measures. For example in **Romania**, low-income people (including retired people with low incomes) are exempt from paying health insurance contributions.

## 2.3 Conclusions and Recommendations

### 2.3.1 Coverage as barrier to access

*A small but significant number of people lack regular healthcare coverage under public programmes.*

With a few exceptions, healthcare coverage is universal and mandatory for all citizens in European Member States. However, illegal immigrants and those without residence permits or working visas are often excluded from health coverage, often with a right to emergency care only. Where health coverage is based on occupational categories, or adherence to other social programmes, or depends on individual initiative to register with an insurance fund, some groups are at risk of not being covered and may receive healthcare under social assistance rules only.

The German country report for HealthQUEST provides an example of change in the EU towards making healthcare coverage truly universal. However, in this case, membership of a sickness fund is now the individual's responsibility and for groups of the population this can lead to unintended problems of access. Some people may be at risk of exclusion from insurance coverage because of lack of understanding and limited capacity to cope with administrative procedures. It is therefore essential that information about obligations, rights to health insurance coverage and how to follow the administrative procedures is easily accessible. Groups at risk of social exclusion, such as people with low educational standards and literacy or those facing language barriers, may need special support within the framework of other social services that they receive or from the community in which they live.

Social support to empower citizens to be better able to navigate public healthcare administration may also be needed in other countries where regulation and procedures of healthcare coverage have over time become more complex, such as for central and eastern European countries after transformation and for countries where parallel public systems exist (like in Greece).

*The impact of social and health policy changes on the number and situation of people without health insurance coverage or at risk of losing insurance status needs more attention.*

A regular monitoring of the number of uninsured people should be part of core health information for policy making<sup>2</sup>. Moreover, systematic research into the reasons why some people fail to obtain a regular insurance status should be undertaken for countries where this puts certain vulnerable groups at risk of exclusion from regular healthcare coverage, which can include people who are already under severe risk of poverty, such as over-indebted households or people without bank accounts.

*People at risk of social exclusion are frequently not able or willing to pay for complementary private health insurance.*

It is therefore essential that the core package of services that is available under universal public programmes is sufficiently broad to respond and does not exclude services or medical goods that are important for meeting their health services needs.

### **2.3.2 Health baskets as barrier to access**

#### **Conclusions**

The health basket of services that countries provide is usually fairly comprehensive, covering preventive health, primary care and hospital services.

However, regulations on health baskets frequently interact with cost-sharing rules, imposing limits on the range of services that are actually accessible. Groups at risk of social exclusion are particularly exposed to this kind of interaction as a result of limited financial resources.

The enforcement of legal regulations in many cases is lacking. In some countries, a number of services are legally included in the health basket but in practice are not extensively available to all population groups. This can lead to significant access barriers for disadvantaged groups and inequalities in access.

Both financial and non-financial barriers limit the access to dental care and mental health services in different countries, particularly for the adult population.

#### **Recommendations**

The expansion of coverage of dental health services is a vital area for improvement. The evidence available suggests the existence of serious access problems for groups at risk of social exclusion, which experience severe consequences in terms of dental health deterioration over time. The experience of Finland in this area can serve as a possible model for other countries.

Countries should make additional efforts to guarantee that legal regulations on the health basket are actually enforced to the benefit of vulnerable groups.

Countries should also devote effort to provide safety nets for people who are not covered directly by any healthcare system. This applies in particular to the provision of sensitive services for vulnerable populations.

### **2.3.3 Cost sharing**

*Cost sharing remains an important policy instrument with the intention to contain costs and to raise additional funds for financing healthcare. It still plays an important role in some countries in financing services or medical goods that are not available in sufficient quantity or quality (such as in a timely manner) under public programmes.*

Evidence from the HealthQUEST country reports confirm that private funding is often regressive and negatively impacts on the uptake of needed services, in particular for vulnerable people at risk of social exclusion.

In order to avoid cost-sharing regulations creating barriers of access to care for those most in need, these regulations usually contain a number of special clauses for certain groups of the population, often in combination with overall caps on the annual maximum amount of cost sharing requested.

However, it is not only the absolute amount of cost sharing that can be a concern for low-income households. First, it is often requested that costs are paid upfront to be reimbursed later, which sometimes involves filling in forms, including forms to apply for tax reductions. Many people living in low-income households either may not know their rights or may be deterred by the bureaucratic hurdle of the necessary paperwork. In some cases, the overall caps defining maximum annual cost-sharing requirements have been reported to be too high to effectively protect vulnerable groups (e.g. Finland). Some countries are now exempting groups with specific health and social risks in total from cost sharing for a range of services and goods (e.g. older people with low income in Spain;

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<sup>2</sup> This usually requires reconciling administrative data from insurance funds with survey data (mainly from micro censuses or from occasional special survey modules on insurance status as part of other household surveys).

or children and low income earners and various other groups in the UK, see Table 2.1 to Table 2.5). For the Netherlands, a range of services of a standard health basket is covered free of cost sharing.

Some countries have put in place a combination of full coverage of basic healthcare services with minimal cost-sharing requirements. These systems avoid the dilemma of cost-containment that can either be effective in curbing cost and limiting utilisation, with negative effects for people at risk (who are heavy users of healthcare), or are ineffective as cost-containment measures if vulnerable groups are fully protected against these negative effects and effectively exempted from cost sharing.

*Administrations should put information systems in place to monitor the impact of cost-sharing regulation on access to healthcare with special attention to the impact on vulnerable groups of the population.*

Administrations in Member States usually do not have the necessary surveys or other data systems in place that would enable assessment of the impact of cost-sharing regulations for policy monitoring, including social inclusion policies. Given the complexity and the frequent changes in cost-sharing regulation, and the evidence reviewed in HealthQUEST, this seems to be an important missing link in the toolbox for policy monitoring (Huber, 2005; and Rannan-Eliya, 2005,<sup>3</sup>).

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<sup>3</sup> The recent special Eurobarometer No. 283, published after the finalisation of this report, provides an example of how to capture access barriers that are due to financial reasons in a European-wide survey. For national instruments, the link of health utilisation and barrier questions in a survey with a household profile on income and employment status would be essential. For the projection of the socio-economic impact of changes in cost-sharing regulations, constructing a specialised microsimulation model might be worth considering.

## 3 Broader System Barriers

### 3.1 Introduction

Having analysed cost and coverage barriers in the previous chapter, this chapter discusses four broader, more complex access problems:

1. Geographical barriers of access to health services;
2. Organisational barriers;
3. Supply-side responsiveness;
4. Health literacy, voice and health beliefs.

The first section, 3.2, brings together questions of the geography of healthcare services that can pose different access hurdles for people at risk. This hurdle can be particularly important for people who live in deprived areas with reduced service availability or who need to travel longer distances to the nearest provider. Section 3.3 on organisational barriers discusses some of the access hurdles at the provider organisation level. These have been a major concern in a number of countries, and frequently interact both with cost issues (e.g. when people pay privately to bypass waiting lists), and with geographical issues, when shortages are more severe in some regions than in others. A second set of hurdles is brought together in 3.4 under the heading of "Supply-side responsiveness". Although the term 'responsiveness' is often used in health policy discussions in a broad way, when referring to many of the access problems discussed in sections 3.2 and 3.3, it is used here mainly to bring together aspects relating to certain client groups, such as responsiveness to special needs (for disabled or older people) and the provision of gender and culturally sensitive services. The chapter ends with a consideration of demand-side barriers, that is, characteristics of service users and populations that interact with health systems to precipitate inequities in access.

### 3.2 Geographical barriers of access to health services

This section considers three aspects of geographical barriers of access to healthcare services: transport, regional variations and rural-urban inequalities. Among other questions, this section addresses the extent that travel/transport costs to see a health professional are included in systems of coverage. It also analyses specific policy measures that have been taken to alleviate cost, help reduce travel hurdles or to ensure the nearest facilities are never far away.

It is important to note that in many of the countries analysed within the HealthQUEST report there is substantial variation in the way eligibility is

implemented under local budgets, especially where the responsibility of organising health and social care provision has been devolved to lower level governments (see Huber et al., 2008,). The process of decentralisation of healthcare services and how this can influence different areas within countries is therefore an important backdrop to this section.

#### 3.2.1 Transport

Transport to access healthcare is an important issue, particularly because many people are dependent on public transport. Even when primary care services are geographically close, people with functional impairments, especially if they belong to vulnerable groups, may still need help to reach healthcare services and countries differ in the support they provide.

Research evidence on transport barriers is very limited. However, where available, such as in the **UK**, it suggests that geographical factors may inhibit the use of services by groups who experience difficulties in mobilising the practical resources required to access distant services. Rates of car ownership are lower in more disadvantaged groups, making travel more difficult, especially out of hours when access to public transport is limited. Older people have identified concerns over safety as well as availability and cost of public transport as a barrier to access distant services (especially for rural populations) and primary care out-of-hours services (Foster et al., 2001; Stark et al., 1997). Mothers whose first language is not English report that journeys to treatment centres for their children are more difficult (Carter and Bannon, 1997). More generally, living further away from a primary care centre, being a lone parent and having a larger family all appear to make accessing distant services more difficult because of the problems of arranging support and care (many studies are summarised in Goddard and Smith (1998) and Dixon-Woods et al. (2005).

In **Finland**, research on equity issues in transport related to the use of healthcare is lacking, but transportation is considered to be an issue mostly in remote rural areas. There is growing awareness of transport problems becoming more of an issue along with ageing of the population and the geographical centralisation of healthcare.

#### 3.2.2 Concerns about regional variations in access

Geographical variations in access are an important topic associated with patient entry to the system. Evidence collected in several countries points to significant regional differences, which have the potential to limit access to healthcare, in particular for people at risk of social exclusion.

Research indicates that regional equity in health has not been achieved in **Finland** (Gissler et al., 2000). There are striking variations between municipalities in terms of healthcare expenditure per capita. Expenditure varied from €940 to €2,310 per inhabitant in 2004 (including long-term elderly care) and need-adjusted expenditure was 2.5 times more in the “most expensive” municipality when compared to the “cheapest” municipality (Hujanen et al., 2006). Moreover, the issue of accessibility to healthcare is expected to become more pressing in **Finland** due to depopulation of the north-east following internal migration to the south-west, centralisation of the healthcare system and ageing of the population. A general threat is that there will be difficulties in access to care due to long distances, especially in the north-east where the population age distribution is skewed towards old age. Another example concerns the effects of hospital centralisation, especially in connection with impacts for ageing populations. The distribution of hospitals across different regions is an important topic, which has been shown to influence the utilisation of certain classes of services. In countries such as the **UK**, the ‘distance-decay’ relationship has been documented, mainly in the context of specialist coronary care units, showing that those who live closer to such centres have higher rates of utilisation after adjustment for need. The impact of distance on utilisation of preventive services such as screening appears to be stronger than on curative treatments, especially where follow-up treatments are required (Goddard and Smith, 1998; Haynes, 2003).

### 3.2.2.1 Regional variations in healthcare resources

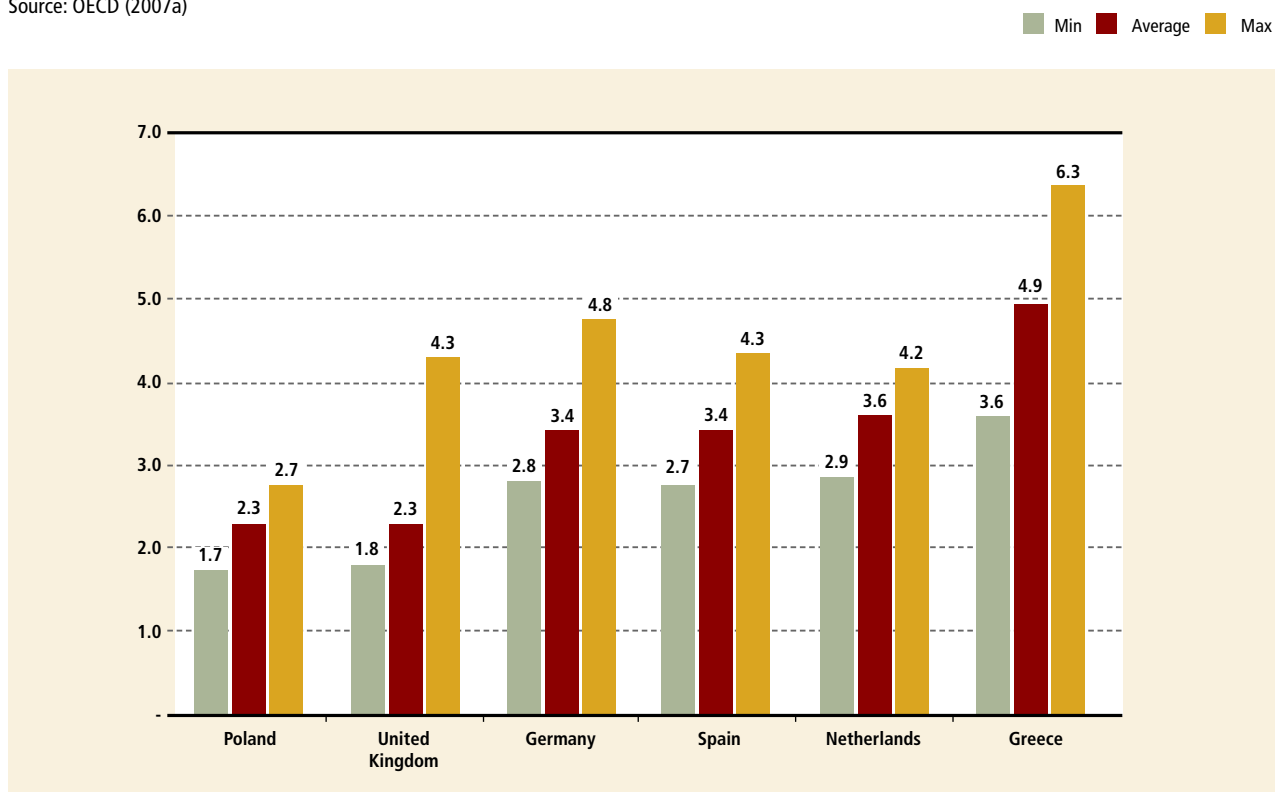
The OECD report, *Regions at a Glance* (OECD, 2007a), presents a series of indicators comparing the allocation of healthcare resources across different regions within selected countries, enabling the characterisation of intra-regional disparities. Regional variations differ across countries. As the OECD (2007a) report notes, in the regions with the highest density, the allocated resources may be almost twice the national average. Generally, the regions with the lowest density do not have above half of the national average of available resources. Consequently, regional disparities within countries are greater than disparities among countries.

Figure 3.1 and Figure 3.2 provide a snapshot of two indicators provided by this new OECD data set. Not surprisingly, disparities are smaller in small and more densely populated countries, like the **Netherlands**. Moreover, this data set suggests that there are marked differences (not shown in the figures) between urban and located rural areas, for example in **Greece**. **Germany** shows substantial discrepancies in the regional distribution of physicians, which are clearly concentrated in the western part of the country.

The data also suggest a direct relationship between the average number of physicians and the variation across regions. Whilst **Poland** has the lowest overall physician density (see Figure 3.1) and the lowest level of variation

**Figure 3.1: Regional variations in practising physicians per 1,000 population (2004)**

Source: OECD (2007a)



across regions, **Greece** has the highest density of practising physicians and the highest variation across regions. The **UK** is an exception, with low overall physician density and high variation across regions.

In **Germany**, the density of hospital beds is slightly higher in the eastern than in the western part of the country. In addition, the current level of investment per acute bed is substantially higher in the eastern part than in the western part (except for Brandenburg, the scarcely populated state surrounding the city state of Berlin) (Busse, Riesberg, 2004; Wörz et al., 2005). This pro-east inequality in hospital care reflects the agreement in the state treatise following the 1990 reunification of Germany. The agreement sought to reduce geographic inequities in acute hospital infrastructure and set up federal grants to be used as investment for the modernisation of hospitals (Busse, Riesberg, 2004).

There is also some evidence suggesting that regional variation in the prescription of outpatient antibiotics in **Germany** is substantial. According to Kern et al. (2006), the use of antibiotics is relatively higher in the western part of the country.

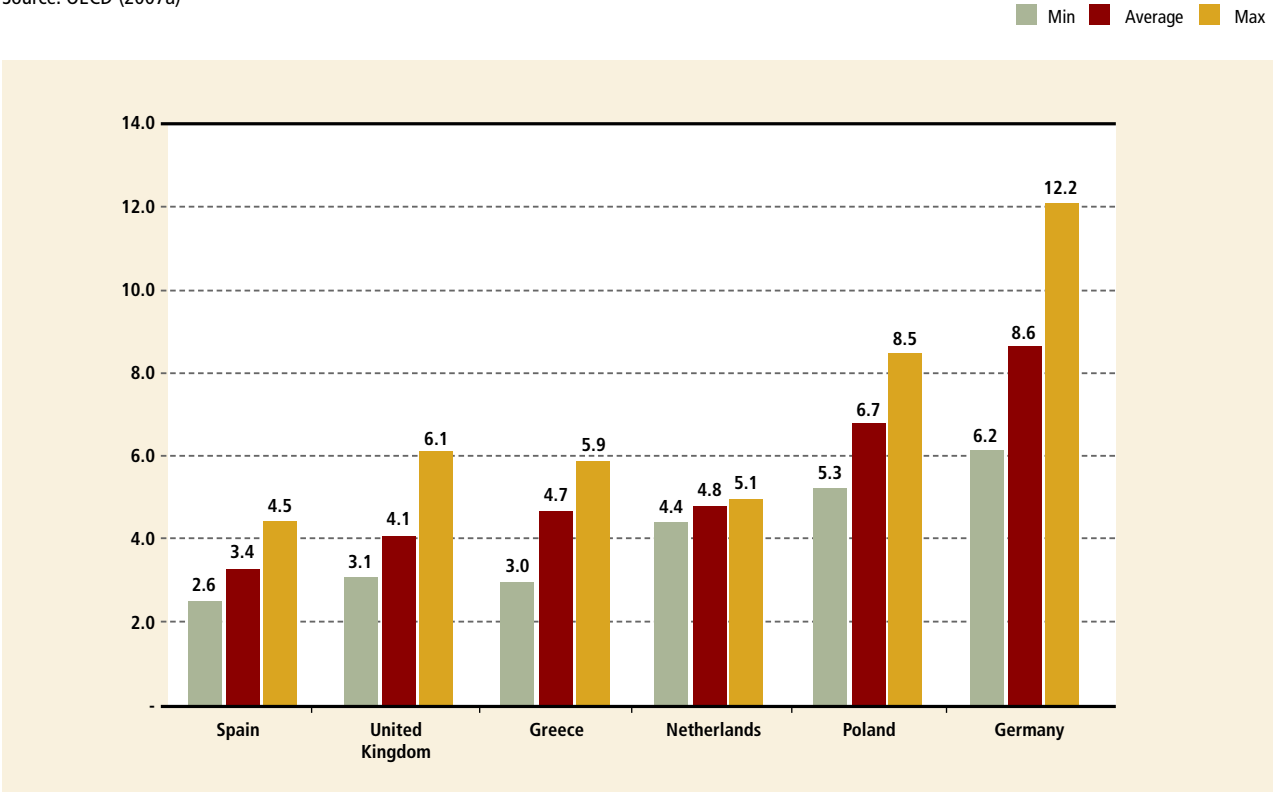
In analysing these or similar data, it is important to bear in mind that the issue of geographical access is complex. The quality of care provided in centralised services may be higher than if they were more evenly dispersed, as illustrated by empirical evidence on the volume-quality link for some specialties in the **UK**.

Thus, improving access to central services may be a more sensible policy response than providing localised services in some contexts.

There is some evidence that the distribution of healthcare resources is linked to the socio-economic profile of the regions (OECD, 2007a). With respect to the physician density, Nocera and Wanzenfried (2002) review some of the main factors that affect the location of a physician's practice. The most important single factor is the population in the region, which gives a direct measure of the market size and income potential for the physician. This also helps explain why the density of physicians is normally higher in urban areas. The second important factor is the professional climate in the region, namely, the possibility of interactions with colleagues, access to hospitals and other medical facilities. Finally, the extent of social amenities can also influence the physician density in a region. In this sense, the current infrastructure of health and educational services, such as the existence of postgraduate facilities, is another factor that frequently motivates physicians' location decisions. All these factors are likely to be positively associated with the level of economic development in the regions. For example, physicians in **Germany** are less likely to be located in the more economically deprived eastern part. The resulting inequities have the potential to limit access to healthcare for people at risk of social exclusion, especially for people with functional limitations and those dependent on public transportation.

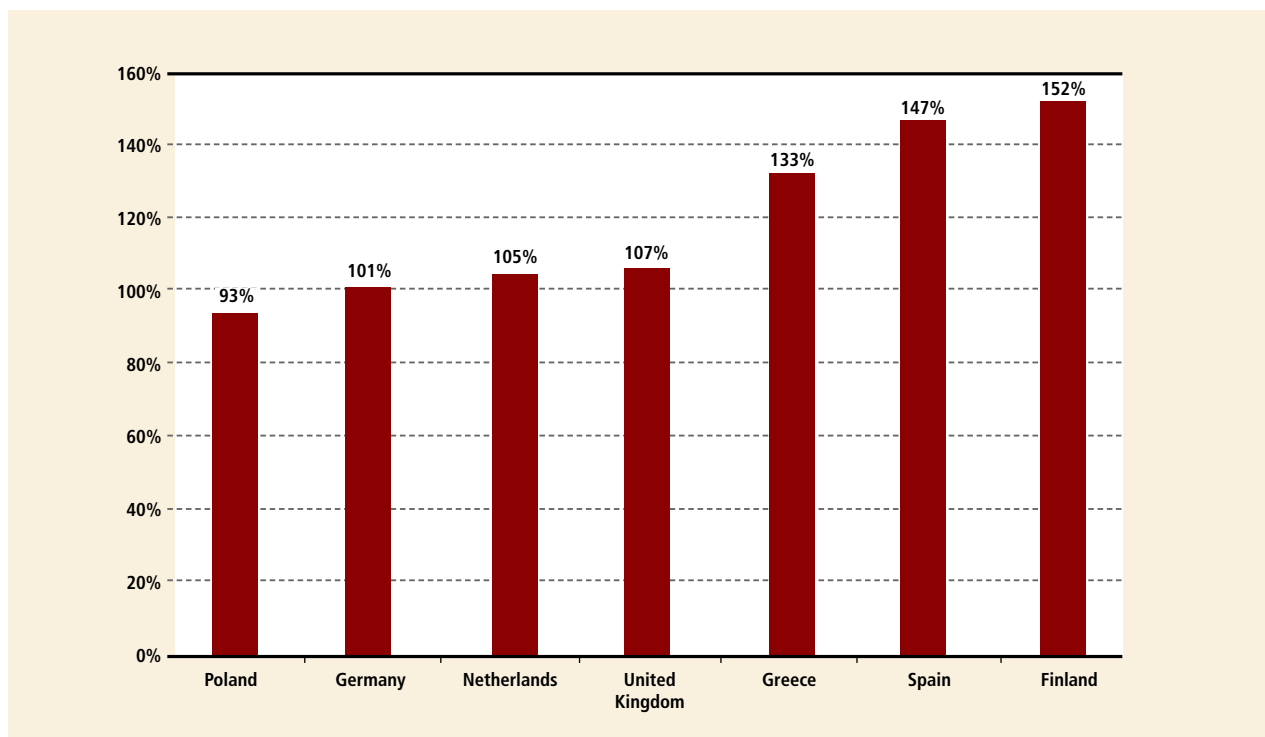
**Figure 3.2: Regional variations in hospital beds per 1,000 population (2004)**

Source: OECD (2007a)



**Figure 3.3: Dependency ratio in rural areas relative to urban areas, 2003**

Source: OECD (2007a)



### 3.2.3 The growing divide between rural and urban areas

In many countries there is evidence of concentration of services in urban areas, which raises the question of how to ensure accessibility for rural populations, in particular for people living far from more densely populated areas. Rural-urban inequalities in access to healthcare are an important issue in some countries, particularly given that rural areas often experience a more fragile economic and demographic situation, with more people at risk of poverty and social exclusion.

For instance, in **Finland** private health services are mainly found in larger cities, meaning that rural areas rely mostly on public health centres. Health centres and public hospitals in rural and sparsely populated areas do not attract enough physicians and other skilled staff. Research in Finland has shown that the lack of private health services and adequate staff in public health services in remote areas affects the health services provided, creating geographical inequity in access to healthcare and regional differences in the use of hospital services (Arimen et al., 1998).

Similarly, in **Germany** there is evidence of urban concentration of physicians and specialised tertiary inpatient care. A recent review of the evidence (Rambøll Management, 2005) concludes that there is an undersupply in certain regions, which will become more undersupplied without any counteracting measures. Most of these undersupplied regions are located in rural areas of the eastern part of Germany.

#### BOX 3.1: RURAL-URBAN DIFFERENCES IN GREECE

In **Greece** there are marked disparities between rural and urban areas (specifically Athens and Thessalonica) in the distribution of doctors, with heavy over-concentration in the two main urban centres.

A deficiency in the overall numbers of nursing personnel in particular means that many public health units and services are under-functioning due to a lack of staff appointments. Furthermore, the emergency departments of all state hospitals are available for use by anyone in need, regardless of age, nationality or health insurance coverage and in the major urban centres hospitals operate an emergency rota system for different categories of disease.

Source: Greece country report

Obviously, the simple fact that there is a greater concentration of older people in rural areas can contribute to an increase in the need for healthcare, especially among those with functional limitations. However, rural areas have also been shown to have more difficulties in attracting and retaining physicians and other health personnel. Box 3.1 further describes the situation in **Greece**.

In addition, it has been observed that health beliefs of rural peoples can delay early consultation/contact with health services and late appearance. For instance, one

study covering patients applying for sickness benefits in **Poland** revealed that some groups of patients, mainly those living in villages, approach a doctor in late and advanced phases of their diseases. This can reduce treatment effectiveness and may lead to more patients than necessary being granted a status of disabled person (Golinowska, 2004). There is also evidence that people in rural areas make lower use of healthcare services, especially dental services (Tymowska, 2003; 2005).

### 3.2.4 Policies to reduce geographical variations in access to services

Reducing differences in access to healthcare across geographical regions has been identified as an important objective in several countries. All countries, without exception, considered in their NAPs the question of how to tackle regional differences in the type of care provided/covered, waiting times and the uneven distribution of healthcare facilities and professional staff. Country reports also provide several examples of innovative solutions.

#### 3.2.4.1 Improving coordination across regions

As noted above, the process of decentralisation can in some cases challenge the cohesion across country regions in terms of access to healthcare. Therefore it is important to make sure that vulnerable groups are not

left behind. **Finland** provides some examples of innovative nationwide policies to reduce regional differences. These include the promotion of financial mergers in order to extend the municipal population base (see Box 3.2), incentives for cooperation between municipalities and the establishment of national guidelines for access to care.

According to the recent **Spanish** NAP, the process of decentralisation is widely regarded to have promoted more adaptability to local needs, but to have also resulted in regional differences in provision of services. Geographical variations in access have been an important political question in Spain, centred on providing equity in term of access for all citizens, irrespective of the country region in which they reside. Data from the 2006 Health Barometer suggest that the majority of citizens believe that the Spanish healthcare system is equitable with respect to age, income and nationality. However, 46.1% of the interviewees felt that geographical residence (urban or rural) affects access to healthcare.

Several initiatives have been recently implemented to counteract this, and to reduce inequalities and improve coordination among Autonomous Communities in Spain. The Spanish NHS has established countrywide portfolios of common standardised services and created a social cohesion fund, which has been used to compensate some regions. This cohesion fund aims to improve coordination and promote equal access to technology across Autonomous Communities. Under this

### BOX 3.2: POLICY EXAMPLE: RESTRUCTURING MUNICIPALITIES TO GUARANTEE SUSTAINABILITY

**Finland** has recently introduced reforms to restructure municipalities and their services by mergers and mutual cooperation. The driving force behind the recent recentralisation trend has been the financial difficulties faced by municipalities trying to provide high-quality health and social care to their residents. Especially, small municipalities in rural areas suffering from depopulation are facing major financial constraints due to decreased tax income. In order to support depopulated and poor municipalities, there has been an increase in the central government transfers to the municipalities during recent years. In spite of this, it has been perceived that municipalities in some cases have provided sub-standard services, leading to a plea for more centralised steering of healthcare to ensure provision of high-quality care all over the country. The enactment of maximum waiting times and the extension of the supervising functions of the National Authority for Medico-Legal Affairs should be interpreted as government efforts to reduce geographical inequalities and to ensure that all municipalities provide high-quality health

services. Also, the purpose of restructuring municipalities is to create a firm structural and financial basis so that the organisation and provision of services is secured in the future. The project concerns not only healthcare, but also all services organised by the municipalities, and is expected to restructure both municipalities and services. In 2007, the Act on Restructuring Municipalities was introduced to support financial mergers of municipalities. The Act states that primary healthcare and social services closely related to health services should have a catchment area of at least 20,000 inhabitants. Currently only about one in four health centres has a population base of 20,000 or more. The legislation does not necessarily imply mergers of small municipalities, because they can create the necessary health centre catchment area by, for example, forming municipal joint federations. Municipalities must present a plan in 2007 on how these goals will be achieved. Additionally, according to the Act, funding of forensic examinations and examinations related to sexual abuse of children will be transferred from the municipalities to the state no later than 2009.

Source: Finland country report

arrangement patients are transferred to the health centres outside their own regions that are better equipped to provide the necessary services, thus guaranteeing equal access to technology (González et al., 2004).

Box 3.3 describes some of the elements behind the tendencies for decentralisation and recentralisation in healthcare that are currently in place in several European countries.

### BOX 3.3: POLICY TRENDS: DECENTRALISATION AND RECENTRALISATION IN HEALTHCARE

The recent experience in **Finland** and, to a large extent, the experience in **Spain** can be placed at two opposite poles in the balance between decentralisation (Spain) and recentralisation (Finland). Recent analyses have identified a tendency of a “small but growing number of countries that appear to be retreating from key tenets of decentralisation and are, instead, re-centralising important health system functions” (Saltman et al., 2007, p. 3). This trend is found in particular among Nordic countries, such as Finland, that “had placed decentralisation at the core of their health sector strategies and now are reworking key elements of that prior strategy.”

The reasons behind these changes are very complex. They can involve elements related to: administrative and economic efficiency, responsiveness to local needs, empowerment of local governments, accountability, cross-regional equity and demands for an increase in quality of healthcare services and the introduction of new technologies. The implications of this debate for access to healthcare are very important and particularly consequential for groups at risk of social exclusion.

Source: Saltman et al. (2007)

### BOX 3.4: POLICY EXAMPLE: HIGH RESOLUTION SPECIALIST CENTRES IN SPAIN

In **Spain**, some Autonomous Communities have created High Resolution Specialist Centres to improve the access to diagnosis and treatment of the population living in remote areas. These centres are oriented to achieve a maximum diagnosis resolution in a minimum time period for patients in remote areas. Diagnosis, emergency units, rehabilitation and, in some cases, primary care are also provided. The objective is to guarantee that citizens have access to an integrated and high-resolution healthcare service in less than 30 minutes. This model attempts to solve the problem of waiting lists, improve access for people who live far away from large cities, reduce the ever-increasing costs of hospitalisation and address.

Source: Saltman et al. (2007)

#### 3.2.4.2 Extending coverage and reaching out to rural populations

Difficulties in placing doctors in rural areas have been mentioned as an important issue for many countries. In **Germany**, recent changes in the law governing contracts between physicians and statutory health insurers have tried to accommodate this, promoting better distribution of physicians and avoiding medical bottlenecks, especially in the new *Länder* and rural areas. This reform, under the scope of the National Reform Programme 2005–2006, included the following elements: the extension of the range of local and regional professional service centres entitled to provide services, the provision of greater compatibility between family and employment through more favourable employment opportunities for physicians in outpatient services and elimination of age limits for physicians in planning areas with insufficient numbers of professionals (National Reform Programme Germany 2005–2008, Implementation and Progress Report 2006, §35 and Table 7).

In **Romania**, an attempt to address this problem through increasing the overall numbers of medical staff has not been successful, with the new population of doctors remaining largely in the urban areas.

Likewise this remains an important issue in **Greece** due to the geographical peculiarity of the numerous islands. There is a recent trend among municipalities to extend their social and healthcare provision in the country through the creation of a local authorities' network. This network aims to prevent social exclusion by facilitating access to healthcare for the population in need. It is believed that such a network of services developed at the local level will improve access to care for people living in less densely populated areas such as on the Greek islands or in villages on the mainland.

Also in **Finland** actions have been undertaken to improve access for the population in rural areas that are currently underserved (see Box 3.2). These are supposed to respond to the significant regional differences in the provision of services and in the availability of resources, including physicians and other skilled staff.

#### 3.2.4.3 Policies to improve access by providing better transport

Several countries have implemented mechanisms to guarantee access for people dependent on public transport. This can include the reimbursement of taxi expenses in areas with no public transport (e.g. **Finland**) and the provision of transportation to community health centres (e.g. **Greece**). In **Finland** there is a policy of reimbursement of treatment-

related transport expenses and an annual excess limit beyond which the NHI covers all transport expenses (see Box 3.5).

The **UK** NHS has a patient transport system and a hospital travel costs scheme available to help the poorest people access services. However, some commentators have noted that these services are badly publicised and both professionals and patients are unsure about eligibility criteria (Office of the Deputy Prime Minister, 2003).

In **Germany**, however, there is no access guarantee for people who are dependent on public transport. Access to public transport has rather deteriorated for people who are dependent upon welfare benefits, since with the introduction of unemployment benefit type II these benefits are paid out as lump sums and the calculated lump sum for transport is rather too small (this is particularly the case for children). Therefore regular access to public transport is not guaranteed.

### BOX 3.5: POLICY EXAMPLE: REIMBURSEMENT OF TRAVEL EXPENSES IN FINLAND

In **Finland**, to enable visits to healthcare facilities, the NHI reimburses expenses for transport in connection with treatment and examination of a disease or accident if expenses exceed ?9.25. There is also an annual ceiling: if the cost of transport paid by patients due to disease or accident exceeds ?157.25 per year (2007), the NHI reimburses all transport costs in excess of this limit. If public transport is not available or cannot be used, the NHI will reimburse the use of a taxi.

Source: Finland country report

#### 3.2.4.4 Using ICT to reduce access barriers

Information and communication technologies (ICT) are becoming progressively more important in helping Member States to improve standards of healthcare provision across the EU (see European Commission, 2004). In some cases, the introduction of ICT innovations can also contribute to reduce geographic barriers to access.

One example relates to the use of teleradiology. This technology enables radiology departments in hospitals to connect to radiology specialists in other geographical areas, who can then analyse remotely the results of imaging diagnostic exams such as magnetic resonance imaging (MRI) and computed tomographies (CT). Stroetmann et al. (2006) describe the establishment of a similar arrangement between hospitals in **Sweden** and telecentres in **Spain**. Doctors and nurses carry out the MRI and TC scans on patients in two hospitals in Sweden. With the assistance of teleradiology technology, the resulting images are then reviewed and analysed by the

radiologists in Spain, who provide diagnostic services. As emphasised by Stroetmann et al. (2006), the benefits from such an arrangement are multifold. In their review of the experience of the Sollefteå and Borås hospitals in Sweden and the TMC telemedicine clinic in Barcelona, Spain, Stroetmann et al., (2006) document significant improvements in terms of cost reduction and greater flexibility for the hospitals. The costs of setting up the infrastructure that enables the operation of the teleradiology system are far outstripped by the economic benefits, with an estimated productivity gain of a 34% decrease in cost per scan. Patients also greatly benefit from the scheme and enjoy up to 50% reduction in waiting times for exam image review and diagnosis.

Stroetmann et al. (2006) review several other examples of successful and cost-effective applications of ICT to improve the provision of healthcare services. In **Germany**, for instance, the St. Franziskus Hospital Münster has put in place a system of supply chain optimisation, which integrates and provides logistic services for several hospitals in a 300 km radius. This system promotes greater standardisation of supplies for several hospitals, allowing the possibility of bulk purchasing, and also improves rationalisation in stocking medical supplies. This has significantly improved economic efficiency via lower drugs prices for hospitals, decreased waste of materials and better management of the stock of supplies.

### 3.3 Organisational barriers

This section deals with organisational issues within provider organisations that constitute potential or actual barriers to access. In general, rules and conditions of access to healthcare under public programmes are to a large extent established by contractual arrangements between payers and the providers of healthcare, according to the country legal system. In addition, however, patients can normally expect to also face a set of practical organisational limitations, which can create barriers to accessing healthcare.

Beech (2003) characterises some of the main difficulties that patients can face in gaining access to healthcare services. Although Beech (2003) focuses on the **UK** NHS, these barriers can also be found in other systems in other countries. They relate basically to the main types of healthcare services and can be summarised as:

- 'Waits' and delays in accessing services for primary care;
- 'Waits' for acute elective appointments and investigations;
- Problems in obtaining acute emergency treatment; and
- Delays surrounding the subsequent delivery of that care (Beech, 2003, p. 99).

A common characteristic of organisational barriers is that they are often shown to limit demand and restrict healthcare expenditures. The effect of waiting times on the demand for elective procedures is the most common example in this case.

Other examples of organisational barriers include lack of services that allow pre-registration, excessive waiting in waiting rooms and inadequate opening hours.

Clearly some of these issues are more likely to affect vulnerable groups. For instance, it is much more demanding for an elderly person with functional limitations if he/she is forced to visit a provider more than once due to the lack of registration services or an inappropriate booking system. There is also evidence that the organisation of services can influence patient interaction with the system and affect rates of utilisation. This can be particularly difficult for patients with lower ability to navigate complex systems, as is frequently the case for some of the vulnerable groups analysed in this study.

This section is organised as follows. First, some of the main organisational barriers that have been reported by the country studies are described. Policies to improve access to primary care are presented. Second, the problems with waiting times are analysed and some of the main policies that have contributed to reduce waiting times are discussed.

### 3.3.1 Organisational barriers limiting access to healthcare

The HealthQUEST country studies provide some evidence that suggests that the arrangements that suppliers put in place to organise the provision of healthcare can influence the access and use of services, particularly for more vulnerable groups. Nevertheless, we also find that research interest on organisational barriers is still very limited in many countries.

Part of the explanation for this is that in some countries, there is a general perception that organisational barriers are not a very important factor in determining access to healthcare. In some places, there is a widespread perception that issues like co-payments and user fees in public health are more important than other organisational barriers in explaining access to healthcare.

For many years, public health providers in **Poland** have operated a system that requires patients to appear in the morning to get a 'number', which then allows the patient to have a physician visit on that day. Patients, often elderly and sick, used to come early in the morning to register for a visit during the day. In some cases, lines of people form as early as 5 or 6 a.m. to get to a doctor at 8 or 9 a.m., or later. If

there are too many patients, some of them are refused registration and forced to come on another day. Other countries have solved similar problems with the implementation of telephone registration. In Poland, however, the problem persists. Possible causes include large lists of patients for each physician (the official limit is 3,000 patients per GP), short working hours and financial constraints.

Figure 3.4 below lists the main reasons that were mentioned as causing difficulties in accessing primary care in a survey by Centre for Health Information Systems in **Poland**. The requirement for early appearance and the lack of booking services constitute important barriers in Poland. Many patients also mentioned "long waiting in waiting rooms" as an important problem (Borkowska-Kalwas et al., 2004). Patients in Poland also find difficulties in accessing specialist care and diagnostic tests in an ambulatory setting (see Box 3.6). However, if the patient is not able or willing to pay for such services, and the care is necessary or at least justifiable, he/she is referred to hospital and care is provided there. An important consequence has been the rapid increase of hospital admissions.

Evidence from the **UK** suggests that, perversely, the increase in organisational forms aimed at improving overall access including NHS Direct and NHS Walk-In Centres may increase the problems of matching perceived health needs to the appropriate health service. Different professionals are often involved in each sector with their own expectations of what is an 'appropriate' use of the service and this may make it difficult for people in disadvantaged groups to know how to negotiate their pathway through them. Thus services that require a lot of 'work' on the part of the patient to access them are less 'permeable' than others and this might explain the higher use of A&E services amongst disadvantaged groups compared with other groups, as this is a permeable service that is relatively straightforward to access (Dixon-Woods et al., 2005).

#### BOX 3.6: ACCESS TO DIAGNOSTIC TESTS IN POLAND

Family physicians in **Poland** are paid by capitation, getting a certain amount of money per patient per year, which also includes amounts for diagnostic testing. There is a list of diagnostic tests which family physicians are required to perform under the capitation budget.

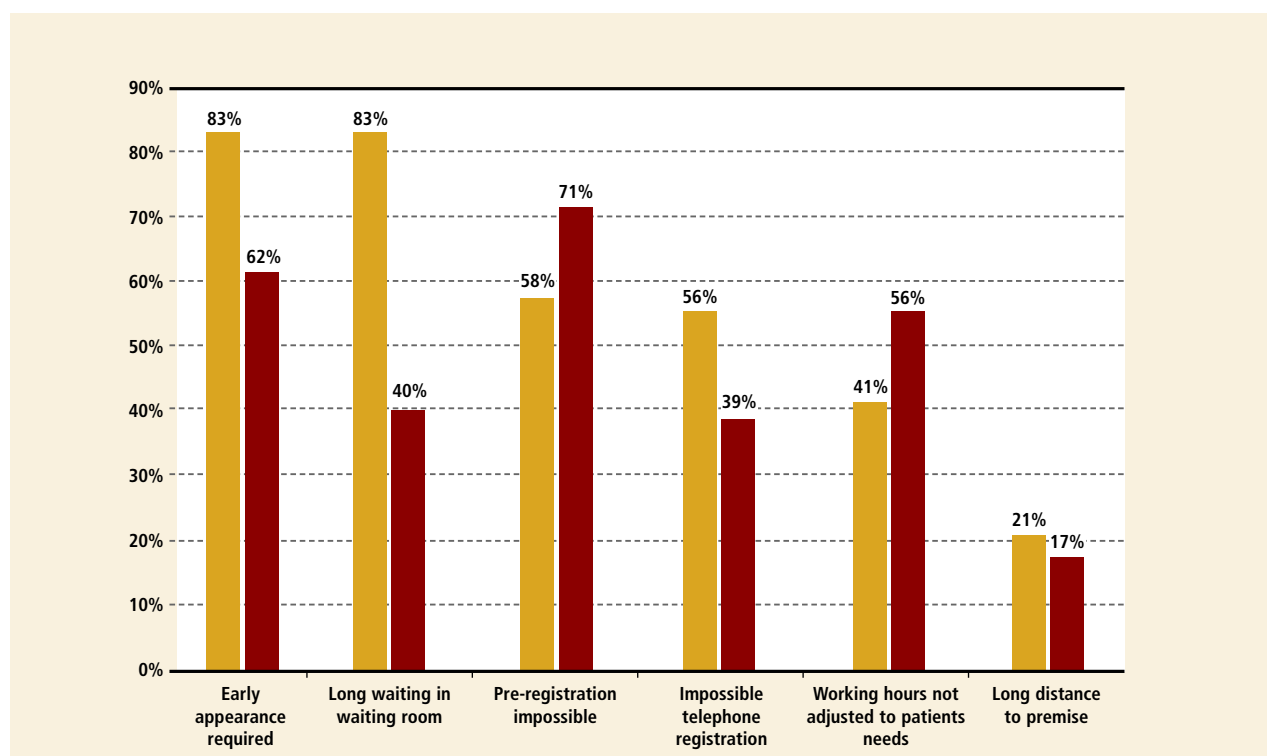
It is thought that this has induced physicians to make excess referrals, particularly into the hospital system. Another practice consists of requesting that the patient pays for the test.

Source: Poland country report

**Figure 3.4: Main reasons for difficulties in accessing primary care in Poland**

Source: CSIOZ, (2004)

■ 1998 ■ 2003



The variety of new forms of service, each using their own terminology and each with a different definition of 'appropriate' access, that may not be easily distinguishable to some groups, may make the services less permeable than initially hoped.

### **3.3.2 Policies to improve access to primary care: out-of-hours services and reduction of waiting times**

Delays in receiving primary care and long waiting times for elective surgeries are some of the main consequences of poor organisational practices. Although this issue is still largely neglected in many countries, there are some examples of policies that have contributed to improve provider organisation.

**Greece** is considering the introduction of 24-hour walk-in centres and has recently initiated the opening of hospitals' outpatients units in the afternoon with co-payments for patients. This has facilitated access to providers and minimised time constraints. However, co-payments create concerns about the impact in terms of inequality.

NHS Walk-In Centres and NHS Direct, a nurse-led 24-hour telephone advice and consultation service, have been implemented in the UK to enhance overall access and the provision of out-of-hours services. In principle,

NHS Direct can improve access to help for groups of the population who have difficulty accessing primary care. Evaluations of the impact of NHS Direct have tended to focus on the volume and nature of enquiries and whether it has been a substitute for or complement to other types of care, rather than on the impact on access or equity of access. Munro et al. (2000) found no obvious impact of this service on demand for A&E services, out-of-hours or ambulance services combined.

However, there appeared to be an effect on halting the increase in use of GP cooperatives. Older people appear to be less likely to use NHS Direct than younger people (George, 2002; Cooper et al., 2005), which may be related to the preference of older people to see their GP (Ullah et al., 2003).

An analysis of awareness of the service amongst patients arriving at A&E who had not contacted NHS Direct suggested older patients, those from ethnic minorities and those from less affluent postcode areas were less aware of the existence of NHS Direct, suggesting that target populations have not been reached by publicity (McInerney et al., 2000).

A postal survey asking about use of and awareness of NHS Direct found that use was significantly lower amongst poorer socio-economic groups and those with communication difficulties (hearing and language problems) (Knowles et al., 2006). Ecological studies that analyse call rates suggest that calls about adults

were generally higher in more deprived areas (Burt et al., 2003; Cooper et al., 2005), but this may not be evenly distributed by age as calls about children appear to be lower in the most severely deprived areas (Cooper et al., 2005).

### 3.3.3 Persistent problems with waiting lists

The specific barriers to access caused by waiting lists for elective surgery and other specialist care continue to be a major political problem in a number of Member States. Using data on patients above 65 years from the SHARE survey (see <http://www.share-project.org>), Mojon-Azzi and Mojon (2007) have estimated the percentage of patients waiting longer than three months for cataract surgery in 10 European countries. The results suggest that this amounts to 17.9% in Germany and in the Netherlands, 31.8% in Greece and 56.3% in Spain.

This is first and foremost seen as a problem of deficits in 'responsiveness' of healthcare services, but has also recently been addressed under the aspect of basic social rights. A number of NAPs express concern with the issue of waiting times for medical treatment under the public system, especially for elective surgeries. In some cases, such as **Spain** and **Poland**, this is described in NAPs to be partially associated to a relatively low supply of hospital beds and general practitioners in comparison with the EU standards. **Poland** also reports problems of extensive waiting times, in spite of current improvement in the monitoring and management system. The **Netherlands** and the **UK** report improvements from reforms, which had a positive impact in reducing waiting times. In the **UK**, this has included increases in investment and expenditures, and the use of financial incentives for providers in some places. However, problems still persist for some procedures and some geographical areas in particular.

A more detailed analysis was possible based on the country studies under this project. In some countries there are suggestions that waiting times increase health-related problems that enhance the risk for social exclusion. For instance, studies in the **UK** suggest that people of lower socio-economic status and old age receive lower priority and wait longer for treatment. Other research from the **UK** found that after adjusting for age, sex and type of operation, socio-economically deprived people were less likely to have their operation for coronary heart disease classified as urgent when compared with those from higher socio-economic groups (Pell et al., 2000). They were reported to wait on average an extra three weeks for surgery as a result of this. Hacker and Stanistreet analysed by multivariate regression the waiting times between placement on the waiting list and receipt of surgery in two specialties (Hacker and

Stanistreet, 2004). In ophthalmology, women, those aged over 70 and those from a deprived area were found to wait significantly longer for surgery than their comparison groups. Age had the biggest effect. In orthopaedics, similar trends were noted but did not reach statistical significance.

There is also evidence to believe that waiting lists contribute to aggravating the risks of older people with functional limitations. In the **Netherlands**, the majority of people waiting longer than the norm without any obvious explanation (this accounts for 20% of all people waiting) are waiting for procedures such as hip replacement, knee replacement and cataract surgery, all of which tend to affect older groups (Singeling, 2004).

A large body of literature suggests that those from vulnerable groups, including older, socio-economically disadvantaged and people from ethnic minorities may be viewed as 'less good' candidates than those from more advantaged groups (Goddard et al., 2001; Dixon-Woods et al., 2005). This is related to the process by which people get onto the waiting list in the first place which, in turn, is heavily influenced by the social construction of the professionals' views on suitability of people for treatment.

In **Greece**, there is also evidence that socially disadvantaged people may be more exposed to the burden of high waiting times. In Greece there is no referral system, therefore patients are free to choose hospital care in the public sector. As a result, there are long waiting lists for specific hospitals and interventions, especially in the urban areas, while in other areas there are no people waiting. However, long waiting lists can be bypassed by informal payments, placing at a disadvantage the vulnerable populations that do not have the ability to pay.

At the moment, most countries only monitor information with respect to waiting times for elective surgery. In recent years, the **UK** government has been raising the awareness on the issue of waiting times for diagnostic services, especially in the case of patients waiting for cancer diagnosis, which can be a particularly stressful situation for patients and their families. With the objective of offering "patients a maximum one month wait from an urgent referral for suspected cancer to the beginning of treatment" the NHS Cancer Plan supported, among other actions, the reduction of waiting times for diagnosis of cancer (Department of Health, 2000). Progress has been monitored through the collection of information on waiting times for patients with suspected cancer and those subsequently diagnosed with cancer at NHS Trusts in England. The NHS publishes quarterly information by cancer site (e.g. breast cancer, lung cancer, gastrointestinal cancer, etc.) for a large number of NHS Trusts. This information is available via the NHS

Performance Data website<sup>4</sup>, which also provides monthly and biannual data on a number of waiting times indicators for several diagnostics services in audiology, cardiology, endoscopy, physiology, imaging, ophthalmic services, pathology and urodynamics. For most other countries, however, information on waiting times for specific diagnostic services is relatively scarcer.

### 3.3.4 Policies to improve access by reducing waiting times

One of the most active areas in terms of health policy interventions targeted on improving access to healthcare has been the introduction of regulations in relation to **waiting times for elective treatment**. In recent years several initiatives have been introduced to address the issue of waiting times. And there are a number of examples for successful interventions in this area in several countries.

In **Finland**, regulations were introduced to set maximum waiting times for primary care and non-acute specialist care. Finland had an era of long waiting lists, during which it was common for high-income households to go private. Since March 2005 this situation has improved with the introduction of maximum waiting times designed to tackle regional inequalities, which have shortened waiting times considerably. Limits for waiting times for mental health treatment for children/young people is stricter than for other groups. It can be argued that the successful reduction of waiting times has increased equity in access to elective healthcare. This policy is considered to have increased equity in access to and quality of healthcare, and to have partially addressed the considerable differences in waiting times between municipalities. An important component of this policy included giving every resident the right of access to primary care within a defined time limit and access to secondary specialist care based on needs assessment. This has been successful in reducing inequity in access to physical healthcare, but does not seem to have improved access to psychiatric care.

Other countries that have implemented successful waiting times interventions include **Greece**. The introduction of one-day clinics reduced waiting times for cancer-related surgeries, although there are some concerns about the likely effects in terms of inequality since these clinics charge out-of-pocket expenditures (see Box 3.7).

In the **Netherlands**, waiting times for hospital admission fell 17% in the period 2002–2004 following agreement between providers and insurers on ‘acceptable waiting times’, within which 80% of patients should be seen (see Box 3.8).

<sup>4</sup> <http://www.performance.doh.gov.uk>

#### BOX 3.7: POLICY EXAMPLE: REDUCING WAITING TIMES FOR CANCER PATIENTS IN GREECE WITH THE INTRODUCTION OF ONE-DAY CLINICS

Cancer patients face serious access problems in **Greece** due to elevated waiting times. Severe problems with waiting lists for oncology services have been registered, especially in the metropolitan areas since such services are only provided in the urban areas. There are only three specialised oncology hospitals providing oncology services for the whole country. Waiting lists for the first appointment for outpatient care in these cancer centres, including the choice of doctor, are at about six to eight months. Young cancer patients are given priority for hospitalisation. In the case of non-malignant surgical cases, waiting times are longer than three months, depending on the choice of hospital and medical department.

One-day-clinics were introduced in these hospitals in 2006. This has helped to significantly reduce waiting lists for surgical and medical cases with no choice of doctor by up to two to three weeks.

Source: Greece country report

#### BOX 3.8: POLICY EXAMPLE: BUILDING STAKEHOLDER COMMITMENT TO MEET WAITING TIME TARGET IN THE NETHERLANDS

In 2000, representatives of healthcare professionals, health insurers, health service providers, and government in the **Netherlands** reached an agreement on what should be considered ‘acceptable waiting times’ for elective treatment and care (Busch, 2005). In doing so, they also agreed to make a distinction between overall waiting norms, and an acceptable limit within which 80% of patients should be seen. The agreement on these norms still holds and they are set as follows:

##### Acute care/hospital services

First appointment	4 weeks
Assessment and diagnosis	4 weeks
Outpatient treatment	6 weeks
Inpatient admission and treatment	7 weeks

##### Nursing/long-term care

Nursing care	6 weeks
Home help	13 weeks
Home care	6 weeks

##### Mental health services

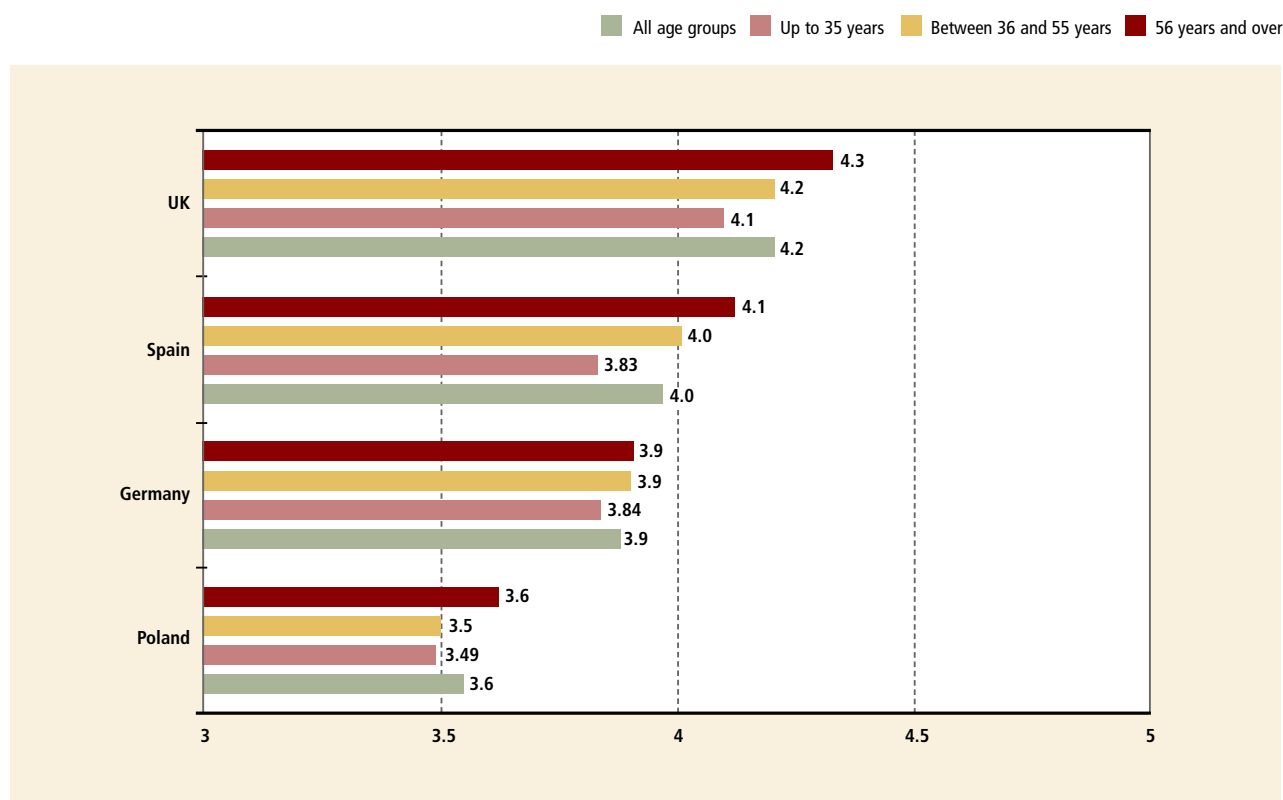
Registration	4 weeks
Assessment	4 weeks
Outpatient treatment	6 weeks
Sheltered living	6 weeks
Inpatient treatment	7 weeks

Between 2002 and 2004, the number of people waiting for clinical hospital admission fell by nearly 17%.

Source: Netherlands country report

**Figure 3.5: Quality of doctor-patient communication (2002)**

Source: Coulter and Jenkinson (2005)<sup>5</sup>



In **Spain**, packages aimed at reducing waiting lists have been successfully introduced. These included extra funding, maximum targets, use of private sector and financial incentives related to average reductions in waiting times. According to Hurst and Siciliani (2003), between 1996 and 2000 the volume of surgery in the public system in Spain increased by an annual growth rate of 6.5%. Average waiting times for patients on the list fell from 210 days in 1996 to 67 days in 2000.

In the **UK**, waiting times have been reduced significantly since 2002 and evidence comparing England and Wales (which did not consistently have targets) suggests that targets with financial penalties attached have helped achieve reductions in waiting times (Hauck and Street, 2007). There are other recommendations for maximum waiting times for certain types of care, for example, the National Cancer Plan contains a number of different waiting times for aspects of cancer care, e.g. maximum one month wait from an urgent referral for suspected cancer to the start of treatment.

### 3.4 Supply-side responsiveness

Inequitable disparities in healthcare utilisation can exist even where health services are accessible because patients' expectations and other non-health-related aspects also affect access and utilisation of services.

Culturally determined health beliefs can influence help-seeking behaviour and, more indirectly, the outcome of healthcare interventions.

The WHO defines health system responsiveness as all "aspects related to the way individuals are treated and the environment in which they are treated" (Valentine et al., 2003). This definition emphasises that non-health factors have the potential to influence the environment where the treatment takes place and can consequently affect its outcomes. More specifically, Bramesfeld et al. (2007, p. 881) argue that responsiveness "has the potential to reduce the threshold for seeking medical help and thus increase the likelihood of early intervention and improved compliance". The WHO definition also emphasises that "responsiveness is related more to some of the interpersonal dimensions of quality of care rather than to technical quality".

In terms of groups at risk of social exclusion that form the focus of this report, some of the most pressing responsiveness issues relate to the level of gender-responsiveness put in place by healthcare providers, and particularly to the extent to which cultural and ethnic considerations are taken into account in the

<sup>5</sup> Respondents were asked: **Overall how would you rate how well healthcare providers communicated with you?** Range from (1) very bad to (5) very good.

provision of services. The remainder of this subchapter evaluates whether there is any evidence to demonstrate that gender, cultural factors or ethnic background prevent people from accessing healthcare. It also presents some examples of policies implemented in countries to improve provider responsiveness to these issues.

### **3.4.1 Evidence on the influence of supply-side responsiveness**

One of the main aspects of supply-side responsiveness refers to the interaction between doctors and patients and more specifically to the quality of communication that doctors manage to provide. Coulter and Jenkinson (2005) present the results of a survey on health system responsiveness carried out in 2002 in several European countries. Respondents who had consulted a doctor in the previous year were asked to evaluate different aspects of the communication within the consultation. The patients assessed specifically the doctor's listening skills, whether the doctor gave time for questions, the quality of the doctor's explanations and the overall quality of the communication. Figure 3.5 presents the mean scores in overall rating of communication given by respondents in Germany, Poland, Spain and the UK.

The authors emphasise that several factors may influence the patient perception of the quality of communication, including the overall level of patient involvement and expectations about what constitutes good communication. Therefore, it is difficult to make cross-country comparisons. It is interesting to note that these results suggest that older people tend to give more favourable ratings than younger people in the evaluation of provider responsiveness.

This supports evidence provided by the country report from **Greece**, which suggests that older people respond better to preventive invitations and also give better ratings in terms of provider responsiveness and satisfaction (see also Zavras et al., 2006; Economou et al., 2004). Below we discuss problems affecting specific groups.

The quality of physician communication is an important aspect of care that has been shown to influence treatment outcomes. Aspects such as interpersonal communication, information exchange and facilitation of patient involvement in decision-making can have a positive impact on patient health outcomes even for serious illness such as cancer (Arora, 2003).

At the same time, this can be an important issue affecting vulnerable groups. Evidence from Europe is erratic. However, results from a study carried out in the US suggest that doctors adjust the quality of communication according to patients' characteristics.

In this study, doctors are more patient-centred with patients they perceive as better communicators, more satisfied and more likely to adhere; more specifically, physicians were more contentious with black patients, whom they also perceived as less effective communicators and less satisfied (Street et al., 2007).

#### **3.4.1.1 The provision of geriatric assessment**

Doctor communication is one aspect of the quality of care which provides an important measure of the responsiveness of healthcare services. In the case of elderly patients this is further explored within the context of geriatric assessment models. Elderly people can be considered vulnerable in several aspects and face several significant challenges, some of which are directly related to their health condition and the quality of attention that they receive.

The issues relative to the problems affecting older people and the relation to access to healthcare are further developed in chapter 5. Here we discuss the case of geriatric assessment, providing some evidence on the current situation in selected countries and directions on how this service can respond to the needs of frail elderly people.

As Schroll (1997) remarks, "The problems of frail older people revolve mainly around their abilities to look after themselves and their affairs in the face of physical and cognitive decline, hence the importance of comprehensive assessment". Interventions in the area of geriatric assessment can help the identification of health needs among elderly patients and the elaboration of services plans according to identified needs. Recent research evidence suggests that interventions in the area of geriatric assessment can have significant health benefits and prevent health deterioration in elderly patients (Caplan et al., 2004).

Research in this area is relatively new in European countries and results from the newly available SHARE Survey<sup>6</sup> can provide some evidence. Santos-Eggimann et al. (2005) describe a group of indicators collected by SHARE that can be used as a tool to compare the care provided to elderly in European countries and to describe their relationship with age, gender or subjective health.

Figure 3.6 presents some indicators of the quality of geriatric assessment considering some of its basic elements, without reference to specific diseases. The elderly individuals (above 50 years) included in the

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<sup>6</sup> For more information on the SHARE Survey see Börsch-Supan et al. (2005) and visit <http://www.share-project.org/>

sample reported having a general practitioner to whom they usually turn for common health problems. Figure 3.6 shows the estimated proportion of individuals who reported that the general practitioner, at every visit or at some visits, does the following:

- Asks whether the patient has experienced falling down;
- Checks the balance or the way the patient walks;
- Asks about any drugs the patients takes, either bought over the counter or prescribed by another doctor;
- Asks how much physical activity the patient does;
- Tells the patient that he/she should get regular exercise; and
- Checks the patient's weight.

Again it is not possible to make cross-country comparisons about the overall quality of geriatric assessment based on these tabulations. However, the results suggest some interesting patterns, which can point to directions for improving current policies and research priorities.

Overall 85% of respondents declared that they have a general practitioner or a doctor to whom they usually turn for current health problems. Questions about falls and balance checks are the most infrequent aspects of geriatric assessment. As Santos-Eggimann et al. (2005) show, these are also related to age and much more common in older age groups. Checking the patient weight is also an important aspect. Whilst weight loss is a manifestation of frailty in old age, being overweight can also have important consequences.

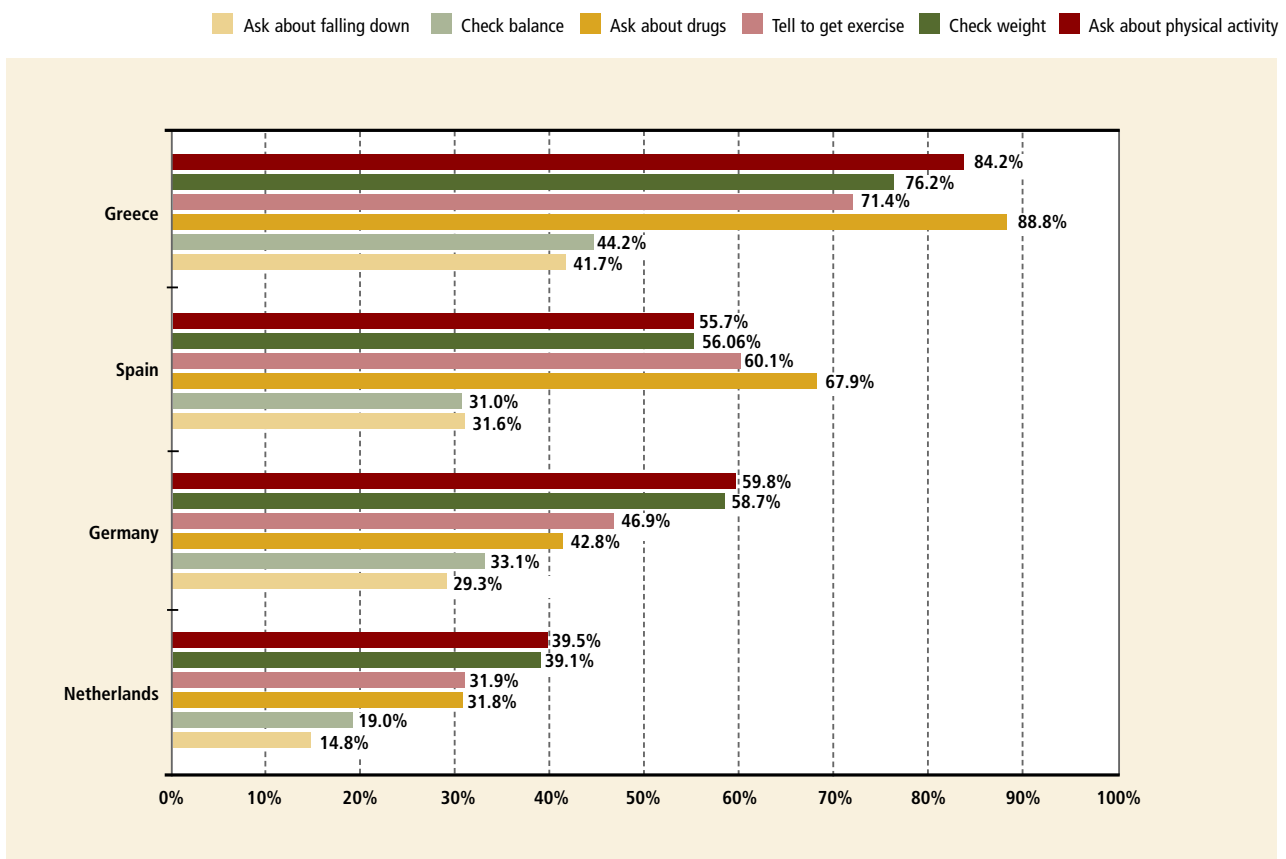
Drugs management is also a very important part of geriatric assessment. Elderly patients with chronic conditions very often take more than one drug and sometimes they are not all prescribed by the same doctor. Given the potential for interacting effects among different drugs, it is very important that GPs control the range of medications taken. Nevertheless, data from SHARE suggests that this is not extensively taken into account in primary care consultations in some countries.

### 3.4.1.2 Gender

Differences in rates of utilisation of services according to gender effects, the gender of the practitioner, socio-economic status and education exist in several different

**Figure 3.6: Geriatric assessment in primary care (2004)**

Source: Own calculations based on the SHARE Survey



countries. In particular, there are gender-related differences in the use of health services and in some countries women are shown to have higher utilisation of services. However, in general it is very difficult to determine whether such differences are attributable to problems of supply-side responsiveness, since they may also be related to differences in need between men and women, particularly due to reproductive health reasons.

For example, in **Finland** women visit the doctor more often, and the difference between genders has been increasing (see Hemminki et al., 2006). In 2004, Finnish women visited a doctor on average five times a year. This is partly explained by the age distribution differences between men and women, but age-adjusted statistics indicate that working-age women visit doctors more often than men. The same pattern is seen regarding visits to a dentist. The difference is remarkable, as many risk factors (e.g. smoking and alcohol use) are much more common among the male population. As mentioned above, the gender difference in the use of health services is partly explained by reproductive health issues, but it cannot be excluded that there is lack of health service sensitivity for the needs of the male population.

In **Spain** and the **UK** research shows that the gender of the practitioner can influence the use of services. In **Spain**, evidence provided by Delgado et al. (2004) suggests that female general practitioners use more time in consultations and provide more information, and their patients seem to be more active and participative during the consultation. Delgado et al. (1999) also documents that in primary healthcare men prefer a male practitioner for genital and anus problems and that women indicate preference for a female practitioner for psychosocial and familial problems. In the **UK**, attendance rates for cervical cancer screening are higher in practices with female practitioners (Majeed et al., 1994; Bentham et al., 1995), while men have also indicated a preference for male practitioners for some procedures and problems (Cameron et al., 1998).

In the **UK**, there is a broader issue of the importance of 'gender-sensitive' care which requires practitioners to recognise where gender-related issues are relevant and to attend to the needs of the individual within this context rather than to approach men and women in different ways as a matter of routine. Research suggests that providers' inability to respond to health problems in a sensitive manner can affect service use. Some examples include the need for an understanding and friendly attitude by staff involved in emergency contraception rather than staff focused on risks that women had taken; ability to deal with embarrassment and stigma for women using sexual health services; privacy in a hospital's A&E department for women seeking help for domestic violence and anonymity for young men seeking counselling for mental disorders (summarised in Dixon-Woods, 2005).

### 3.4.1.3 Migrants and ethnic minorities

The specific needs of migrants and ethnic minorities and the policies currently in place to address them are discussed in more detail in chapter 4. Here we discuss only the aspects specifically related to the interaction with healthcare providers and what can be done to improve this.

Specific patterns of help-seeking behaviour were identified among migrants and people from ethnic backgrounds. In particular, migrants are reported to rely more on emergency services.

Language barriers have also been shown to limit access to healthcare among migrants and ethnic minorities. For instance, in **Finland** several studies have indicated that Swedish-speaking people experience a need for health services in Swedish, but also that they have difficulties in accessing health services in their own language even in bilingual municipalities (Helsinki and Uusimaa Hospital District, 2004; Herberts, 2004). Problems can be even worse in the Sami municipalities (Lukkarinen, 2001).

Perceptions of cultural sensitivity of services have been reported as an important influence on both entering into the healthcare system and maintaining contact in the **UK**. Barriers to seeking help include perception of language difficulties, lack of awareness about beliefs and values and lack of translation facilities. Dixon-Woods et al. (2005) summarises 14 studies that report such perceptions amongst people from ethnic minority groups.

The Roma population in **Romania** faces specific access barriers related to both educational level and religious beliefs. The fact that many Roma are nomadic and lack documents of identification makes it difficult to follow them during vaccination campaigns. They also have lower utilisation of preventive services, including vaccination, pregnancy care, birth control and preventive dental care.

### 3.4.1.4 Disabled persons

Disabled persons have very specific needs in terms of the accessibility of healthcare facilities and access to information. For instance, in some cases it is necessary to guarantee that physical facilities are easily accessible for wheelchair users or that leaflets or other sources of information are provided in appropriate formats for those with visual impairment.

Most countries reveal a lack of evidence on the current implementation of this type of measure. This suggests that this issue is not being appropriately addressed in most countries. An exception comes from **Finland**, where a recent report on well-being and living conditions

among disabled persons mentions problems with contacts with the healthcare system. These encompass problems both in terms of attitudes toward disabled people among the healthcare personnel and in lack of information. In particular, there is need for information in a suitable form about the services and the healthcare system among disabled persons and their families (Haarni, 2006; Ministry of Social Affairs and Health, 2006).

### **3.4.2 Policies to improve supply-side responsiveness**

Some important examples of helpful policy interventions addressing the issue of how to provide gender, ethnically and culturally appropriate services have been reported under this study. Some of these examples across different countries are reviewed below, according to the target groups to which they relate.

#### **3.4.2.1 Providing gender-sensitive medical care**

In **Spain**, there is increasing awareness about the importance of a gender approach in health. Concepts like 'gender-based-medicine' and 'gender-sensitive' are actually integrated in health strategies. Most of the Health Plans of the Autonomous Communities have included the gender approach focusing on the need to extend research in gender inequalities and health (Observatorio de Salud de la Mujer, 2006). Nevertheless, further research is needed on the role of gender stereotypes in healthcare decisions and gender connections between supply of and demand for health services.

#### **3.4.2.2 Responding to the health needs of migrants and ethnic minorities**

An important issue relates to the language difficulties that many migrants and ethnic minorities experience in the interaction with healthcare providers. Countries have responded to this issue in different ways and their experience suggests trends that could be also followed in other places.

In **Finland**, the Act on the Status and Rights of Patients determines that the mother tongue and culture of the patient have to be taken into account as far as possible in his/her care and other treatment. However, producing services in two or more languages always causes extra costs for the municipalities and the state subsidies are often too small to cover the costs.

In the **Netherlands**, professionals are required by law to communicate with their patients in a language and manner that is understandable for the patient.

Ensuring adequate communication is therefore the responsibility of the professional. The professional can opt to rely on professional translators to facilitate this process. These translation services are held to confidentiality and impartiality, and are usually provided by telephone. In case of emergency, they can be available within minutes. Costs for translation services are borne by the Ministries of Health or Justice (the latter if the patient is an asylum seeker) (IGZ/Pharos, 2005).

In **Spain**, several Autonomous Communities have developed actions to improve the attention given to immigrants. Some have elaborated guides such as the *Manual for Immigrants' Healthcare* in Andalusia and the *Guide for Intervention with the Immigrant Population in Primary Care and a Guide for Clinical Interview* edited in several languages in Castilla la Mancha. The Andalusian Health Service is also introducing a simultaneous teletranslation system in their health centres in order to overcome language barriers. Catalonia has initiated a *Training Plan on Healthcare for the Immigrant Population* with actions for cultural training of health professionals.

Surveys in the **UK** have revealed lack of knowledge amongst health service staff about religious and cultural beliefs and practices of minority groups, but there is increasing evidence that this problem is recognised and is being addressed. For instance, McLean et al. (2003) report that patients feel there has been a reduction in institutional racism.

Some countries have implemented interventions targeted specifically at the Roma people. **Finland** has established an Advisory Board on Roma Affairs, which aims to enhance the equal participation of the Roma population in Finnish society, to improve their living conditions and socio-economic position and to promote their culture. The Advisory Board functions in conjunction with the Ministry of Social Affairs and Health.

#### **3.4.2.3 Recruiting healthcare professionals from the communities: Peer-based models and ethnic matching**

Recruitment of healthcare staff from ethnic minority communities eases communication problems and enhances accessibility (Council of Europe, 2001). This is supported by evidence from the **Netherlands**. Peer-based models, whereby lay members of the community are trained and supervised to provide information, counselling and advice to people from their own community have also proven to be successful. While they are often set up to improve health information and deliver culturally sensitive health promotions, they also play a role in preventive health services, in bridging gaps in acute healthcare settings, in mental health, and in services for drug users. Peer-based

approaches have not only been implemented to improve services for black and minority ethnic communities, but also for other groups that may encounter specific barriers with regard to health services, such as women, gay men and lesbians, and older people (Voorham, 2003).

In the UK, however, there are mixed views about 'ethnic matching' as a means of promoting access. There is the concern that in some cases gender and social issues are the driving force behind access limitations. For instance, Asian women have expressed concern about being seen by Asian male doctors because of social status issues and confidentiality concerns (Chapple et al., 2001). There is growing interest in the use of Link Workers which some see as going beyond provision of language services and addressing advocacy and coordination issues, but little evaluation exists especially in terms of facilitation of access.

### 3.4.3 Community health initiatives to promote access

A number of community health initiatives to promote access to health services have been described in the 'Health and Social Inclusion', 'Closing the Gap' and 'Healthy Ageing' projects and are listed in this section as examples of policies to improve supply-side responsiveness. The establishment of low barrier community health programmes that address needs identified by target groups themselves, through programmes that they also then facilitate, are

successful health policy interventions in a number of cases. Indeed, community engagement, ownership and empowerment, achieved through participatory approaches, are particularly good practices that enable better access to healthcare and reduce social exclusion by actively involving vulnerable people.

Involved communities and individuals are more likely to be aware of their own local context and available local health and social services through their active participation. Experience also suggests that interventions where the target population are helped and supported to conduct their own needs assessments, informing health promotion action plan development and facilitating implementation, lead to the generation of better responsive services. Such projects are strengthened and can be sustainable when partnerships involving a number of actors in health are built and maintained.

The Welsh Pembrokeshire 'SHARP' project (see Box 3.9) and the Scottish 'Gorbals Healthy Living Network' project (see Box 3.10) are cutting-edge examples of such practices.

In fact, the UK has developed a whole network of pilot schemes including Healthy Living Centres aimed at increasing physical activity, improving diet and nutrition, immunisation and management of influenza amongst the elderly. In particular, the 'LinkAgePlus' pilots seek to involve all sections of the community in the design and delivery of the pilots. They provide community-walking projects for older people, facilitate access to advice and information (through phone services, one-stop-shops, and training staff from

#### BOX 3.9: EXAMPLE OF SUCCESSFUL COMMUNITY HEALTH INITIATIVE

The Pembrokeshire 'SHARP' project in the UK is an example of the 'Healthy Living' UK-wide approaches in urban and rural Welsh communities, funded by the Welsh Assembly's Sustainable Health Action Research Programme between 2001–2005 and managed by Pembrokeshire County Council. The project was a partnership between community forums, statutory and voluntary sector representatives and academic collaborators and was operated through community-based healthy living forums, developed as an innovative response to local situations where service delivery was perceived to be affected by economic decline, social exclusion, rural isolation and poor health.

Pembrokeshire 'SHARP' employed an innovative participatory action research approach where local needs assessments were conducted by trained Community Researchers, informing the design, implementation and dissemination of feasible and adaptable Community Action Plans. This community participation enabled ownership over the project, giving it

'status and credibility'. Project activities comprised improving living and working conditions (individual lifestyles, healthcare services, cultural and environmental conditions) through advice and guidance, capacity building to deal with health-related problems, community work, education and information, training courses and group workshops.

The evaluation reported some changes with regards to new community activities focusing on healthy living, improved physical environment (including better access to and liaison between social and primary care services) and policing initiatives in the communities. Insight into wider community issues, raised expectations and a sense of responsibility provided communities with confidence thus overcoming, for example, initial fears of consulting a GP. The project also led to a gain in knowledge, skills, training and qualifications enabling better responsiveness from health and social services and allowing individuals to acquire knowledge on available services and how to navigate them.

Source: "Closing the Gap" project

### BOX 3.10: A SCOTTISH EXAMPLE OF A SUCCESSFUL COMMUNITY HEALTH INITIATIVE TO IMPROVE ACCESS

'Gorbals Healthy Living Network' (GHLN) project in **Scotland**, part of the UK-wide 'Healthy Living Network' schemes, based in a highly deprived area in Glasgow.

The project is a partnership between a broad spectrum of actors in health and uses a community development approach to involve vulnerable groups and implement a wide range of action research methodologies (Participatory Appraisal) to develop a holistic health project reflecting the health views, wishes and needs of the Gorbals community with a focus on equity, empowerment, participation and cooperation.

The project is implemented through a variety of activities: networking, supporting forums (Gorbals Health Forum Sub-Group), community health development, health awareness events/activities, training programmes, counselling services, mental health awareness training courses. GHLN provides information to individuals/communities on health-related opportunities and services related to individual lifestyle issues (accidents, alcohol, drug abuse, mental health, nutrition, physical activity, smoking), social and community networks (social inclusion, social support, violence etc.), and living and working conditions (education, healthcare services, housing, transport, unemployment, working conditions/environment).

Source: "Closing the Gap" project

a variety of departments to respond to needs), promote neighbourliness and community support to encourage active citizenship and social responsibility.

These activities also promote social inclusion through engaging vulnerable populations in social activities and creating supportive communities. The integrated sharing of information between organisations through better systems therefore ensures that issues which matter to target populations are given adequate weight in the community planning process, support teams, partnerships and training of health mediators.

The 'Northside Community Health Initiative' (NICHE) in Ireland is another example of a successful community health initiative to promote access. It aims to institutionalise a holistic, social model of health by introducing and managing projects that promote health: developing mechanisms for community consultation and participation; bringing health services to the area and promoting inter-agency collaboration; improving access to health information and consolidating the role of community health workers. The participation and commitment of the local community is key to NICHE's success.

In the **Netherlands**, the educational programme 'In Anticipation of Golden Years' has been shown to be highly effective in improving proactive competencies. The programme is a low barrier intervention community initiative focusing on mental health and social capital of people aged 50 to 75. Active participation is central to the project and has led to improvement competencies in preparing for ageing and better integration of elderly people in society.

Another example comes from the 'Health and Social Inclusion' project: 'Programme for promoting health in ethnic communities in Navarra', **Spain**. The programme has improved access to services via direct involvement of health agents/mediators (see also the section on

intercultural mediators), employed from the Gipsy community, liaising between health services and the community thus improving access to services. Success of the initial intervention in four health zones has led to the expansion to 15 health zones since 1987.

**Scotland** (see Box 3.11) also provides a good example of a well structured system allowing policy implementation through pilot schemes, which once evaluated inform further policy making and sharing of good practices and lessons learnt countrywide.

#### 3.4.3.1 *Partnership working to make health promotion and treatment more accessible*

Previous studies and EuroHealthNet work have identified partnerships and collaboration as being essential to support health promotion practice. Partnerships between public, private and voluntary sectors ensure the necessary information and care reach people.

They also ensure active involvement of all actors for health and a truly inter-sectoral approach to health promotion initiatives, thus enabling the adoption of a multidimensional and holistic approach to health. In fact, the success and the sustainability of a project is generally dependent on active partnerships with other government, academic, local and national organisations and agencies, whose plans and actions impact on the health of the population, a key health promotion principle.

Partnerships have been shown to facilitate a seamless interface between health, social and local services maximising efficiency; reducing administrative burdens and ensuring that the necessary assistance is sought and provided. Partnerships are therefore key to improving access to health services. In fact, many EU

### BOX 3.11: A SCOTTISH EXAMPLE OF INTERVENTIONS USING HEALTH MEDIATORS TO IMPROVE ACCESS

'KeepWell/Prevention 2010' is a pilot scheme in **Scotland** aimed at reducing inequalities in health by providing HP interventions and better access to health and local services through direct referral and provision of health information. It adopts a multisectoral and holistic approach to health promotion, empowering individuals to take control of their own health and employing adequately trained health coaches/mediators to deliver the interventions.

The project is based in the East and North Glasgow CHCPs, some of the most deprived areas in the UK and is targeted at groups most at risk of developing coronary heart disease CHD with a special focus on 'hard-to-reach' groups. Trained practice nurses refer individuals identified from the target group into individually tailored local services offering a set of HP

interventions: food, weight and exercise programmes; smoking cessation services; alcohol support; stress management centres; debt and money advice; literacy and employability services. Key 'KeepWell' principles comprise efficient partnerships, behaviour change through health promotion, improved access to healthcare services, improved opportunities for debt management and employability with an emphasis on literacy services for 'hard-to-reach' groups.

This partnership between the local authorities, local GP practices, NHS PCTs, NHS Greater Glasgow and Clyde and the Scottish Parliament is currently being rolled out to the rest of Scotland following the recent £25,000,000 funding support from the Scottish Parliament.

Source: **Keep Well, Scottish government**, <http://www.scotland.gov.uk/Topics/Health/health/Inequalities/P2010>;  
**NHS Health Scotland**, <http://www.healthscotland.com/Prevention-2010.aspx>

### BOX 3.12: GOOD PRACTICE EXAMPLE OF EFFICIENT PARTNERSHIP WORKING IN SPAIN: THE 'INTEGRAL PLAN FOR PUBLIC HEALTH IMPROVEMENT IN VALLECAS'

In **Spain**, following a 2000 agreement between the government of Madrid and Community and Residents' Associations in the region, an 'Integral Plan for Public Health Improvement in Vallecas' was initiated. The project's main aim was to reduce the inequalities existing in health between residents of Vallecas and other areas of Madrid. The project is an inter-institutional coordination/collaboration and citizen participation intervention to expand the knowledge of the state of health of the population of Vallecas. It aims to improve habits and lifestyles; strengthen promotion actions by volunteers and mutual help groups; assess the needs of the communities and improve living conditions and social inclusion of particularly vulnerable groups. It does so through the development of specific actions on health promotion targeted at vulnerable groups such as the 'Help for the Elderly. Face up to it' programme, discussion forums and support for the immigrant population and the training of socio-health professionals on the subject of immigration and health.

The programme is characterised by successful active dissemination campaigns to spread the plan and findings and share lessons learnt and good practices.

This project has resulted in capacity building of the population and health services to deal with health-related problems, through various investigation studies revealing a wide range of information and drawing a detailed map of it, thus enormously improving the initial knowledge of the situation and the start-up and strengthening of numerous activities on prevention and health promotion. The majority of these projects have been planned to have continuity since, in order to obtain results on improvement of habits and reduction of risk conduct, these activities need to be carried out over time rather than on a punctual basis. Moreover, the key inter-sectoral partnerships have been strengthened through community work, education and information initiatives, peer approach, service provision and training courses and have made this project achievable

Source: "Closing the gap" project

Member States acknowledge the importance of partnerships and have worked towards developing such relationships to support all health fields. Most of the good practice examples described in this report have ensured partnerships were central to the implemented schemes and projects.

This section will therefore concentrate on describing a single example of good practice, that of the Spanish 'Integral Plan for Public Health Improvement in Vallecas' (see Box 3.12).

## 3.5 Health literacy, voice and health beliefs

Vulnerable groups not only shoulder the greatest health burdens, but may also have poorer access to information, communication technologies, and face important shortcomings in their overall literacy levels or have general language barriers. Consequently, they often have a reduced capacity to navigate complex modern healthcare systems, understand vital health and healthcare information, make the best choices for themselves and their families on healthcare services, as

### BOX 3.13: CONCEPTS OF HEALTH LITERACY

The **WHO Health Promotion Glossary** defines 'health literacy' as follows:

Health literacy represents the cognitive and social skills, which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.

Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment. Health literacy is itself dependent upon more general levels of literacy. Poor literacy can affect people's health directly by limiting their personal, social and cultural development, as well as hindering the development of health literacy.

Within this framework it is useful to distinguish different levels of health literacy (Nutbeam, 2000):

#### **Functional health literacy**

This term refers to the ability to understand factual information on healthcare matters, health risks and health service utilisation, including information on healthcare administration and the consequences of more complex consumer choices, such as the choice of insurance funds, where public or private programmes offer this choice.

#### **Interactive health literacy**

This term refers to the capacity to 'find your way' through complex healthcare systems. This includes the 'voice' to negotiate with healthcare professions about healthcare service demand, treatment choices and to deal with healthcare administration, such as for timely registration with insurance funds, submission of reimbursement claims and filling in forms needed, e.g. to claim exemptions from cost sharing or to request that these are reimbursed. Interactive health literacy usually requires commanding over functional health literacy (including language and basic literacy skills).

well as make decisions on healthy lifestyles more generally (Healthy People, 2010). The term 'health literacy' has been coined for the complex concerns that this has raised. Box 3.13 provides a broad definition of health literacy that corresponds to this complexity and is used as starting point for this section.

This section then reviews evidence on health literacy as a barrier of access, before turning to the broader issues of voice and health beliefs. As this section will argue, most of the evidence provided in country studies is more indirect, pointing to instances where participating experts interpreted evidence on lower uptake of services as sign of lack of health literacy. As health literacy can be linked to language and cultural issues, we will also further elaborate on these specific topics under the group-specific discussions in the next chapters on people at risk, for example for people with a migrant background.

Much of the research on health literacy was pioneered in the US and Canada, with Europe lagging behind on basic research and policy strategies. This is also illustrated by the limited evidence on health literacy issues that country reports under HealthQUEST were able to provide. This has also been confirmed by a search for the term 'health literacy' in documents of NAPs and among the documents on the web pages of the DG Employment, Social Affairs and Equal Opportunity. This search revealed only few hits.

Health literacy has, however, recently received increasing attention in a number of European countries as well as on the European level. Nonetheless, it is difficult to

find initiatives targeted specifically at improving health literacy and there is a lack of research and measurement instruments (see e.g. Kickbusch et al., 2004a, b). Health literacy is likely to become more prominent in European healthcare policy in the future, particularly as it has been included in the goals under the recent Communication on Patient Mobility.

In the US, much of the research has focused on the ability of people to understand medical information that is essential in interactions with healthcare providers, for complying with treatment regimes; on the healthcare safety problems and healthcare costs caused by low health literacy; and on the links between low (health) literacy and high healthcare needs.

An estimated 75 per cent of persons in the US with chronic physical or mental health problems were found to have limited literacy (Davis et al., 1996). A particular concern is the lower (health) literacy of older people, many of whom are not able to read and understand basic materials such as prescription labels and appointments (see Williams, 1995, for a small-scale US study).

In general, measurement seems more straightforward for aspects of functional health literacy, for which evidence is reviewed below from the OECD *International Adult Literacy Survey* (IALS). The evidence about the complex issue of individual and family capacity to 'negotiate your way' through healthcare systems is gathered more indirectly from examples provided in country reports.

### 3.5.1 What do we know about deficiencies in health literacy?

A main source of evidence on deficits in health literacy, on how it affects access to healthcare, and which are the groups at risk of social exclusion comes from the US and Canada, where research in this topic has been stepped up over the last decade. Studies in the US not only suggest that poor health literacy is widespread, but also that people at risk of social exclusion are more severely affected, including the groups at risk that are studied in detail in HealthQUEST.

Health literacy is closely linked to overall literacy levels, for which a few international surveys have been conducted in the last 10 years. In this context, it is interesting to note that the OECD international adult literacy test –the latest large-scale international attempt to compare and analyse adult literacy across a selection of European and other OECD countries– has included health-related skills in its test scores at each of its three literacy levels.

The OECD has also used test questions that are related to health literacy as illustrations at each level when discussing their policy relevance.

#### BOX 3.14: HEALTH LITERACY ILLUSTRATIONS FROM THE OECD ADULT LITERACY AND LIFE SKILLS TEST (ALL)

The OECD ALL test has dimensions that are ranked as successive levels of literacy that measure: prose literacy; document literacy; and quantitative literacy: The OECD included health-related test items under each of three levels. These tests request successively more complex tasks to be fulfilled.

The OECD test distinguishes six so-called contents categories for skill assessment. One of these is the health domain:

“Health and safety: may include materials dealing with drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy.”

“Level 1 indicates persons with very poor skills, where individuals may, for example, be unable to determine the correct amount of medicine to give to a child from information printed on the package.” (OECD, 2000)

On Level 2, more complex tasks of interpreting health-related material are assessed, and on Level 3, much more advanced skills are requested, involving numeracy, such as simple calculations needed to understand the contents of an article about the nutritional contents of food consumed at McDonalds.

Source: OECD (1999, 2000)

Although the OECD ALL test does not have a focus on health literacy per se, the OECD draws a number of conclusions from its findings that are relevant for health policy.

The OECD reports acknowledge that the results of the *Adult Literacy Survey* raise the concern that a worrying number of people have limited capacity to understand, and to interact with social programmes and administrations that have a tendency of becoming increasingly more complex in many countries (OECD, 1999) The concern about limited health literacy, as defined in this more narrow sense of limited capacity to process health relevant material is therefore an overarching policy concern that interacts and can counteract other attempts to improve quality of and access to healthcare of people at risk of social exclusion.

The OECD report also notes that high literacy is statistically correlated and in complex ways associated with better health outcomes, increased longevity and healthier habits and lifestyles.

For example, the likelihood of being overweight is inversely linked with years of education, as are smoking rates. Overall, the OECD report found that economic inequality is linked with inequality in the distribution of literacy.

It is interesting to note the overall ranking of the countries studied both in the OECD survey and in HealthQUEST with respect to adult literacy: **Finland** and the **Netherlands** are among the high-ranking countries, **Germany** and the **UK** lie more in the middle, whereas **Poland** is at the lower part of the OECD country ranking.

The evidence from both the US and from the health literacy related component of the OECD survey suggests that there is a large, but currently not fully diagnosed health literacy problem in Europe, which calls for research and survey instruments to study health literacy in Europe more broadly than is currently the case.

### 3.5.2 Evidence from country studies of access problems due to low health literacy

This section provides some evidence on the scope of limitations of health literacy in the population in different countries. This section first summaries some indirect evidence provided in country reports about problems that groups of the population have coping with the growing complexities of healthcare systems that have been analysed in other parts of this study, mainly under cost-sharing and coverage concerns The rest of this section focuses mainly on the aspects of ‘voice’ and ‘health beliefs’ as part of health literacy more broadly, for which some information is available from country studies under HealthQUEST.

This includes discussions on problems of self-management and lifestyle (mainly health promotion and prevention issues) and more genuine access issues, such as with making contact with health services, and when using services (such as problems of compliance, understanding of instructions, 'self-management' in the role as patient).

Several country studies report that an important reason why some people do not get the healthcare they need, or do not get insurance coverage in a timely fashion is likely to be due to lack of understanding of administrative procedures and requirements, which can be compounded by language barriers, a low literacy level in general, or difficulties in organising regular payments to insurance funds.

Where applying for reimbursements of cost sharing is an individual responsibility, many people in vulnerable groups may not understand how to do so, or are deterred by the bureaucratic procedures needed. This has been mentioned in several country reports, including the reports from **Germany** and **Poland**.

Even where corresponding quantitative research is not available, a substantial non-take-up rate of benefits (here reimbursements of cost sharing) should not be surprising. For other social benefits, where there are data available, such as social assistant payments, there is evidence that non-take-up rates can be very high (Fuchs, 2007).

Health literacy is also an important prerequisite for making appropriate choices in social insurance systems or in a mandatory private system, where funds are competing for clients, and where contracting is an individual obligation, such as in **Germany** and the **Netherlands** after the latest reforms.

For **Germany**, there is some evidence that many people need some time to adapt their healthcare seeking behaviours and their contracting with insurance funds to new rules. Such a time lag has been reported for the introduction of new the cost-sharing requirement in 2004, and for the new obligation for everyone to register with insurance funds. Lag of knowledge and understanding in the initial stages of the implementation of reform seems to have had an important role.

The **Netherlands** country report raises the issue that the restructured Dutch healthcare system has many features that could make it relatively susceptible to 'health literacy bias'. After all, "patients are encouraged to make prudent choices through the introduction of a relationship between the amount of care requested and the cost and by increasing the transparency of the care system"<sup>7</sup>. However, to make

sound choices, healthcare consumers need to be able to analyse the increasingly detailed information that is becoming available about a more and more complex market for services and insurance. This includes being aware of healthcare costs, taking this into account in deciding what service to access, when, and what kind of insurance to take up.

In the course of that process, language skills and computer literacy can be of great help. The much-needed market-related information is made available via various websites. The most prominent one, KiesBeter, is commissioned by the Ministry of Health, Welfare and Sports ([www.kiesbeter.nl](http://www.kiesbeter.nl)). The site is only available in Dutch, however, and its use obviously requires good language and basic computer skills.

The **UK** country study suggests that differences between groups in consultation behaviour and management of symptoms can be explained by whether health is managed as a series of minor and major crises rather than treating disease as requiring maintenance and prevention (see also Dixon-Woods et al., 2005). People from more disadvantaged social groups tend to judge their need for treatment as event based. Thus they will often require a specific event to occur before they think it is legitimate to seek help. This also explains the lower uptake of preventive services and lack of responses to invitations for screening; immunisation etc. as they are more likely to wait until there is a specific problem to report. There is also an issue about whether people feel they are entitled to ask for help and this can be linked to socio-economic status and whether people have a history of high use of services and fear being classed as 'over-users'.

### **3.5.3 Policies to improve health literacy and to empower people at risk of social exclusion**

National information strategies have been developed in a number of EU Member States in order to improve the information available to populations and provide information of available services. Some strategies are described here.

In **Spain**, the government has elaborated a number of large-scale strategies (such as the Cancer strategy and the Diabetes strategy) and programmes that have enabled better access to health and access to healthcare-related information thus raising health literacy in the sense of awareness of existing and available services.

**Germany** has set up health literacy and health promotion measures to improve access to health services. Such measures include statutory health insurance pilot projects that are targeted at people with mental disorders, the elderly and people from low

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<sup>7</sup> European Commission (2007) *National Strategy Report on Social Protection and Inclusion in the Netherlands 2006–2008*, p. 5.

socio-economic backgrounds. The pilots are aimed at increasing qualifications for mental and geriatric care, provider information, quality regulations (e.g. anti-stigma campaigns) and patient information (partly in several languages and through government projects).

In the **UK**, almost all areas of the health sector have put together directories of local services and made them available. Several programmes have enabled this progress such as documents and other sources of information mapping local health and social services (e.g. maps and liaison health cards for homeless clients), also available in other EU Member States. However, these generally remain local small-scale initiatives.

Social marketing has applied commercial marketing technologies to communicate with and inform target audiences, and has been shown to be an effective health literacy delivering tool to raise awareness about specific issues such as stigmatisation and discrimination and provide health information about the existence and relative advantages of health interventions/services (e.g. flu immunisation campaigns – Box 3.15) addressing issues of price, access and environmental support.

### 3.6 Conclusions and Recommendations

#### 3.6.1 Organisational barriers to access

##### Conclusions

Policy makers and the research community currently still neglect to a large extent the importance of organisational barriers as an element in the determination of access and use of healthcare services. Yet, some of the evidence from country studies

collected for this project suggests that this can be a serious limitation for access to healthcare, particularly for groups at risk of social exclusion. The situation in **Poland** deserves particular attention.

The increasing complexity of health systems from the user perspective will certainly increase the importance of this issue. This is especially the case since vulnerable groups might have limited ability to navigate intricate systems.

For a number of years now, the persistent problems with waiting times have received significant attention in a number of countries. This has contributed to the implementation of several policies, which have been shown to be effective in reducing waiting times in some countries.

##### Recommendations

The implementation of reforms that increase the system complexity and demand more from patients should consider the consequences of increasing complexity for vulnerable groups and avoid that they are left behind.

Countries considering the introduction of regulation on waiting times should contemplate the successful policy examples that have been based on the use of waiting-time targets, additional activity and agreement among different players.

At present, most new EU Member States still lag behind in the implementation of policies that regulate waiting times for healthcare treatments. Nevertheless, the experience collected in this study suggests that they would certainly benefit from additional activity in this area.

#### BOX 3.15: SOCIAL MARKETING INITIATIVE TO PROVIDE INFORMATION FOR FLU IMMUNISATION CAMPAIGNS IN THE UK

Since 2003, the Department of Health in the **UK** has been delivering an annual flu immunisation campaign. The strategic objectives address the myths around flu, highlight the seriousness of the virus and reach out to black and minority ethnic (BME) audiences (a group that have traditionally low take-up of the free vaccination). The strategy was aimed at building strategic alliances across the voluntary and corporate sectors to deliver local credibility to national messaging. Combined with carefully targeted media relations and stakeholder engagement (with separate strands for BME audiences, parents of at risk children, and health professionals) the campaign has resulted in consistent increases in the number

of at-risk people receiving their flu jab thus accessing health services. The campaign has also secured active engagement from many business and voluntary sector partners and has achieved high media coverage.

Social marketing campaigns have been particularly used for raising awareness around stigma and successfully brought these issues to the health services' attention. Such anti-stigma campaigns along with comprehensive workforce training schemes, such as the UK NHS Workforce Plan, have led to great improvements in the ability of health professionals to deal with and provide tailored healthcare to people suffering from mental disorders.

Source: UK country report

### **3.6.2 Supply-side responsiveness**

#### *Conclusions*

Patient interaction with healthcare providers has been shown to depend on several important factors related to the way that individuals are treated.

In some cases, treatment effectiveness can be affected by the quality of interpersonal communication offered by the service supplier and by the extent to which services are tailored to the special needs of certain groups of patients.

This important issue has the potential to affect many groups of individuals at risk of social exclusion. In particular, women, migrants and ethnic minorities, disabled persons and the elderly are some of the groups with greatest potential to benefit from more responsive services. Therefore, improving the level of health system responsiveness should be seen as an important way to reduce the vulnerability of excluded groups and to guarantee wider access to healthcare.

#### *Recommendations*

Health systems should seek to guarantee the provision of responsive services. This can encompass several factors, including ensuring good quality communication, translation and interpretation services where appropriate, accessible facilities for disabled people and also the provision of gender-sensitive services.

Research suggests that it can be very difficult to isolate the effect of specific factors in the determination of access and utilisation since they often influence each other. Moreover, supply-side responsiveness is currently not widely studied in many countries. Therefore EU Member States should support further research in this topic.

### **3.6.3 Geographical barriers and regional variations**

#### *Conclusions*

Evidence collected from several countries suggests the existence of significant variation across regions in terms of availability of resources, installed capacity and health personnel. Recent data collected by the OECD for some of the HealthQUEST countries (OECD, 2007a) show that the volume of healthcare resources can vary greatly across country regions, in some cases the better equipped regions can have up to four times the density of the worst equipped regions. The differences between rural and urban regions are particularly worrisome in view of the fragile economic situation and the more rapidly progressive ageing of rural areas.

These variations can impact the utilisation of healthcare services and in some countries published studies have documented detrimental effects of distance to providers on rates of utilisation. These differences are also shown to impose further restrictions in access to healthcare for groups at risk of social exclusion, especially for elderly people and those with limited mobility.

Addressing the needs of rural populations is also a vital area for investment. Rural areas are disadvantaged in several dimensions, being characterised by worse access to transport infrastructure and healthcare services, lower economic development and also by having a greater concentration of elderly people.

Therefore, it is crucial to provide resources to support access to healthcare, especially for people at risk of social exclusion and those with mobility limitations.

#### *Recommendations*

The provision of services in decentralised systems requires benchmarking and monitoring to unravel and counteract any tendencies of increasing inequality of access to healthcare.

Country policies should take into account the potential negative effects of inter-regional variations in healthcare resources and should consider ways to ensure accessibility for people in regions with lower than average endowment. In doing so, it is, however, important to take the growing evidence into account that suggests that high-quality specialist provision needs an increasing concentration of care in facilities with large numbers of similar cases per year.

Countries currently are already taking regional variations into account in their NAPs. However, more has to be done in order to improve access to healthcare for vulnerable groups.

The country reports provide a number of interesting policy initiatives that could be extended to other EU Member States. There are several examples of initiatives to strengthen local initiatives, whilst at the same time keeping a central steering. A promising way forward consists of promoting coordination and collaboration among local and regional administrative levels.

There are still considerable gaps in research, which limit the amount of necessary information to improve the understanding of the most pressing problems and to guide the identification of priorities. More research evidence is needed, for example in topics such as the issues related to transport barriers for vulnerable groups and regional variations in emergency services response times.

### **3.6.4 Measures to improve health literacy for reducing barriers of access**

#### *Conclusions*

Poor health literacy is disproportionately more likely among older people, immigrants and those with low incomes. Poor access to health services is also more prevalent amongst these disadvantaged groups and health literacy interventions targeted at these special needs groups are therefore essential to improve their access to services.

Health literacy, voice (that is, the ability to negotiate with health administration and staff in order to express needs and to realise care choices), together with health beliefs play a central role both for the successful interaction of people with the health system and for their self-management ability. Improving health literacy in a broad sense is therefore crucial.

The important and persistent numbers of persons with overall very low literacy level across Europe has important implications for the evaluation of the impact of a number of recent healthcare reforms that have had a tendency to create ever more complex systems, with the risk of 'leaving behind' those who do not have the capacity to understand how to deal with them, and/or lack the support needed to enable them in this respect.

The importance of awareness and the ability to self-manage makes the empowerment of clients –by raising their health literacy levels and increasing their ability to act– a key policy intervention to improve health access.

Although there is a general scarcity of empirical research on health literacy in Europe, the available evidence points to serious health literacy shortcomings and reduced capacity of vulnerable groups of the population to successfully negotiate their ways through modern healthcare systems of growing complexity.

#### *Recommendations*

Member States should ensure that they have clear policies in place to address both supply and demand side health literacy for vulnerable populations.

Member States who are changing their healthcare systems should pay particular attention to ensuring that active ongoing measures are in place to support vulnerable populations in effectively using the system.

The EU should ensure that there is a strong evidence base to support Member States in addressing health literacy.



## **Part 3**

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## 4 Migrants, asylum seekers and illegal immigrants

### 4.1 Introduction

The share of the EU's population born abroad has been growing. A recent publication by the Portuguese Presidency of the EU Council estimates the number of non-nationals living in EU countries in 2004 at 5.5% of the total population, with a significant proportion coming from countries outside the EU (Padilha and Miguel, 2007). This population plays an important part in the EU economy and for ageing populations in Europe. However, there remain many challenges on how to achieve better social integration and basic human rights for such groups as refugees, asylum seekers and illegal (undocumented) immigrants.

Although improving access to services in general has been identified as an important factor for improving the situation of immigrants, improved access to healthcare services plays a particularly important role. The barriers to accessing healthcare are reviewed in this chapter together with policy initiatives and good practice examples that have emerged from the HealthQUEST project. This includes identifying local and voluntary action in the field and the lessons that can be learnt from these initiatives.

For migrants, barriers to accessing healthcare represent a complex picture. It has long been recognised that newly arriving migrants may face special health risks and frequently do not receive the care they need. There are also important access problems faced by people living in temporary reception/detention centres and by illegal immigrants in general. Moreover, there are many challenges for providing healthcare within a multicultural setting, some of which can be persistent for migrants who have stayed in the host country for some time. These challenges can overlap with those faced by ethnic minorities who might have been long-time residents in a country. These include: lack of knowledge about available services; language differences; and varying cultural attitudes to health and healthcare. Looking at the situation of migrants in detail provides an 'analytical lens' for the barriers to access at the supply side that this study has also addressed under the chapter on health literacy, voice and health beliefs.

It is also important to note that analyses of the access problems of various groups of migrants have to contend with a lack of information about migrant health needs and access to services. This is partly related to the difficulty in identifying a person's status as a migrant in administrative data, and therefore in collecting relevant information. Moreover, even if information about utilisation of services is available, epidemiological evidence about need as measured by the prevalence of health problems is rarely collected (Ingleby et al., 2005).

The remainder of this chapter is organised as follows. First, a brief summary of the differences between host countries and a brief analysis of the different concepts of the word 'migrants' is presented. Sections 4.2 to 4.4 then analyse the situation of three different groups of migrants, highlighting the specific challenges of access to the health systems of the host countries that they face. Section 4.5 addresses the specific health needs and problems of accessing healthcare services experienced by older migrants, with a focus on older migrant women. Finally, conclusions are reviewed in section 4.6 and policy recommendations presented in section 4.7.

#### 4.1.1 How do countries differ in their role of host country?

Following the typology proposed by Begg and Marlier (2007), the countries included in this study can be classified according to their typical trajectories of immigration as:

- a) *Long-standing host countries*: states that have been prepared to take in substantial numbers of migrants for many years and will continue to do so, but in which the current political debate centres on the limits to the scale of the flows: **Germany**, the **Netherlands** and the **UK**;
- b) *New hosts*: states that see controlled immigration as a means of dealing with potential labour shortages: **Finland**;
- c) *New gateway countries*: countries that are seen by non-EU migrants as entry points which also offer the prospect of extended stays. **Greece** and **Spain** have shifted in the last two or three decades from being countries of persistent emigration to this category. According to some accounts, immigrants currently make up 10% of the population of Madrid, with most individuals coming from Latin America and Africa (Perez-Rodriguez M et al., 2006);
- d) *Emigration countries*: states where the tendency is still for there to be net emigration with limited opportunities (yet) for immigrants: **Poland**; and
- e) *Segregated minorities countries*: where there is substantial population (especially Roma) that has been poorly integrated with the mainstream population, in spite of policies aimed at doing so: **Romania**.

With respect to the countries of origin, most immigrants in **Finland** come from Russia, Estonia, Sweden and Somalia; in the **Netherlands**, from Turkey, Suriname, Morocco and Dutch Antilles; in **Poland** from Germany, Belarus, and Ukraine, and in **Spain** from Morocco, Ecuador, Colombia, and other African and EU countries.

#### 4.1.2 Which definitions and concepts for 'migrants' does HealthQUEST follow?

Definition of the categories of migrants is important but difficult, and is further complicated by the fact that different countries adopt different terminologies that reflect differing policies towards the social integration of migrants. An important distinction is found when it comes to granting health access on equal terms with the resident population, which often depends on legal categories defined differently between countries.

In the 2003 report, *International migration, health & human rights* (WHO, 2003; Carballo and Mboup, 2005), the World Health Organisation (WHO) provides a framework that helps clarify the terminology. A first distinction is made between documented and undocumented (or illegal) migrants. According to the WHO, regular or documented migrants are those people whose entry, residence and, where relevant, employment in a host or transit country has been recognised and authorised by official state authorities. Undocumented or illegal migrants, on the other hand, are people who have entered a host country without legal authorisation or overstayed authorised entry as, for example, visitors, tourists, foreign students or temporary contract workers.

A further helpful distinction can be made between voluntary and forced migrants. "Voluntary migrants are people who have decided to migrate of their own accord (although there may also be strong economic and other pressures on them to move). This includes labour migrants, family members being reunified with relatives and foreign students. Forced migration refers to movements of refugees and internally displaced people (those displaced by conflicts) as well as people displaced by natural or environmental disasters, chemical or nuclear disasters, famine, or development projects" (WHO, 2003).

Alongside the general category of migrants who have moved voluntarily and have documents, the WHO's definitions allow the helpful delineation of two subcategories with particular health needs and barriers in accessing services, namely, asylum seekers/refugees (forced migrants) and illegal immigrants (undocumented migrants).

#### *Migrants and ethnic minorities*

Several EU Member States have been traditional immigrant countries for many years and have a history of migration and multiculturalism. In some cases, migrants have established themselves in the host country and formed distinct subgroups of the population, which may also include descendents of first-generation migrants. At times it is difficult to establish "how long before a group of people thought of as 'migrants' begin to simply

constitute a socially or culturally distinct or ethnic group of residents" (Mladovsky, 2007a), as in the case of African-Caribbean groups in the UK.

Ethnic minorities refer to groups of people with a common origin, common cultural and linguistic features (e.g. religion, norms, and language) and some kind of social organisation or a sense of belonging together (ethnic identity). Such groups may have lived in a country for a long time and can share important issues of barriers of access to healthcare with migrants.

#### *Asylum seekers or refugees*

Following the 1951 Convention Relating to the Status of Refugees of the UN High Commissioner for Human Rights, a refugee is defined as any person who "owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country" (OHCHR, 1951). Asylum seekers, by contrast, are those in the process of applying for refugee status (although many research papers use the terms interchangeably). Failed asylum seekers are either waiting for a decision on appeal, awaiting the means by which to leave the country, or become illegal immigrants if they fail to leave.

#### *Illegal migrants*

Illegal immigrants are defined as persons without a legal residence status in the country. Among them are rejected asylum seekers; foreign workers without a work permit; victims of human trafficking; travellers and tourists who have overstayed the duration validity of their visa; and partners and family members of people whose residence permit is linked to a resident but have lost their legal ties with that person (for instance as a result of divorce).

These different migrant groups have been reported to have –besides some problems that they may share– specific problems of healthcare access. They can also differ in terms of health problems, needs and in the degree to which they are at risk of social exclusion in general. In addition, the evidence suggests that older migrants are at particular risk of not accessing healthcare. There is consequently an individual subchapter devoted to the analysis of each of the groups defined below:

- Migrants and ethnic minorities;
- Asylum seekers or refugees;
- Illegal immigrants; and
- Older migrants.

**Table 4.1: Migrants and people with immigration background**

Source: HealthQUEST country reports

	NUMBER OF INDIVIDUALS	% OF TOTAL POPULATION	MAIN COUNTRIES OF ORIGIN OF IMMIGRANTS
Finland	113,000	2.20%	Russia, Estonia, Sweden and Somalia
Germany	15.3 million	18.60%	Turkey, FYR and Italy
Greece	900,000	8.50%	
Netherlands	3.1 million	19%	Turkey, Suriname, Morocco and Dutch Antilleans
Poland	700,000	1.80%	Germany, Belarus, and Ukraine
Romania	25,000	0.10%	
Spain	3 million	8.70%	Morocco, Ecuador, Colombia, Africa and other EU
UK (England)	3 million	5.20%	India, Pakistan and the Caribbean

## 4.2 Migrants and ethnic minorities

In general, most European countries grant full equality of treatment to migrants who have permanent residency status. Nevertheless, there are other reasons why migrants still experience unequal access to healthcare.

According to Mladovsky (2007a, 2007b), three groups of factors contribute to explain this for the case of migrants with a legal status:

- a) Requirements for obtaining permanent status can be very stringent;
- b) Literacy, language and cultural differences; and
- c) Administrative and bureaucratic factors, lack of knowledge of the system and mistrust of health providers (particularly for undocumented migrants fearing detection).

The barriers to access created by these factors impact on migrants' health, as evidenced by the differential patterns of mortality and morbidity affecting migrant populations (see section 4.2.2). This also influences patterns of services utilisation, inducing increased use of emergency services (Ingleby et al., 2005).

This section begins by providing some basic background information on the main countries of origin and other socio-economic characteristics that are relevant for analysing migrants' access to healthcare. It then considers the health needs of migrants and ethnic minorities and the services available to them, before analysing the barriers to accessing healthcare, using the typology delineated above.

### 4.2.1 The socio-economic situation of migrants and ethnic minorities

An important facet of analysing the health status of immigrant populations is understanding the interaction between deprivation and ethnicity. For instance, using the 2004 EU-SILC survey sample from 14 European countries, Lelkes (2007) shows that migrants from outside the European Union can be exposed to a risk of poverty that is several times higher than for the 'indigenous' population. Migrants of non-EU origin tend to have a risk of poverty nearly twice as high as EU-migrants.

In the **Netherlands**, ethnic minorities account for 23.4% of the total number of minimum-income households, with ethnic minority women being at particular risk of poverty (European Commission, 2007). In the **UK**, ecological research that links utilisation rates to the socio-economic characteristics of geographical areas usually picks up utilisation by people from ethnic minority groups as there is a tendency for such communities to be located in areas of relative deprivation. Similarly, studies that set out to analyse the link between ethnicity and utilisation of services often fail to control for socio-economic differences which often swamp differences picked up by ethnicity variables (Goddard and Smith, 1998). Establishing whether observed variations in utilisation rates between white and ethnic minority groups is an indication of inequity is also subject to methodological difficulties due to higher rates of morbidity in ethnic minority groups for some conditions and lower rates for others. The way in which studies adjust for need is therefore of key importance.

An understanding of the socio-economic situation of migrants is of particular importance for this study. Migrants frequently face very high risk of poverty and

social exclusion. This can contribute to worsen overall health status, which in turn can also often lead to greater risk of poverty. Therefore, more effort to explain the causal links between ill health and poverty could be useful in devising the most effective policies to break those links.

#### 4.2.2 Health and illness patterns

Despite a number of important studies on migrant health, the data available for analysis show significant lacunae. However, there is evidence from a number of countries about specific health challenges of migrant groups in the population. The comparison of several health indicators in different countries suggests that the health status of large immigrant populations is poorer than that of natives, as is their overall perceived health.

Carballo et al. (1998) have reviewed a large literature on some of the main health issues and problems that affect migrants in the EU. Their review found that migrants were at particularly higher risk of contracting TB.

Evidence from the **Netherlands** also suggests that immigrants have both worse health and worse self-assessed health than the native population, although illness prevalence patterns differ across the four main migrant populations. Higher rates for CHD can be found among Turkish and Surinamese people. Prevalence of diabetes is higher among Turkish, Moroccan and Surinamese groups, but particularly among the Asian-Surinamese population. By contrast, breast cancer rates are considerably lower among migrant women as compared to Dutch natives. There is also elevated perinatal and maternal mortality, with Surinamese and Antillean women being at highest risk. Data on mental health problems show older Moroccan and Turkish migrants are at higher risk of depression, with older Turkish women showing the highest depression rates.

In **Germany**, Kyobutungi et al. (2006) analysed patterns of mortality from external causes among ethnic German immigrants from the former Soviet Union. Following a cohort of around 34,000 adults who arrived in Germany between 1990 and 2001, the authors estimate that male immigrants had a 39% higher mortality from all external causes and accidents and 30% higher suicide mortality compared to their German counterparts. They also show that this mortality disadvantage tends to decrease with length of stay. Razum et al. (2004) have also studied the situation of ethnic Germans from the former Soviet Union, observing that health satisfaction deteriorated quickly after immigration (though starting from a better level than in the German background control group, and though socio-economic status improved).

Although overall the age-standardised mortality rate from cardiovascular disease was lower in ethnic Germans than in the non-immigrant population, other studies from a population-based database in the region of Augsburg show that ethnic Germans perceived their health to be worse than other migrants (Wittig et al., 2004; Aparicio et al., 2005). They were more likely to be obese, not to exercise and to have hyperlipidemia. It is important to note that these differences decreased with the length of stay in Germany.

Research from the **UK** suggests that the definition and specification of health needs of migrants is further complicated by what has been named the “healthy migrant effect” (Mladovsky, 2007a). This refers to the health advantage in mortality rates that benefits some migrant groups. Results from a literature review on international migration and health also suggest that migrants groups do not necessarily exhibit a disadvantaged profile in mortality risk (McKay et al., 2003a). However, this effect tends to diminish with the length of stay in the host country and vanishes for second and subsequent generations. McKay et al. (2003b) also note that migrants do not necessarily display worse mental or cardiovascular health than non-migrants. However, migrants “generally tend to exhibit disadvantaged risk factor profiles and are more frequently subject to hypertension, chronic conditions and obesity”.

The information gaps, methodological problems and lack of research that have been described above for migrants also apply in many cases for the evidence that is available on the situation of ethnic minorities. Among the most deprived ethnic groups are the Roma people, who are of particular importance for the HealthQUEST project, as they comprise a substantial share of the population in a number of the countries analysed.

Although there has been more research in their situation in recent years, including from an overall European perspective (Mladovsky, 2007c), reliable information on **Roma** health is still relatively scarce. However, as one commentator has remarked, “the information that does exist paints a bleak picture, pointing to significant gaps in health status between Roma and non-Roma populations” (Ringold et al., 2005).

Roma are estimated to live about 10 years less than the general population in Central and Eastern Europe. In **Romania**, the infant mortality rate among Roma children was found to be two times higher than the national average. Mladovsky (2007c) points out some of the major problems faced by this group. Traditionally, communicable diseases have accounted for the most part of the burden of disease. Major problems include TB, measles, sexually transmitted infections and child health problems, in particular malnutrition. Moreover, in recent years the prevalence of chronic diseases (e.g. cardiovascular diseases, hypertension and obesity) has also become increasingly important.

The situation of the Roma also highlights the relationship between poverty, poor health and lack of access to healthcare. In **Greece**, the living conditions of the Roma population are notoriously poor. Many live in plastic tents, lack basic utilities (electricity, water, heating, toilets) and endure unacceptable environmental and sanitary conditions of living. An international survey by the NGO Doctors of the World (Programme ROMEUROPE, 1999) directly associates the poor living conditions in the settlements with the poor health of Roma tent-dwellers in Greece. The results of hepatitis tests in the Municipalities of Nea Liosia and Aspropyrgos of Attica District, for example, are significant: 99% of the population has been exposed to hepatitis A in addition to hepatitis B (50%) and 18% are carriers while the healthy remainder of 32% are aged 10 to 18, most of which go to school. The prevalence of chronic diseases (cardiovascular and respiratory diseases and depression) and dental problems is also elevated.

#### 4.2.3 Coverage and health basket

Most countries provide some level of coverage for immigrants who have acquired a residency status. In some cases, however, this happens only after they have stayed for a minimum period in the country, which can severely limit their access to healthcare. Table 4.2 provides an overview of the regulations governing coverage for ethnic minorities and documented migrants.

In the **UK** and the **Netherlands** migrants with a residency status are entitled to the same access as any other resident. In **Finland**, immigrants are entitled to the same basic coverage available to natives, after a period of one year, or from their arrival in the country if they intend to stay for at least one year and have a residence permit, if required. They are also liable for the same cost-sharing requirements.

As mentioned above, migrants who are eligible for the main system of coverage are normally subjected to the same cost-sharing regulations as others in the population. Nonetheless, given the overall more fragile financial situation of migrants, this has resulted in problems in some cases. In **Greece**, for example, migrants report high out-of-pocket expenditures and there are suggestions that for only a small proportion (2%) of the hospital treatment they receive benefits from the system of health-book for the uninsured. In **Spain**, where co-payments exist only for drugs, there is evidence that financial hardship negatively affects the use of medication among migrants. In a study carried out in an area of Andalusia, 24.2% of immigrants were unable to obtain the medication they needed mainly due to lack of finance (Vilarmau, Vila, 2003). In **Germany**, there are suggestions that cost-related barriers tend to affect migrants more than others, partly because exemption mechanisms require writing skills and healthcare literacy. In many cases migrants have low socio-economic status and face a double burden of having to share earnings with more dependents, both in the host country and in the home country.

**Table 4.2: Coverage and cost-sharing regulations for migrants and ethnic minorities**

Source: HealthQUEST country reports (NB no information available for Poland)

	COVERAGE UNDER PUBLIC PROGRAMMES	COST-SHARING
<b>Finland</b>	Migrants are entitled to same rights as any Finnish resident if they have been resident in Finland for at least one year, or from their arrival to the country if they intend to stay for at least one year and have a residence permit, if required	Same as general population
<b>Germany</b>	Mandatory coverage by SHI for immigrants who have an allowance to settle down (Niederlassungserlaubnis) or an allowance to stay (Aufenthaltslaubnis) for more than 12 months, and who have not been required to earn their own living (and contribute to SHI accordingly)	Same as general population
<b>Greece</b>	Access to welfare system is limited even for migrants with residence permit. Ethnic minorities have the same rights as the general population	Migrants report high out-of-pocket expenses and low take-up of coverage for non-insured
<b>Netherlands</b>	Migrants with residency status are entitled to same access as any Dutch resident. New immigrants only eligible for long-term care under AWBZ after 12 months	Same as general population
<b>Romania</b>	Foreigners with residence permit are covered if they can pay premiums. Foreign children automatically covered	
<b>Spain</b>	Residents, minors and pregnant women have complete coverage. Dental care is not covered	As for natives, residents have co-payment only for medication. In some cases, there is evidence that financial hardship affects use of medication
<b>UK (England)</b>	Migrants with residency status are entitled to same access as any UK resident	Same as general population

#### 4.2.4 Healthcare services utilisation

In terms of use of services, some degree of variation across migrant groups has been reported in the **UK**. Primary care consultation rates are higher for some groups (South Asians, Pakistani, Indian, Bangladeshi), but lower for others (e.g. Chinese). Utilisation of specialist outpatient and inpatient care appears lower amongst ethnic minority groups than white groups with equivalent need characteristics. Most research has been done in cardiac services where the focus has been on lower rates of surgical procedures such as revascularisation and angioplasty amongst some groups (South Asian). In the area of mental health problems there is a generally consistent picture of greater than expected rates of diagnosis and compulsory forms of psychiatric treatment amongst black patients than amongst their white counterparts.

Evidence from Finland suggests that immigrants generally use health services less than the general population, except women aged 15 to 29 years, who have more hospitalisations and hospital outpatient visits, in particular in connection with pregnancy and childbirth. Although the evidence is not extensive, a few studies have investigated the quality of healthcare received by immigrants. One survey (Pohjanpää and Seppo et al., 2003) investigated living conditions of Russians, Estonians, Somalians and Vietnamese in Finland. The majority of the immigrants considered healthcare services in Finland to be relatively good. Most critical were Russians, of whom one fifth were dissatisfied with the services provided. Degni (2004) studied the use of contraception among Somali women focusing on the interaction between Somali women and public health nurses during consultation visits. The lack of common language was reported to degrade social interaction, which led to misunderstanding in both ethical and cultural matters.

In the **Netherlands**, the evidence suggests that non-western migrants use more GP services when compared to native Dutch (Foets et al., 2005). When adjusted for socio-economic status, age and health status, these differences diminish considerably (Kunst et al., 2006). For some migrant populations, under-utilisation of other services has been reported for physiotherapy, home care, medications and specialist services, but research outcomes are not consistent and differ across groups. Overall, differences in care utilisation are considered to be small, with a slight over-utilisation of medical specialist and hospital care. However, adjusted data indicate that older (55+) Turkish and Moroccans visit medical specialists less often than their native Dutch counterparts. It has been argued that this could point towards unmet care demands among the first generation immigrant population (Westert and Verkleij (eds.), 2006). Differences seem to decrease for second-generation migrants (Droomers et al., 2005; Lanting et al., 2007).

With respect to outpatient mental health services, migrants use these four times more often (Kunst et al., 2006). This might be related to higher mental health needs of migrants. However, given that need, the relative under-utilisation of inpatient mental health services reported in the same study is a cause for concern. A study of outpatient mental health services in Amsterdam also revealed that Moroccan and Turkish patients were treated for a shorter period of time than native Dutch and Surinamese patients, calling quality of care into question. Use of medication was equal in all groups (Schrier et al., 2004).

In **Spain** there is also some evidence to suggest that migrants under-use psychiatric services. Perez-Rodriguez et al. (2006), for example, have analysed data on psychiatric emergency room attendances and hospitalisations in the main provider of services to the immigrant community in Madrid. Results suggest that immigrants had lower rates of psychiatric emergency visits and hospitalisation admissions compared to the native population. Visits per user and readmission rates were also lower, and suicide attempts more frequent among immigrants.

#### 4.2.5 Barriers of access to healthcare

There is normally a variable pattern between groups and between diseases in terms of the tendency to seek help. In a study of reasons for inpatient admission for asthma in the **UK**, for example, South Asians talked about their illness in passive terms and were more likely to be admitted than white people. In contrast, pregnant Chinese women had low attendance at antenatal care because they did not view pregnancy as a health problem and obtaining confirmation of pregnancy was not a high priority for them (Chan, 2000). It would be simplistic, however, to attribute differences, especially with respect to help-seeking behaviours, merely to lay beliefs and cultural differences.

Just as important, if not more so, are other influences on help-seeking behaviour. These relate to the difficulties of mobilising the resources necessary to access care which (in common with barriers faced by socially disadvantaged groups in general) include lack of easily accessible information about what is available and difficulties in organising the social and practical support necessary to facilitate attendance for treatment, especially out of opening hours or where services are distant. These are overlaid with specific problems related to the challenges faced by those who do not speak the national language. So for example, organising a bus journey to a distant provider may be difficult for anyone from disadvantaged circumstances because of the cost of arranging care for dependents, especially if they are a lone parent. Reluctance to use family and children as interpreters and fear or lack of confidentiality means even if translation is available it may not be taken up.

This section considers three particular barriers of access to healthcare faced by migrants: requirements for obtaining residency; literacy, language and cultural differences; and bureaucratic and administrative factors.

#### *a) Requirements for obtaining residency*

One of the main hurdles for getting coverage under public programmes, and consequently access to healthcare is the often complex and time-consuming administrative process for obtaining documents, including work and residence permits and health insurance papers. Countries differ in the specific ways these hurdles may affect access but they are reported for a number of countries.

One of the main barriers to access to health services in countries such as **Spain** and **Greece** is obtaining the documents to register as a resident. Lack of knowledge of the immigration law and fear of contacting authorities are some of the reasons that lead people to fail to provide documents necessary to be eligible for healthcare coverage.

The complexity of the legislative framework for the acquisition of work and residence permits is a predominant barrier to migrants in **Greece**. The extensive legislative process of the Greek state intensifies the debate of immigration and highlights legislative weaknesses. Acquiring a residence permit is characterised by inflexible, complex and costly administrative procedures. Competent authorities do not provide assistance with interpreters or special explanatory leaflets and legal support for migrants.

Similarly, the Roma population in **Greece** and **Romania** faces especially severe problems because of lack of documents. This is reflected in low coverage rates under publicly funded healthcare programmes and has serious implications, leading to low rates of infant vaccination and to discontinued treatments. A recent publication from the Council of Europe Commissioner for Human Rights (Gil-Robles, 2006) notes that the lack of identification documents is often one of the main factors limiting access to healthcare for the Roma. In many cases Roma individuals cannot afford the cost connected with the issue of birth certificates. Gil-Robles (2006) argues that the authorities should facilitate and reduce the costs for obtaining birth certificates and other identification documents in order to improve access to healthcare among the Roma.

#### *b) Language and cultural barriers*

The issue of interpretation services has received considerable attention in **Finland**. According to the ongoing *Equality in Health Study* (Kuusio and Kuivalainen) the main concern in provision of health

services were interpretation services, which need more resources to meet the need. Also the need for more capable interpretation services was a concern. From the point of view of healthcare, plain translation does not suffice in many cases, but interpreters who are also skilled in cultural interpretation are needed. This problem is especially relevant for mental health services, where diagnosis is culture-sensitive and it is necessary to decide whether a professional with the same or different cultural background is needed to ensure successful therapy. The Swedish-speaking minority also have difficulties in getting services in their own language especially in **East-Finland** and in small municipalities with a Finnish-speaking majority (Kalland and Suominen, 2006).

In **Spain**, the lack of knowledge of entitlement and of mutual understanding between users and staff has been shown to limit the use of services among immigrants. Health personnel have also reported difficulties in handling culturally challenging situations such as bigamy and clitoral excision (Vilarmau Vila, 2003; Agència d'avaluació de Tecnologia i Recerca Mèdiques, 2004).

Evidence from the HealthQUEST country reports suggests that the Roma are one of the ethnic minorities most affected by cultural differences. Roma individuals are also often stigmatised and victims of discrimination. In **Greece**, for example, in spite of legal equality it has been found that cultural differences can lead to access difficulties for this group. Roma lack awareness of their legal entitlement to benefit, often distrust healthcare providers and feel the staff are not accommodating. A very difficult barrier to access concerns the lack of any translation services in healthcare units.

In some cases, there is also evidence that discrimination leads healthcare providers to refuse treatment for Roma patients. Gil-Robles (2006, p. 29) argues that "the reluctance of doctors to receive Roma patients is among the reasons cited for the fact that 30% of Roma in **Romania** are not registered with general practitioners, and that many Travelling families in the **UK** had been refused registration with a doctor or health treatment of some kind".

#### *c) Administrative and bureaucratic factors*

It is quite often the case that migrants come from countries with very diverse health systems, which can differ greatly from the one they find in the host country. Moreover, migrants can display different attitudes towards health and illness, and different patterns of health-maintaining behaviour (see Dixon-Woods et al., 2005, p. 139, for examples related to the **UK**). Together with the language problems described above, these characteristics can lead to problems that can limit access to healthcare.

In **Spain**, the lack of information and fear of contacting authorities have been shown to limit access for some categories of migrants. According to a study by Doctors Without Borders carried out in Madrid in 2005, 31% of immigrants had not accessed healthcare because of ignorance of the system itself, 8% had not accessed it due to ignorance of their rights, and 29% due to lack of knowledge of administrative procedures (Médicos Sin Fronteras, 2005). In response there have been initiatives such as the *Guide to Healthcare for Immigrants*, edited by the Department of Employment and Social Affairs of Murcia, which aimed to facilitate relations between foreigners and the SNHS, providing basic information about the health system, the services offered and the methods of access. The *Guide* is published in Arabic, English and Spanish.

The lack of knowledge of the scope of the health basket affects the patterns of use of care. Almost 30% of resident immigrants in **Spain**, although entitled to other categories of services, use only emergency care (both primary and specialist) (Vázquez et al., 2006). Although this solves some specific problems, the quality of care is often compromised, since there is, for example, frequently no follow-up (Vázquez et al., 2006).

Schemes, such as 'Accessing the Inaccessible' in the **UK**, provide a variety of interventions aimed to improved health literacy of ethnic minorities (Stegeman and Costongs, 2004). The programme offers training in drug awareness of Asian community volunteers, as mediators for the community, spreading information, support and knowledge through information packs, information stalls, community events, community drugs awareness courses, rehabilitation services, language information and treatment. This low barrier initiative builds bridges between isolated groups from the community and health services, through the use of mediators, the building of partnerships and participation/empowerment of the community. This bottom-up approach enables local issues to influence partners' agendas and policy-makers.

In **Finland**, no research is available on access to healthcare services by Roma people, and no research regarding discrimination. However, it should be noted that the Roma people are a stigmatised ethnic minority, and discrimination of Roma in healthcare services is probable. Roma people are not always aware of how to find information regarding healthcare services or what kinds of services are available (Ministry of Social Affairs and Health, 1999).

Geographical barriers are especially important for the Sámi in **Finland**. Distances to healthcare services in the Sámi area in Northern Finland are long and the number of healthcare centres has been reduced in northern Finland. This affects access to healthcare services, especially among elderly Sámi.

In **Germany**, 98% of inhabitants with immigrant background are living in the western part of the country or in Berlin, and 2% in the new *Länder* in the eastern part. Most live in metropolitan and urban areas (Statistisches Bundesamt, 2007) and are thus, in general, less affected by geographical barriers to healthcare access than inhabitants without immigrant background. However, geographical barriers affect in the same way immigrants who are living in rural areas. Racism in public places and public transport may pose an important barrier for migrants, particularly in areas with a low density of migrants and little experience of living in multicultural settings as in the eastern part of Germany (Stakeholder information from Thomas, 2007).

In **Spain**, there is variation across the different regions in the level of health coverage for immigrant individuals according to their legal situation (Puig-Junoy et al., 2006). Some Autonomous Communities provide coverage similar to state law (e.g. Aragón, Asturias, Cantabria, Castilla la Mancha, Canary Islands, Galicia and La Rioja), others provide full healthcare for residents and non-residents independently of their legal or administrative situation (e.g. Balearic Islands, Castilla León, Madrid, Basque Country and Andalusia) and others still provide full coverage for residents independently of their legal or administrative situation (e.g. Murcia, Extremadura, Navarra and Catalonia).

#### 4.2.6 Policy and practice initiatives

One of the most relevant examples of good practice is that targeted at the Roma ethnic minority group through the 'Roma Health Mediator' programmes (see Box 4.1). Roma Health Mediators are agents specially trained to inform and to advise the members of Roma community in the fields of education and health. The system has been tested in **Romania** during the last five years. **Finland** and **Romania** are leaders in the field of Roma Health Mediators and provide a model of good practice that could be rolled out to other EU Member States (Borke, Wilkens, 2006), and adapted for other vulnerable groups and inform systems change.

In Spain, the Health Boards of different Autonomous Communities have promoted a series of initiatives aimed at improving healthcare for the immigrant population and reducing linguistic barriers. An example of this is the *Guide to PHC Action for the Immigrant Population* and medical appointment forms for foreigners who have difficulties understanding Spanish (Arabic, Bulgarian, Chinese, French, English, Romanian, Russian, other population groups in the community) (Castilla la Mancha); the *Immigration and Health* guide for AP professionals (Aragón); a *Plan to Train Professionals Attending to the Immigrant Population*; and the translation of educational health material into different languages (Catalonia). At the

#### BOX 4.1: ROMA HEALTH MEDIATOR PROGRAMMES

A recent evaluation of EU Member States' government strategies to improve access to health services and social inclusion of Roma people has provided evidence on the potential effectiveness of Roma Health Mediator programmes (Open Society Institute, 2005) in the EU.

Roma Health Mediators are individuals from Roma communities who play a crucial role in the promotion of Roma health. They mediate between Roma patients and physicians during medical consultation, communicate with Roma communities on behalf of the public health system (by visiting the ill and convincing them to see a doctor, encouraging pregnant women to get antenatal care, informing the community about family planning and how to prevent sexually transmitted infections and reminding individuals of the need for child vaccination), provide basic health education and assist Roma in obtaining health insurance or identity documents necessary to visit the doctor.

In the 2006 evaluation, Roma Health Mediators were shown to "reduce bureaucratic and communication obstacles to improved

health by facilitating patient/doctor communication and assisting clients in navigating bureaucratic procedures relating to health insurance and social assistance", and to enable community empowerment through health literacy approaches and provide great assistance to individual Roma clients.

However, the Open Society Institute warned that Roma Health Mediators should be combined with adequate training of mainstream healthcare staff, to encourage them to adopt a health promotion approach to health and patient education, in order to avoid Roma Health Mediators being the sole mediators of understandable essential information. In fact, laws such as that in place in the Netherlands should ensure that it is the health professional's responsibility to communicate in a language understandable to the patient. Furthermore, Roma Health Mediator programmes could be improved to better address issues of discrimination, patient financial limitations and particular needs of doubly marginalised groups and facilitate individual and community health empowerment.

Source: Open Society Institute (2005)

state level a Strategic Citizen and Integration Plan (2007–2010) has been created. This plan underlines the importance of guaranteeing immigrants' rights to the protection of health and effective access to the healthcare system as one of the objectives in the context of integral healthcare. Another objective is to treat not only the illness, but also the patient's social environment, support network and quality of life

In **Germany** (Box 4.2), 'scout services', provided by migrants for migrant patients, have been developed. The MiMi project is a very good example of best practice in the field of health promotion improving access to health services by linking migrant populations to health services.

The 'Bridge' programme in Rotterdam in the **Netherlands** (Box 4.2), targeted at migrant women with psychosomatic symptoms, has also achieved the provision of culturally sensitive information, counselling in migrants' native language and liaison with health services via migrant health educators.

### 4.3 Asylum seekers and refugees

Norredam et al. (2006) argue that a host of pre- and post-migration risk factors contribute to increase the vulnerability of asylum seekers, particularly in their access to healthcare. Pre-migration factors include torture and refugee trauma, while post-migration

factors may include detention, length of asylum procedure, language barriers, and lack of knowledge about the new healthcare system. As with other categories of migrants, these factors often interact with a component of deprivation in the host country. Asylum seekers also frequently experience social exclusion.

This section begins with a brief description of the countries of origin of most refugees and asylum seekers within the countries considered in the HealthQUEST project. An overview is then given of the health and illness patterns of asylum seekers and refugees and the baskets of services available to them are analysed. This section moves on to look at particular barriers to accessing healthcare services and concludes with an analysis of particular policy initiatives that have been put in place to improve access.

#### 4.3.1 Main countries of origin

Table 4.3 shows the main countries of origin for asylum applicants and the rates of successful applications in the period 2001–2006:

As the table shows, some of the main countries of origin of asylum seekers currently include (by order of total number of applications in 2006) Iraq, the Russian Federation, Afghanistan, Pakistan, Iran and FYR states. In 2006, the countries with the greatest numbers of successful asylum applications were the **UK, Germany,**

## BOX 4.2: INTERCULTURAL MEDIATORS

With Migrants for Migrants (MiMi)<sup>8</sup> is a **German** intercultural health project serving migrant health through multilanguage and culture-sensitive interventions in health promotion and prevention. MiMi aims to promote immigrants' health responsibility and awareness in order to provide equitable health opportunities in the long term. Central to MiMi is the concept of health mediators. Individuals from immigrant backgrounds are trained on health issues and act as contacts for target groups, supported by partnerships between immigration services, health services and immigrant associations. This highly participatory approach to health promotion designed to improve access to health services and health information has enabled the dissemination of information about health-related knowledge and a coordinated action in healthcare. In 2003, MiMi compiled a health guide, continually updated, available to all partners free of charge. The trained health mediators deliver the campaign stage of MiMi through information events on health issues in their native languages. The project builds capacity to deal with health-related problems, strengthens community work and development, and provides education and information to target populations. The use of intercultural mediators as multipliers and links between health services and migrant populations appears to be a very successful approach to health promotion and improves access to health services and information. MiMi also integrates fundamental principles of active participation of migrant groups and involvement thus enabling these disadvantaged groups to gain control over their health and improve self-worth, feeling of being valued in society

and social inclusion. This participatory approach also ensures sustainability of the project.

In the **Netherlands**, migrant health educators have been active in a liaison role in primary care since 1996. They provide culturally sensitive information and counselling in migrants' native language, support the communication between GP and patient and inform the primary care provider on culture-specific matters. Such peer-based models have proven to be successful in improving health information and delivering culturally sensitive health promotion. (Voorham, 2003). The 'Bridge' programme (Joosten-van Zwanenburg et al., 2004) in Rotterdam is an example of how this approach has been built on to improve communication and health beliefs. Targeting migrant women with psychosomatic symptoms, the programme's migrant health educators helped to clarify health problems and their implications, transferred specific knowledge and advice on dealing with psychosomatic symptoms and helped to ensure doctors and patients fully understood each other. The evaluation of a randomised control trial of the project demonstrated its impact and showed improved communication, better GP insight into and understanding of patients' personal problems, and enhanced doctor-patient relationship. Patients were better able to cope with symptoms, felt more supported and better informed by their GPs, reported better understanding of their GP's messages and followed the doctor's advice more often. The migrant health educators' counselling sessions also led to improved perceived health and mental health.

Source: HealthQUEST country reports

the **Netherlands** and **Greece**. The rates of successful asylum applications vary among recipient countries and had an increasing trend in some countries.

### 4.3.2 Health and illness patterns

There is a large body of evidence that outlines the specific health problems often experienced by those seeking asylum. However, similarly to the situation of migrants and ethnic minorities, not all of their health problems are necessarily linked to refugee status but often overlap with those associated with deprivation and ethnicity.

An important aspect to note is that health problems can worsen after arrival in the host country; some studies suggest a steady decline (for evidence on the

UK see Kralj and Barriball, 2004). An in-depth interview study of destitute asylum seekers in south-east England (Dumper et al., 2006) reported that almost all felt their physical and mental health had deteriorated since arrival in the **UK** and a majority said they felt depressed or suffered symptoms such as stress and sleeplessness. Research in the **Netherlands** suggests that mental health of asylum seekers deteriorates with length of stay due to acute stress factors linked to living conditions, inability to work, frequent relocation and lack of independence (see Laban et al., 2004).

In terms of morbidity, specific problems experienced by asylum seekers in the **UK** include: physical after-effects of war, torture and journey to the UK; greater risk of communicable diseases (e.g. HIV/AIDS, hepatitis, TB); mental health problems, either following trauma of war or torture or as a result of coping with a new culture and loss of their home (Bardsley and Storkey, 2000; Burnett and Peel, 2001). Evidence suggests that the prevalence of mental health problems among asylum seekers in the **Netherlands** is also quite high, with 68% reporting depression/anxiety and 28% post-traumatic disorder (PTSD).

<sup>8</sup> With Migrants for Migrants – Intercultural Health in Germany <http://www.health-inequalities.eu/?uid=8566e282133e63c137dccc7db2d2efa&id=search3&sid=list&idx=203&x=detail> – from *Closing the Gap*.

**Table 4.3: Asylum seekers: Main countries of origin and percentage of successful applications**

Source: Eurostat

	FINLAND	GERMANY	GREECE	NETHERLANDS	POLAND	ROMANIA	SPAIN	UK
2002	20.8	4.7	N/A	6.8	N/A	11.7	4.4	N/A
2003	16.9	4.0	N/A	16.2	4.1	14.4	5.8	16.4
2004	18.9	4.5	0.6	21.5	24.3	18.2	5.5	11.5
2005	18.5	6.9	2.7	34.4	26.9	11.7	6.7	16.3
2006	31.1	6.8	0.3	22.7	44.5	16.9	5.0	19.8
Mean	21.2	5.4	1.2	20.3	25.0	14.6	5.5	16.0
Total applications <sup>†</sup>	2,255	20,180	12,045	13,410	4,190	355	5,280	28,285
	Bulgaria, FYR, Iraq, Russian Federation	FYR, Iran, Iraq, Turkey, Russian Federation	Bangladesh, Pakistan, Iraq	Iraq, Afghanistan, Azerbaijan, FYR	Russian Federation	Iraq, Somalia, China	Colombia, Nigeria, Morocco	Eritrea, Iran, Afghanistan

Figures represent percentage rates of positive decisions over total number of decisions plus pending applications.

<sup>†</sup> 2006; N/A: Not available

The mobility of populations after arrival creates other problems with healthcare treatment. The dispersal of asylum seekers with HIV may lead to increased medical and psychosocial problems for the people affected as well as an uncertain impact on the spread of HIV/AIDS (Creighton et al., 2004). Enforced dispersal of non-indigenous peoples to areas with little previous ethnic diversity can stigmatise. People are sometimes dispersed without adequate supply of drugs and without case notes, which can make treatment difficult (Yoganathan, 2004). A survey in **Germany** showed that asylum seekers had little knowledge about disease transmission, prevention and treatment as well as about the availability of anonymous testing (Steffan, Sokolowski, 2005).

In addition, some limited evidence has become available on the mortality risk of asylum seekers. The **Netherlands** is among the few countries that provide some evidence on this issue, suggesting that standardised mortality rates are similar for asylum seekers and the Dutch population, but with distinct age profiles. In the **Netherlands**, the mortality rate among male asylum seekers in the age groups 5 to 19 and 20 to 29 is twice as high as for their Dutch counterparts, but for men aged 40 to 64 mortality rates for male asylum seekers are twice as low. Infant mortality is twice as high compared to Dutch infants and primarily due to congenital abnormalities.

In the **Netherlands**, the most frequent cause of death for men is external (including accidents, drowning and suicide). Here, the mortality rate for men is twice as high compared to Dutch men, but no differences were found for women. Asylum seekers are five times more likely to die of an infectious disease, HIV/AIDS being the most frequently occurring cause of death (GGD Nederland, 2006a).

### 4.3.3 Coverage and health basket

Table 4.4 below presents a summary of the main coverage regulation for asylum seekers in the countries studied. A common aspect is that in most countries asylum seekers are entitled to at least basic treatment for acute diseases. Nevertheless, current regulations in some countries impose severe limitations on the entitlement of asylum seekers to healthcare services under public programmes. This can have severe consequences for the access to medical attention and the health situation of asylum seekers.

In **Finland**, health services for asylum seekers are provided in their assigned reception centre or in the health centre of the municipality their assigned reception centre is located in (Lukkaroinen, 2005; Malin and Gissler, 2006). All asylum seekers undergo a basic health screening by a nurse. They also have access to municipal healthcare if they require urgent medical treatment or essential dental treatment. These services are free for asylum seekers.

In **Germany**, asylum seekers are covered by a specific governmental scheme. However, the benefits covered are explicitly limited to acute care, maternity care and pain relief. Thus, chronic diseases (e.g. high blood pressure, coronary heart disease) are not covered officially and mental problems are not clearly covered. In addition, access to healthcare requires an application to the local office either by the migrant or by the provider.

In **Greece**, recognised refugees and asylum seekers who have submitted an official asylum request receive a card that entitles them to free medical, pharmaceutical and

**Table 4.4: Coverage regulations for asylum seekers**

Source: HealthQUEST country reports

<b>Finland</b>	Free services provided through the assigned reception centre. Municipal health system can also be accessed for urgent treatment
<b>Germany</b>	Covered by a specific governmental scheme with no co-payment, but limited to acute care, maternity care and pain relief
<b>Greece</b>	Free healthcare provided to those who have received a card. Those not in possession of the card are not covered and severe delays are registered in the card issue
<b>Netherlands</b>	Agreement between COA and a private insurer covers asylum seekers for health and long-term care costs, with coverage similar to standard baskets. There is no free choice of physician and dental care for 18+ is restricted to acute treatment/pain relief
<b>Poland</b>	Asylum seekers entitled to free medical care: first doctor contact takes place on reception centre and further treatment available upon referral. Transportation costs are also refunded
<b>Spain</b>	Asylum seekers receive care in reception centres and can also access the health system. Accepted refugees covered by public system on equal grounds as general population
<b>UK</b>	Free access to (applicant and dependents): accepted refugees; those given leave to remain; asylum seekers: waiting for a decision, appealing against a decision or detained in detention centres  Failed asylum seekers: no right to NHS, except emergency services, sexually transmitted diseases (except HIV/AIDS), communicable diseases, family planning, compulsory psychiatric care and A&E; user fee for secondary care not considered "immediately necessary"

hospital care. However, severe delays have been registered in the emission of these cards due to staff workload. Asylum seekers not in possession of the card are not eligible to medical treatment and their access to medication is also severely restricted.

In the **Netherlands**, those who have applied for asylum status are covered for health and long-term care costs via a mandatory arrangement between the Central Agency for the Reception of Asylum Seekers (COA), which is responsible for the accommodation of asylum seekers, and one large health insurer, VGZ. Coverage is similar to the Zvw standard healthcare basket and the AWBZ basket. Dental care for people over 18 is, however, restricted to acute treatment or pain relief that can be dealt with in one session. VGZ purchases health and long-term care services with mainstream service providers. Asylum seekers are not free to choose their own physician. GPs receive a higher (factor 1.75) fee for asylum seeker patients.

The COA contracts preventive health services from the local 'municipal health service' (GGD). GGDs provide preventive health services based on local authorities' statutory responsibility in this area. On behalf of all GGDs, their national association has set up regional partnerships to this effect: the Community Health Services for Asylum Seekers (MOA) (GGD Nederland, 2006b).

The prevailing majority of people applying for refugee status in **Poland**, in the course of the on-going proceedings, stay in so-called reception centres, in isolation from the Polish society and normal life. They receive small funds from the government and a lump sum for basic hygiene expenses. The refugee centres

provide full board and learning aids for children. Moreover, their expenses incurred for transportation and medical examinations ordered by physicians are refunded. They have full access to healthcare. The doctor of first contact is available on-site, and they are entitled to further treatment, specialist or hospital, upon obtaining a referral. Non-government organisations, in particular the Helsinki Foundation, the Polish Red Cross, the Polish Humanitarian Organisation and Caritas Polska, assist in providing care services for refugees.

In **Spain**, asylum seekers in so-called Refugee Reception Centres have the right to receive medical care in the event of a medical need and receive information on how to enter the health system. The Red Cross and the Social Work Unit of IMSERSO (Institute for Elderly People and Social Services, Ministry of Employment and Social Affairs) provide healthcare services. Once applicants have been granted asylum they can use social services, education and health services provided by the government the same way as any Spanish citizen, either directly or via an NGO (Alto Comisionado de las Naciones, 2006).

In the **UK**, full access to free NHS care is available to: those who have been accepted by the Home Office as a refugee; those who have made an application for asylum and are awaiting a decision; those who are appealing against a decision; those who have been detained by the immigration authorities in detention centres; and those given leave to remain in special circumstances. This applies to the applicant and all their dependents. Failed asylum seekers have no right to access the NHS, except in the case of A&E

services, sexually transmitted diseases (except HIV/AIDS), communicable diseases, family planning and compulsory psychiatric care.

A recent consultation with ministries and NGOs presents some evidence on the access to healthcare for asylum seekers in the EU (Norredam et al., 2006). Almost all responding countries provide medical screening programmes for newly arrived asylum seekers. Programmes are not always compulsory and include screening for HIV/AIDS and TB, and physical and mental examinations.

Access to general healthcare, however, is much more restricted. The study reports that 43% of the countries impose legal restrictions on the access to healthcare for adult asylum seekers. 33% of the countries impose limits on access for children and 24% for pregnant women.

#### 4.3.4 Healthcare services utilisation

As described above, asylum seekers have major healthcare needs, in particular with respect to mental health problems, which are frequently compounded by deprived living conditions and poor housing. Nevertheless, where available, evidence suggests that these health needs are not being met and that asylum seekers do not access healthcare on equal terms with other population groups.

In the **Netherlands**, although asylum seekers' health needs may be considerable, their overall utilisation of services, including GP services, seems to be similar to the general population (Oort et al., 2003). A similar picture emerges for the utilisation of mental health services, where the very high prevalence of mental health problems is not reflected in a high utilisation of services. Only 14% of all complaints related to mental health lead to a referral to mainstream mental health services. Cultural factors may impact on the uptake of services. Findings for a survey of asylum seekers from Somalia suggest less contact with a GP, less use of mental health services and of medication compared to other groups of asylum seekers (Gerritsen et al., 2005).

Evidence from **Ireland** on the use of paediatric services suggests that asylum seekers' children are less likely to have seen a GP prior to emergency attendances, more likely to go to hospital by ambulance and less likely to be subsequently admitted (Prendiville et al., 2007). This suggests an over-dependence on emergency paediatric hospital services in this population.

As detailed above, asylum seekers in **Germany** are not covered on similar grounds as the general population. In particular, the lack of coverage for chronic diseases and mental health problems combined with other non-treatment related costs (especially transport) affects utilisation of services by asylum seekers.

#### 4.3.5 Barriers of access to healthcare

Several countries have recently implemented changes in the regulation of asylum requirements, arguably with the intention of restricting the inflow of asylum seekers and even forcing out those currently in the country (Norredam et al., 2006). Requirements for obtaining refugees status and the regulations on access to healthcare (for both asylum seekers and failed asylum seekers) have become more severe. A consequence is that such changes in immigration policies can sometimes impact negatively on access to healthcare.

An example is the case of the **Netherlands**, where immigration laws have become stricter over recent years. This has led to a reduction of new applications and of the absolute number of asylum seekers. Consequently, the number of asylum seekers' centres more than halved between early 2004 and late 2005. Asylum seekers living in a centre that is closed down are then faced with relocation to another centre, which may be in a different part of the country. Ties with local health service providers and other services –including education– are cut and have to be rebuilt somewhere else.

In **Germany**, co-payments do not apply for asylum seekers who are covered by their specific scheme. However, social income for this group is below social assistance and often issued in the form of tokens (for food) rather than in cash. This can give rise to a cost-related barrier and can impact on the affordability of non-covered services (such as transport, for example). Moreover, as opposed to other migrant categories, which tend to concentrate in urban areas, asylum seekers in **Germany** are more equally distributed across the territory and have restricted allowance to move around the country. Consequently, they face more stringent geographical barriers. This is further complicated in areas where xenophobia and racism are prevalent and limit their readiness to access public spaces and transport, sometimes also in order to seek healthcare.

Failed asylum seekers are also exposed to increasingly restrictive measures, as in the case of the **UK**. Until 2004, this group had free access to the full basket of services provided by the NHS. Since 2004, however, all secondary care for failed asylum seekers in the UK has been subject to a charge unless deemed by a healthcare worker to be 'immediately necessary'.

These are the same rules that are applied to visitors and reflect the attempt to address 'medical tourism'. In 2004, proposals were also made to withdraw access to free primary care services unless also immediately necessary or life-threatening but at present this has not been enforced and GPs can use their discretion to add failed asylum seekers and illegal immigrants to their lists (Hargreaves et al., 2005).

#### BOX 4.3: SPECIFIC COMMUNITY HEALTH SERVICES FOR ASYLUM SEEKERS (MOA)

In the **Netherlands**, every asylum seekers' centre has a MOA health service department staffed with practice nurses and general practitioners. Key responsibilities include (GGD Nederland, 2005):

- Provision of preventive health services such as immunisation programmes for 4 to 19 year olds and infectious disease control;
- Referral to healthcare, mental health services and long-term care covered by VGZ;
- Coordination of service provision within the mainstream Dutch healthcare system, including transfer of medical records in case of relocation to another asylum seekers' centre or grant of residency;
- Socio-medical advice on request. This also includes advice to the Ministry of Justice on medical needs in case asylum is rejected and the person is to be repatriated;
- Crisis intervention.

For access to mainstream health services the MOA practice nurse is always the first port of call. The practice nurse then decides whether referral to mainstream services –including a GP– via the GGD is necessary: in 35% of patient contacts this is

indeed what happens. It is not clear whether this role of the practice nurse leads to more efficient use of GP services, but it is sometimes perceived as an extra hurdle by asylum seekers (Gerritsen et al., 2005). On the other hand, the MOA practice nurse is trained to provide culturally sensitive services and to understand the often complex needs of asylum seekers, helps to bridge the gap with mainstream providers, and coordinates services when necessary. The rationale behind the system may be apparent to native Dutch people, but confusing to people from non-western cultures.

MOA services are only available during office hours: the COA purchases out-of-hours services via the health insurer as part of the mainstream care package. Given the specific health needs of asylum seekers (vulnerability to injuries and accidents, mental health), this could lead to delay and confusion.

The Healthcare Inspectorate reviewed the MOA services in 2002 and again in 2006, concluding they were accessible and of sufficient quality. Nevertheless, the COA has announced it will terminate the contract with the MOA in 2009. This is partly motivated by the political point of view that healthcare for asylum seekers should be a mainstream responsibility in its entirety ([www.coa.nl](http://www.coa.nl)).

Source: Netherlands country report

These policy developments are obviously detrimental for the welfare and the risk of social exclusion of asylum seekers. Moreover, they may also lead to cost increases for societies if inpatient care is required at a later date (Norredam et al., 2006).

#### 4.3.6 Policy initiatives to improve access to healthcare for asylum seekers

Some of the same organisational barriers affecting immigrants and ethnic minorities also limit access for asylum seekers. This includes the lack of legal aid, interpreters and leaflets in original language. In the **Netherlands**, some initiatives have tried to address these issues, including the use of professional translators who offer their services by phone. Medical specialists, however, are reported to be reluctant to use these services. The Healthcare Inspectorate has expressed its concern about this (Inspectie voor de gezondheidszorg, 2006). Box 4.3 above describes the system of healthcare services provision for asylum seekers in reception centres.

Feldman (2006) summarises several reports and papers that outline good clinical and organisational practice as well as numerous guidelines and standards against

which services for asylum seekers can be measured in the **UK**. Examples of these services in primary care are summarised in three main categories:

- a) *Gateway services*: aimed at facilitation of access (e.g. use of interpreters in walk-in centres, and services to register and facilitate access to a GP, screening and specialist mental healthcare);
- b) *Core services*: usually provided either through dedicated practices (may serve particular asylum seekers' accommodation centres and usually maintain strong links with housing providers and social care services such as child care and baby clinics) or more commonly, in mainstream practices with no specialist provision (often with no language translation service and reports have suggested culturally inappropriate care may be delivered). It is important to note that dedicated practices may become redundant if asylum seekers are dispersed or numbers fall;
- c) *Ancillary services*: providing essential support services that are required to meet the extra needs of refugees and asylum seekers such as health teams for asylum seekers and homeless, link workers and advocacy, interpretation and translation, health

promotion, services for survivors of torture and violence and mechanisms to transfer from dedicated to mainstream services.

Evaluations of specific initiatives have highlighted important general lessons. For example, a lot of mental healthcare can be provided informally – by provision of space for people to talk together with others or help with very practical things such as housing or ability to make culturally appropriate food.

It might not be necessary to label services as mental health services. An example of informal small-scale intervention is the 'LINKS' project in Hastings (Dumper et al., 2006), which is a drop-in centre that provides a comfortable environment where people can access advice and support services under one roof on employment, housing, health, family, debt, clothing and education.

### Targeting vs. Mainstreaming

There is also an important debate about services for asylum seekers and refugees, as for services for ethnic minority groups generally – should they be provided separately or integrated into mainstream services? Arguments for the former tend to focus on the very specific needs of asylum seekers and the need for specialist skills and knowledge amongst practitioners. Also, it may not be possible in areas of high demand,

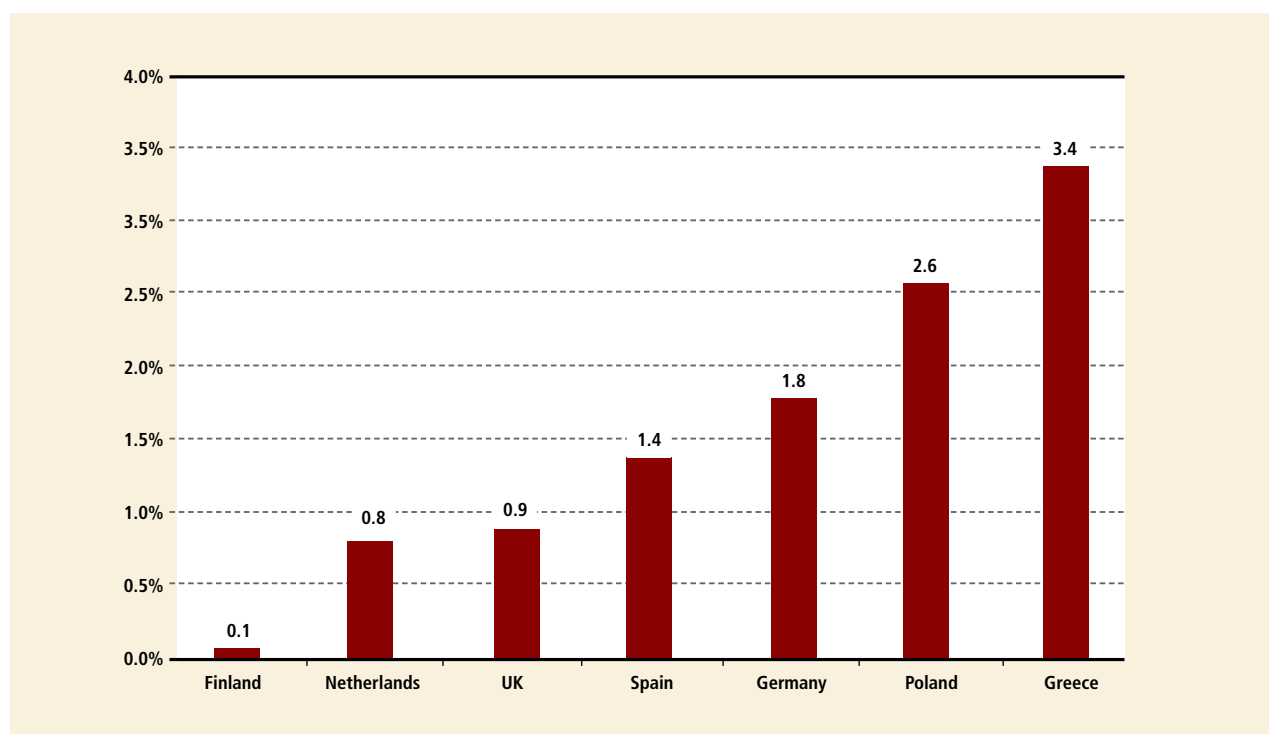
to provide sufficient services to meet demand without creating dedicated services. It can be argued that even if integration is the ultimate aim, there may be an interim need for special services at least for some time.

The danger with this approach is increasing marginalisation and stigmatisation of an already socially excluded group. For instance, some commentators in the UK have argued that the development of UK policy over time reflects attempts at increasing marginalisation of asylum seekers – from income support to vouchers (now disbanded), from provision of local authority housing to segregated accommodation, from opportunity to support themselves through paid work to exclusion from employment (Burchardt, 2005). There is concern that such policies are at odds with other policies emanating from the same government departments aimed at creating an inclusive and tolerant environment.

For some services, it is essential to provide the link between the relevant groups and the services that already exist in the mainstream sector. This might require improving training and providing health professionals with the skills necessary to address the needs of multiethnic clients. For instance, there are calls in the UK for basic and postgraduate training for doctors and nurses to include issues of ethnic diversity and exchange programmes for health professionals in the UK and less developed countries to promote understanding (Khan and Ghosh, 2005).

**Figure 4.1: Estimated number of illegal immigrants as % of total population**

Source: HealthQUEST country reports



However, in some cases it is important to recognise that mainstream policies do not work for the people at risk of social exclusion, such as asylum seekers, who are most in need of them. In such cases better monitoring is required, together with specialisation in relevant care. For example, two hospitals in London have clinics specialising in female genital mutilation.

#### 4.4 Illegal immigrants: 'sans papiers' or 'undocumented migrants'

For obvious reasons it is very difficult to estimate the number of illegal immigrants in any given country. Estimates from the **Netherlands** suggest that between 0.5% and 1% of the population are illegal immigrants, of whom approximately one third are women. Estimates published by the OECD suggest a similar percentage for **Spain** (1.4% in 2005) and slightly higher for **Greece** (3.4% in 2001) (OECD, 2006). In **Germany**, the Foreigners' Central Register estimates the number of illegal immigrants at 0.4% of the population. However, refugee organisations estimate that this number extends to 1.8% of the population (Rabbata, 2006). In **Poland**, estimates of the number of immigrants working illegally also vary widely, ranging between 0.2% (Labour Inspection) and 2.6% (District Labour Offices) of the total population. In **Finland**, the National Bureau of Investigation has estimated the number of illegal immigrants at approximately 0.1% of the total population. In the **UK**, the Home Office estimated the number of illegal immigrants at around 0.9% of the population in 2001.

This section begins with a brief overview of the particular health and illness patterns of illegal immigrants. It then analyses the health basket available to illegal immigrants and other particular barriers that they face. The section concludes by looking at the impact of NGOs in the provision of healthcare services to illegal immigrants.

##### 4.4.1 Health and illness patterns

Illegal immigrants face many of the health needs that also affect asylum seekers and immigrants with a legal status. Furthermore, they encounter problems that are specifically related to their status and situation. Stress-related mental health problems and depression are more common, as are psychosomatic complaints such as high blood pressure, digestive problems, headaches and back pains. Depending on their living conditions, they may also be at higher risk for infectious diseases –including TB– and malnutrition (Muijsenbergh, 2004). However, the analysis of the country studies for HealthQUEST suggests that research on health needs of illegal immigrants is in general extremely neglected. In most countries there is no specific information on health and illness patterns of illegal immigrants.

##### 4.4.2 Coverage and health basket

A common feature across many of the countries analysed in this report is that illegal immigrants have the right to the provision of emergency and medically necessary healthcare only. However, the decision of what constitutes a medical emergency is usually left to the provider. This is of particular consequence for important but non-urgent cases such as diabetes and childhood immunisations, which frequently pose a dilemma for providers if patients cannot afford to pay.

Charges for HIV/AIDS treatments are particularly controversial with commentators pointing out the often debilitated state of patients from whom payment is then meant to be recovered (O'Farrell et al., 2004).

In **Finland**, illegal immigrants have neither organised public healthcare services nor health services provided by NGOs.

In **Spain**, unregistered migrants receive emergency care only.

In **Greece**, migrants without a residence permit are not insured and do not have access to care. Access to the welfare system is limited even for migrants with residence permits.

In the **UK**, a charitable organisation report found evidence that some failed asylum seekers were not able to afford treatment for non-emergency but essential services such as diabetes care or childhood immunisation (Kelley and Stevenson, 2006).

Illegal immigrants in **Germany** are particularly affected by coverage-related barriers, which tend to exacerbate other types of barrier. Although they have the right to access the same set of benefits as asylum seekers and refugees via application at the local social assistance office, there are laws that hinder the realisation of this right in practice. In particular, applicants may receive the publicly financed acute healthcare or pain treatment they need but then risk deportation, as the local social assistance offices are obliged to report to the immigration office. Public healthcare providers are also obliged to report to the immigration office. Private and non-profit providers do not have this obligation but when they claim reimbursement, the patients' data are transferred. Furthermore, providers may potentially be charged with supporting illegal residency, which deters some to provide care (Rabbata, 2005; 2006).

In the **Netherlands**, illegal immigrants have no rights to public services, except legal aid, education (for children between 5 and 16), medically necessary healthcare and preventive health services in the

interest of public health protection. A special fund (*Koppelingsfonds*) was created to cover the costs that primary healthcare providers may have to incur to provide medically necessary care. The fund is resourced by the Ministry of Health, while administration and reimbursement is handled via a charity foundation (see <http://www.stichtingkoppeling.nl>). Hospitals, emergency services, and residential rehabilitation centres must record these costs under a special budget code. The Ministry of Health has stressed that in both sectors (primary care and other) all effort has to be made to reclaim the treatment costs from the individual concerned, similar to the situation as regards uninsured people (Ministry of Health, Welfare and Sports, 2006).

#### 4.4.3 Other barriers

It is important to note that illegal immigrants face additional barriers to those experienced by both migrants and asylum seekers. The evidence from this study demonstrates that most countries make a distinction in the eligibility criteria for coverage under public programmes between failed asylum seekers and refugees which creates significant differences in terms of access for each group. In particular, refugees have legal entitlement to access, which may or may not be difficult to achieve in practice, whereas failed asylum seekers have much more limited access in principle as well as in practice.

In the **UK**, for example, one of the main barriers to access for those who have been declared ineligible for free NHS services (illegal immigrants and those who have exhausted all appeals against failed asylum applications) is cost. Fear of extradition causes delays in seeking help and can result in breaks in treatments, which are especially prejudicial for HIV/AIDS and chronic problems like diabetes.

In the **Netherlands**, illegal immigrants could in principle obtain private coverage. However, all but one health insurance company requires their clients to show a residence permit as a precondition for coverage, which severely limits any effective possibility of obtaining coverage.

#### 4.4.4 The role of NGOs in supporting illegal immigrants

In many countries illegal immigrants are effectively left behind by the official health systems, which normally provide only strictly necessary emergency services. In this context, the work performed by NGOs, providing support and access to healthcare services, assumes great importance in guaranteeing minimum levels of social protection and preventing social exclusion.

In the **UK**, there are also a large range of NGOs involved in the provision of care for these groups but it is not without controversy. For example, their involvement may be limited because they lack access to special funding to make their services available to new groups and there may be a feeling that they draw on already stretched formal and informal resources in communities of high need. They may also be faced with resentment by indigenous users. One particular example is 'Project London', run by Medecins Du Monde, which aims to meet the needs of several groups (vulnerable migrants, homeless, sex workers) and focuses particularly on those groups excluded from free NHS care such as failed asylum seekers or those with no documents (McColl et al., 2006).

In **Germany**, several refugee organisations and welfare organisations are being active to lower access barriers to healthcare for illegal immigrants on a project level, mainly in metropolitan areas. For example, the Berlin Refugee Support Office has referred about 8,000 illegal immigrants to regular providers since 1996. The office does not provide care itself but cooperates with about 100 providers, does fundraising for medication or medical aids, and provides translation services if required. The number of people in need has increased to about 100 per month since the 2005 Immigration Act came into force. Other organisations do provide basic medical care at their premises (Rabbata, 2005), in homes or as part of street work, although the degree depends upon the local interpretation of the ambulatory monopoly of regional physicians' associations and of the professional medical law that requires healthcare to be provided in specific healthcare practices.

In **Spain**, religious organisations and NGOs perform an active role in the provision of health services to the immigrant population, especially asylum seekers and illegal immigrants. Their work is essential in relation to providing direct healthcare, health promotion, help and advice throughout the process of integration in Spanish society, and help in completing forms that shed light on the public health situation of these groups. Many of these organisations receive financing from the government. However, the NGOs themselves point out that if the Immigration Law was applied effectively in these matters, immigrants would experience less difficulty integrating into the public health system, and thus government financing of NGOs would be unnecessary.

In the **Netherlands**, a special national expertise centre was established to provide additional information or support for care providers helping illegal immigrants and other clients 'sans papiers': Lampion ([www.lampion.info](http://www.lampion.info)). This is particularly helpful because only a small number of health professionals are willing to provide care for illegal immigrants and these professionals may have a disproportionately large number of illegal patients (Oort et al., 2001).

## 4.5 The situation of older migrants

Past and current migration trends and the ageing of the population suggest that the issue of health and social care for older people from ethnic minority groups will become more important.

Migration is a challenging experience for anyone, and more so for older people because of the losses not only of a wider family context and of friends, but also of a familiar physical, social and cultural environment. Migration presents a challenge to one's identity, may impose communication barriers, and require significant changes to family structure and practices. It has been recognised that minority ethnic older people do have specific needs, problems and access barriers in their usage of health and social services. The most important reasons are related to language problems, closely followed by clients' cultural norms and values.

In **Finland**, minority ethnic elders are still in small numbers, which helps to explain the lack of services targeted specifically at them. However, according to the Finnish Refugee Council, most difficulties to access healthcare services occur for those immigrants who would need the services most, especially elderly and already sick immigrants. Staff members do not possess language skills and culture specific competence and organisations are not active in promoting services for this particular clientele. Results from a survey show that minority ethnic older people experienced racial harassment in social and healthcare services, both from professionals and other clients. Twenty-eight per cent of Vietnamese experienced racial harassment from professionals, compared to 5% of Russians and 2% of Samis.

A study by Schellingerhout (2004) provides information on health needs, service utilisation and access barriers of older migrants from Turkey, Morocco, Suriname and the Antilles in the **Netherlands**. Overall, the perceived health of Turkish, Moroccan and Surinamese older persons is worse than that of the other elderly groups. On average, men enjoy better health than women. Education level is an important health determinant. The percentage of persons with severe physical limitations and reported chronic disorders is highest among older Turks, when compared to Moroccans and Surinamese, and for all these three groups it is higher than the native Dutch population. Antillean and Moroccan older people report slightly less limitations and disorders than the native population. Due to the interplay of health determinants, older persons with several chronic disorders often have physical limitations, poorer mental well-being and poorer perceived health.

Still according to the same study (Schellingerhout, 2004), the utilisation of healthcare services by older migrants is higher than the native Dutch population,

but mainly determined by perceived health and reported chronic disorders. Adjusted for these factors the take-up of provisions is equal or even lower than Dutch natives. In some respects, utilisation of medical services may be culturally determined. Older persons with a lower degree of social and cultural integration use more prescription medicines, visit the GP more often and visit the dentist less frequently than older persons who are more socio-culturally integrated.

Older migrants do not use home care services as much as their indigenous peers, even when differences in physical limitations and other health indicators are taken into account. Surinamese older persons are the exception to this rule: they use home care services as often as the native Dutch population. Over 45% of Turkish older persons with severe limitations receive no help whatsoever, either formal or informal.

Low utilisation of home care is caused predominantly by a stronger reliance on informal care. Older migrants prefer help provided by children and family, and informal care is often more readily available (larger families, children living nearby). However, older migrants may also encounter difficulties accessing home care services. They may expect language problems, encounter problems applying for the services, consider it too expensive, or may not even be aware these services exist. Lack of knowledge about the service is especially prominent among older Turkish people.

In the **UK**, higher rates of some diseases have been found in specific population groups of elderly migrants, e.g. stroke, hypertension, diabetes, CHD, hip fractures and renal failure in South Asians (Khan and Ghosh, 2005). A recent survey of minority ethnic elders in the UK undertaken as part of a wider European project, reported relatively high levels of overall satisfaction with health and social care services amongst most groups, but also noted significant language barriers amongst South Asians and Chinese/Vietnamese people in accessing services (Policy Research Institute on Ageing and Ethnicity (PRIAE), 2005). Many service providers felt services failed (at least in part) to meet the needs of these groups and suggested unmet need existed.

In **Germany**, the national elderly reports and several surveys have highlighted that long-term care of elderly migrants is largely provided by informal caretakers, but that the need for professional care is increasing. Within the professional structures of healthcare and long-term care, the special needs of elderly migrants are not yet sufficiently met by professional care structures. In particular, language barriers, nutrition and social support issues are seen as challenges. In particular, there is an insufficient number of caretakers with mother tongue or sufficient language skills, especially for Turkish and Arabic patients.

Due to poor language skills, elderly migrants are particularly likely to face communication problems when contacting healthcare providers. Not being able to arrange appointments at short notice, and a difficulty understanding their GP have been mentioned as key problems among Turkish and Moroccan older people in the **Netherlands**. Many Turkish and Moroccan (61% and 53%, respectively) need language assistance when visiting their doctor. This is, however, seldom provided by professionals but almost always by the partner or children instead. The need for language assistance is especially marked among older Turkish and Moroccan women (Schellingerhout, 2004).

Evidence suggests that the same kind of issue is present in the **UK** and can compromise the quality of communication and create potential health hazards, especially when medical terminology is involved (Demirbag and Aldridge, 2003).

On the policy level of social and healthcare the Ministerial Conference on Ageing (Carreras, 2002), proposed a strategy that mentions the need of design and implementation of integration programmes and measures addressed to guarantee economic and health security for ageing migrants. Countries were asked to establish practice standards to govern public and private policies on ageing migrants.

In other instances, communities themselves have initiated interventions aimed at the elderly of their own ethnic group. For instance, Kremla (2001) describes some examples related to elderly refugees in the **UK**. These include numerous facilities and services for the elderly, such as residential homes, day centres, home visits as well as social and cultural activities, which are provided by the ethnic communities.

#### 4.5.1 Specific concerns about older migrant women

Within the group of older migrants, the group of older migrant women has some even more distinct characteristics, which raise specific concerns and require further attention. Immigration often is especially challenging for older women, as they are more likely to be poorer than other migrants (Centres of Excellence Research, 2000). Older migrant women belong to a vulnerable group. They face unique social and health problems. While there is an increase in the number of older migrant women (Salt, 2002), statistically they are still hardly visible and their lives go practically unnoticed (Eldis, 2005). This section provides an overview from the literature on some of the cultural issues of older migrant women and their social care and healthcare services.

This is both to highlight that this group may face problems of access that are reviewed under this chapter on migrants, but also partially may face problems –and often in a more severe form than other groups of the elderly– that are addressed in the following chapter on older people with functional limitations. For these reasons, and because this is an increasing group of the migrant population, health policy needs to pay special attention to older migrant women.

Poverty is one of the key issues of older migrant women. Older migrant women have to deal more with poverty, as they usually have not build up sufficient pensions (Ipek-Demir, 2005). Pension entitlements in many European countries are based on years of work and residency. The increasing number of older migrants within the region is therefore sparking particular concern regarding the needs of older immigrant women. In the **Netherlands**, more than 90

#### BOX 4.4: LESSONS FROM THE MINORITY ELDERLY PROJECT IN 10 EUROPEAN COUNTRIES

Patel (2003) reports on the 'minority elderly care' project that included 10 European countries. It was found that the family was very important to minority elders in all countries and not surprisingly, most elders preferred to be looked after by their family in their own home. Yet, despite a strong desire for independence it was apparent that family circumstances are changing and there are many elders, especially women, who live alone. More than 30% of the elderly minority women in the UK, the Netherlands, Finland, Bosnia-Herzegovina and Switzerland lived alone. The highest proportion was in Switzerland with 47% of women living alone. In France, more men (36%) than women (7%) lived alone. Although family were an important part of care and support for elders, there were many who had no one to turn to when ill or in need of emotional support.

In the use of services Patel found that the use of different health and social care services was not uniform across the different ethnic groups and countries. While each country has its own systems and procedures it is apparent that in all countries there are some elders who are failing to gain access to services. The results show that some groups face more barriers than others. There is clearly a strong desire in every country for culturally sensitive care and for service providers to understand their needs and be willing to understand their preferences. GPs are the most frequently used services and are often an important access route to other services. An example of inequality within an ethnic group is the case of older Turkish women in Germany, who were the most disadvantaged of all in terms of socio-economic status, acculturation and health condition.

Source: Netherlands country report

per cent of Moroccan women aged 55 years or older report never having worked. Among women 60 years and older, 19 per cent from the former Yugoslavia and 23 per cent from Turkey had no income of their own whatsoever (United Nations Population Fund, 2006). The options for building up a proper pension once in the host country are limited for older migrant women. They lack full build-up years, sometime both because of care responsibilities in their families and due to their migration history. Moreover, they are more often unemployed, thus pay less into a pension scheme and build up fewer pensions through employment (Eldis, 2005).

In a study on the situation of minority elderly in **Germany**, Heinecker et al. (2003) argue that also in this country the number of elderly migrant women who have never been employed is increasing. The danger of social isolation resulting from this is associated with an increased risk of mental disorders among individuals in this group.

Researchers have found that there is a general lack of information about the needs of older migrant women. The number of studies that take a gender perspective, focusing on older migrant women is relatively small (Christ, 2004; Eldis, 2005). Research does not usually focus on service use and it has tended to be small scale and limited (Arai, 2005). Kremla (2001) reports that elderly refugees have different specific needs, but there are few investigations that have more closely examined these needs. Similarly, although there are individual projects that address specifically elderly refugees, the refugees' experiences were not investigated and, considering how small the elderly group is, there are few attempts to establish specific programmes within the financial and time restraints of refugee assistance.

Eldis (2005) concludes that older migrant women are invisible in statistics and research results. There is not enough knowledge of the situation of older migrant women in Europe. The invisibility of older migrants or their statistics, may also contribute to their disadvantages. It has been pointed out that older migrant women, in particular, are not seen as an independent target group in government reports and other government publications. This restricts the development of policies and programmes in such areas as social care and healthcare (Equal Opportunities, 2001).

## **4.6 Conclusions**

### ***4.6.1 Migrants are relatively more affected by certain health problems***

Epidemiological evidence from several countries (Germany, Netherlands, UK) suggests that certain health problems affect migrant groups relatively more compared to the general population. In several countries this is reflected in a higher risk of TB,

cardiovascular diseases, coronary heart disease, depression and perinatal and maternal mortality among migrants. The health problems that disproportionately affect the Roma population provide a particular illustration of this. In some cases migrants have benefited from a relative health advantage in mortality rates (the 'healthy migrant effect'); however, this tends to decrease with length of stay and vanishes for second and subsequent generations.

Asylum seekers are affected by similar issues, but tend to also have specific needs, including higher prevalence of communicable diseases and specific mental and physical health problems relating to torture and war traumas. Illegal immigrants share similar health problems as those in other immigrant groups, though in many cases their social networks and access to care are more precarious.

### ***4.6.2 A higher risk of poverty and social exclusion contributes to worsen health status***

The available evidence presented in this report indicates that migrants, asylum seekers and illegal immigrants are frequently socially excluded and, compared to the general population, are exposed to greater risk of poverty. Poverty and resulting poor living conditions contribute to worsen migrants' general health status, making access to appropriate health services vital for lowering their risk of social exclusion.

### ***4.6.3 Multiple risks increase exposure to multiple barriers***

Migrants often face a complex congeries of problems which frequently compound each other and reinforce existing barriers of access to healthcare. The existence of such inter-linkages calls for concerted actions that address migrants' multiple needs.

One key example of multiple risks and multiple barriers highlighted in this report is that of older migrants. It is fairly common that, during their active life, individuals in this group have been employed as manual or hard workers. As a result, they experience lower health status and present more healthcare needs compared to other groups in the population. Their employment history is also likely to be associated with more extensive periods of unemployment and with lower incomes. Therefore, they are less likely to have accumulated contributory years and to have built up appropriate pensions. Moreover, they have lower levels of formal education and less language skills. Taken together all these factors contribute to make access to healthcare particularly difficult for this group.

Another example refers to the situation of elderly migrant women. In addition to some of the difficulties affecting older migrants in general, this group faces further challenges. In addition to lacking pension years, elderly migrant women are often burdened by care responsibilities in their families and very frequently have no history of formal employment. If they lose their family members, their level of social isolation can be high and lead to increased risk of mental disorders (Patel, 2003). Overall, information about this group is currently very limited.

#### ***4.6.4 The protection provided by most countries is not sufficient***

Migrants and ethnic minorities face significant health challenges, at times under much worse conditions than mainstream populations. In most countries migrants who have been granted residency status are generally covered under the same terms as other residents. They are eligible to the same basket of treatments and services, and are liable to the same cost-sharing regulations. However, considering the much more fragile financial situation characterising many migrants, this can result in access problems with significant consequences. In countries where the health system is very fragmented and reliant on informal private payments, such as in Greece, it is frequently the case that migrants are exposed to a very high risk of catastrophic out-of-pocket health expenditures.

#### ***4.6.5 Access barriers limit the use of services***

Migrants show specific patterns of service utilisation. Compared to native-born populations, the evidence suggests that migrants make less use of specialist inpatient and outpatient care and show greater reliance on emergency services or, in some cases, GP services. In spite of relatively high rates of mental health problems, the quality and amount of psychiatric services provided to migrants has been called into question in some countries. These differences are only partially explained by differences in help-seeking behaviour attributable to cultural and religious differences, suggesting the existence of significant access barriers.

#### ***4.6.6 Asylum seekers face additional barriers in accessing healthcare***

There is reason to believe that in many cases asylum seekers are not receiving the necessary level of medical attention. Although many countries provide screening programmes for newly arrived asylum seekers, access to general health is generally much more restricted, especially for the treatment of mental health problems.

Recent developments in immigration policy in some countries have worsened the level of social protection afforded to asylum seekers. This has included more strict immigration laws over the years, reductions in the number of reception centres, the use of benefit payment in the form of tokens instead of cash, and the restriction of the range of services that are made available free of charge to asylum seekers. In some cases these developments have led to decreases in the number of asylum applications. However, they also had negative effects on the risk of social exclusion of asylum seekers. Moreover, they may also lead to cost increases for societies if inpatient care is required at a later date due to more restricted access to healthcare services.

Among the countries included in the study there is great variability with respect to models of reception of asylum seekers. Some countries rely more on centralised accommodation, whilst others have preferred to allocate the asylum seekers in independent units. The models of integration implemented in the different countries can on occasion compound the multifaceted needs of asylum seekers. These models can create a tendency for social isolation and may compromise integration in the mainstream system.

#### ***4.6.7 Illegal migrants likewise face additional barriers in accessing healthcare***

Most EU countries currently deny illegal immigrants the most basic forms of social protection. Illegal immigrants are also frequently socially excluded and receive low wages.

Access to healthcare is particularly restricted since in most countries illegal immigrants are eligible to receive emergency care only. This restriction has serious consequences, limiting the access to treatment for very important but non-urgent health conditions. Illegal immigrants are also exposed to a high risk of catastrophic health expenditures, which has particularly serious consequences given their fragile financial situation.

#### ***4.6.8 The difficulties in obtaining documents place serious restrictions on access to healthcare***

A very significant access barrier facing migrants and ethnic minorities refers to difficulties in obtaining documents, such as residence and work permits and health insurance papers. For many Roma individuals, the costs for issuing birth certificates are considered high and the lack of identification documents has been shown to affect infant vaccination and prevention activities. In most countries migrants received no

assistance for obtaining documents. Other important barriers of access to healthcare affecting migrants and ethnic minorities include the lack of interpretation and translation services.

#### **4.6.9 Research evidence is lacking**

Information on the socio-economic situation, health and illness patterns and barriers of access to healthcare available for all three groups is still very limited. The case of illegal immigrants is particularly important since very little is known, even with respect to health needs, that could be useful in guiding policy interventions.

### **4.7 Recommendations**

#### **4.7.1 Improving the material conditions and economic security of migrants**

Many health problems affecting migrants, asylum seekers and illegal immigrants are heavily associated with poverty and deprivation. The resulting risk of social exclusion can contribute to barriers of access to healthcare services. Improving the economic and living conditions should be a central priority for securing better health for these groups. This might include measures that improve immigrants' employment situation in addition to providing more support in the form of social services and accommodation.

#### **4.7.2 Providing more responsive services**

Part of the solution to reduce barriers of access to healthcare for migrants will involve increasing the level of supply-side responsiveness. Healthcare providers should strive to take into account the specific characteristics of the healthcare demand among migrants and to provide more responsive services. This may include increasing awareness about services available, providing translation/interpretation services, promoting culturally friendly services and combating discrimination.

#### **4.7.3 Improving access to healthcare for older migrants and elderly migrant women**

Access to healthcare for these two special groups is often limited due to the existence of multiple barriers, which might include the lack of pension-years, high unemployment risk, care responsibilities to other family members and social isolation. These problems should be addressed by appropriate policy interventions,

which also need to take into account cultural preferences, for instance those related to long-term care arrangements.

At the same time, information about the overall situation of these groups is currently lacking. Therefore, more resources should be directed at collecting statistics and improving the knowledge about the situation of older migrants in Europe.

#### **4.7.4 Addressing the particular barriers faced by asylum seekers**

A number of measures, some of which are currently in place in some countries, could be potentially helpful in addressing the needs of asylum seekers and improving their situation.

First, because of their high health needs it is important to enlarge the health baskets made available to asylum seekers. Some countries currently offer only acute treatments. However, this should be expanded to encompass more healthcare services, particularly mental health services, in view of the pressing healthcare needs of asylum seekers.

Second, culturally sensitive training aimed at improving the coping skills of asylum seekers is required to improve health and deal with the health deterioration and mental health problems frequently observed after arrival. This should take into account the interaction between physical and mental health symptoms.

Third, it is necessary to consider the impact of policies of relocation and enforced dispersal on stigmatisation. In particular, it is important to provide support in the transition to new healthcare providers for asylum seekers who are relocated; this might require, for instance, that patient information is appropriately recorded and made available to the new provider.

Finally, country reports suggest that the information on morbidity and mortality risks of asylum seekers is meagre. Considering the very specific and pressing health needs of this group, more research is required in this area.

#### **4.7.5 Targeting reception centres**

It is particularly important to safeguard the special needs of asylum seekers in reception centres. Some countries provide good examples of coverage regulations that can promote greater integration. For instance, asylum seekers in Poland are also covered for indirect costs of treatment and in Spain they receive information on how to access the health system.

Another example of good practice in this area can be found in the Netherlands. The central agency responsible for the accommodation of asylum seekers also contracts preventive health services for asylum seekers in each reception centre. Asylum seekers are always seen first by a practice nurse, who acts as a gatekeeper and decides whether access to mainstream healthcare is necessary. Practice nurses receive special training to deal with the special needs of the asylum seekers.

#### ***4.7.6 Reducing hurdles in obtaining documents***

In some cases, significant improvements in access to healthcare could be achieved through the reduction of bureaucratic hurdles in obtaining documents. In particular, hurdles for obtaining residence and work permits, identification documents and health insurance papers should be reduced. In the case of

Roma, the process for obtaining birth certificates and identification documents should be facilitated and the costs reduced. Proper systems should be put in place to provide information and to assist migrants on how to obtain the necessary documents.

#### ***4.7.7 Investment in research***

It is important that the health systems react to the access barriers affecting migrants, asylum seekers and illegal immigrants and address the specific needs of these vulnerable groups. However, as this study has demonstrated, there is often a lack of research evidence to support policy recommendations. In particular, more specific research is necessary to accurately determine the demographic and epidemiological profiles of these groups in the different countries and to guide policy interventions.



## 5 Older people with functional limitations

### 5.1 Introduction

On average, older people in the EU live longer lives and many enjoy higher retirement incomes than previous generations. However, dependency presents major risks for older people, who are currently the fastest growing share of total populations in the EU (Grammenos, 2005). Improving health and social care for the growing number of older people with functional limitations who need constant support with basic activities of daily living is therefore a major concern of both social and health policies in EU Member States.

This chapter reviews the multiple, and often-interrelated problems of access to healthcare that older people with functional limitations face in the eight countries analysed in the HealthQUEST project. The chapter starts with a brief discussion of definitions of terms, methodological problems in studying access to healthcare and the levels of dependency among older people. The chapter then goes on to outline the compound risks that dependent older people face and links with deprivation, before considering nine particular barriers to accessing healthcare.

The chapter also considers additional barriers in the two main contexts for older people with functional limitations: care in the home and care in nursing homes. It ends with an outline of key policy initiatives and a delineation of key conclusions and recommendations.

#### 5.1.1 Research and methodological issues

It is important to note from the outset that access to healthcare for dependent older people is an area where there are many gaps in the available data. Indeed, there is a general lack in many countries of basic data on healthcare utilisation by age and functional status.

Even where age-specific data are available, these are difficult to interpret as it is difficult to assess if growing utilisation with age –which is commonly observed–adequately reflects growing demand in higher age groups. Difficulties in measuring ‘appropriate care’ also arise because age and demand-standardised utilisation rates are largely absent from national statistics, as confirmed by HealthQUEST’s country reports.

The evidence presented in this chapter is therefore inevitably fragmented and incomplete. Important gaps in research for the topics covered in this chapter have been reported for all countries, but particularly for Poland and Romania.

#### 5.1.2 Definitions

Older people with ‘functional limitations’ are defined here as people aged 65 or older with at least one restriction in activities of daily living (ADLs). This includes people with dementia, such as Alzheimer’s disease. The terms ‘older people with functional limitations’ and ‘dependent older people’ are used interchangeably in this report.

Activities of daily living (ADLs) refer to mobility and self-care activities that a person must perform every day, such as bathing, dressing, eating, getting in and out of bed or chair, moving around, using the toilet and controlling the bladder and bowel movements (OECD, 2005b).

#### 5.1.3 The prevalence of dependency in old age

There are different ways to describe prevalence of dependency in old age. The most widely used data in an international context rely on self-rated health status and functional status from survey data, either from national sources or from coordinated surveys on the European level, such as from the SHARE project.

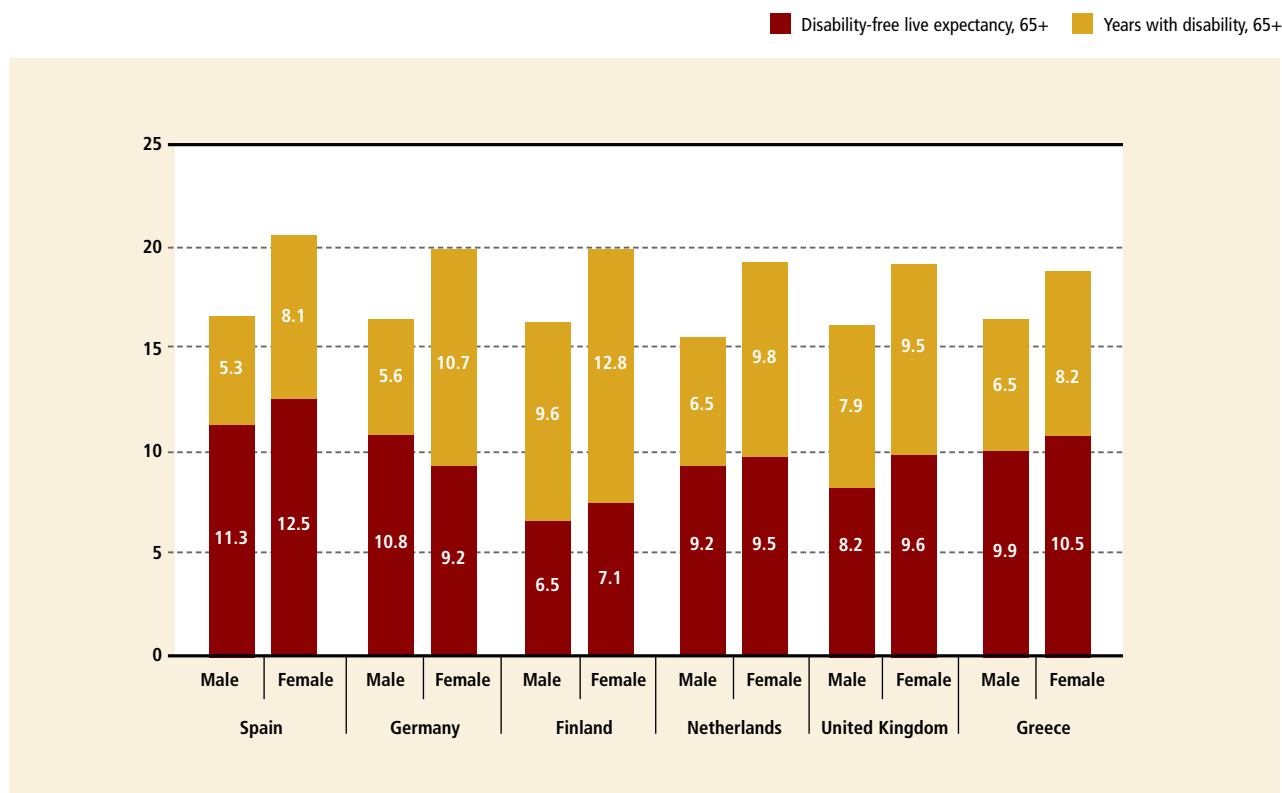
According to first results from SHARE (Börsch-Surpan et al., 2005), subjective health status declines with age, and this is linked to higher prevalence of chronic conditions and mental health problems. Moreover, according to the *International Indicator of Activities of Daily Living* in the SHARE survey, those affected by disability often suffer from limitations concurrently, such as visual impairment; hearing impairment; and lower mobility. These functional limitations put people at risk of falls, injuries and accidents, social isolation and depression.

During the last 40 years, both elderly men and women at age 65 have gained about four years of life expectancy in the European Union (Grammenos, 2005). However, on average a considerable number of these years are spent with one or several disabilities (Figure 5.1).

Although the trend of increasing life expectancy is common in Europe, there is still much uncertainty about how much of the added years are lived with disability among elderly people when compared over time. This has been confirmed by two recent studies that are based on national data (Lafortune, 2007) and on European households surveys (EHEMU, 2005). The picture becomes even more complex when different surveys are used for alternative estimations in countries where multiple sources are available. For example, the time trend on disability prevalence among older people for the UK is currently inconclusive, with contradicting results from two different surveys, which illustrate the severe data problems in this field of analysis (Lafortune, 2007).

**Figure 5.1: Disability-free versus overall life expectancy of older people, 2003**

Source: Eurostat New Chronos Database, 2007



## 5.2 Age, functional limitation and compounded health risks

Older dependent people often face compounding risks. They are heavy users of healthcare services and therefore often face significant cost-sharing burdens. At the same time they have social care needs that often cannot be met by family members and friends alone. In cases where they need –at least partially– to rely on formal long-term care services, these often require important financial contributions, because public programmes for social services for dependent people are frequently means-tested, or only partially cover the full costs of the care needed. As the examples of the Greece, Polish and Romanian country reports illustrate, care systems under public budgets are only emerging in some countries, leaving most of the care responsibilities to families, as well as the high cost of paid services if these are bought privately. Moreover, there is some evidence that resources in acute care institutions have sometimes been used to accommodate older people in need of long-term care.

In addition, there is evidence that dependency is more prevalent among people with lower socio-economic status and lower educational attainment who are at higher risk of pension poverty – independent of the financial demands of funding elderly care services. This means that many dependent older people face compounded risks of high health and social care needs and associated high costs that come on top of a general risk of pension poverty.

As the HealthQUEST country reports have argued, many of the access problems faced by dependent older people also compound each other. Among the interrelated factors are:

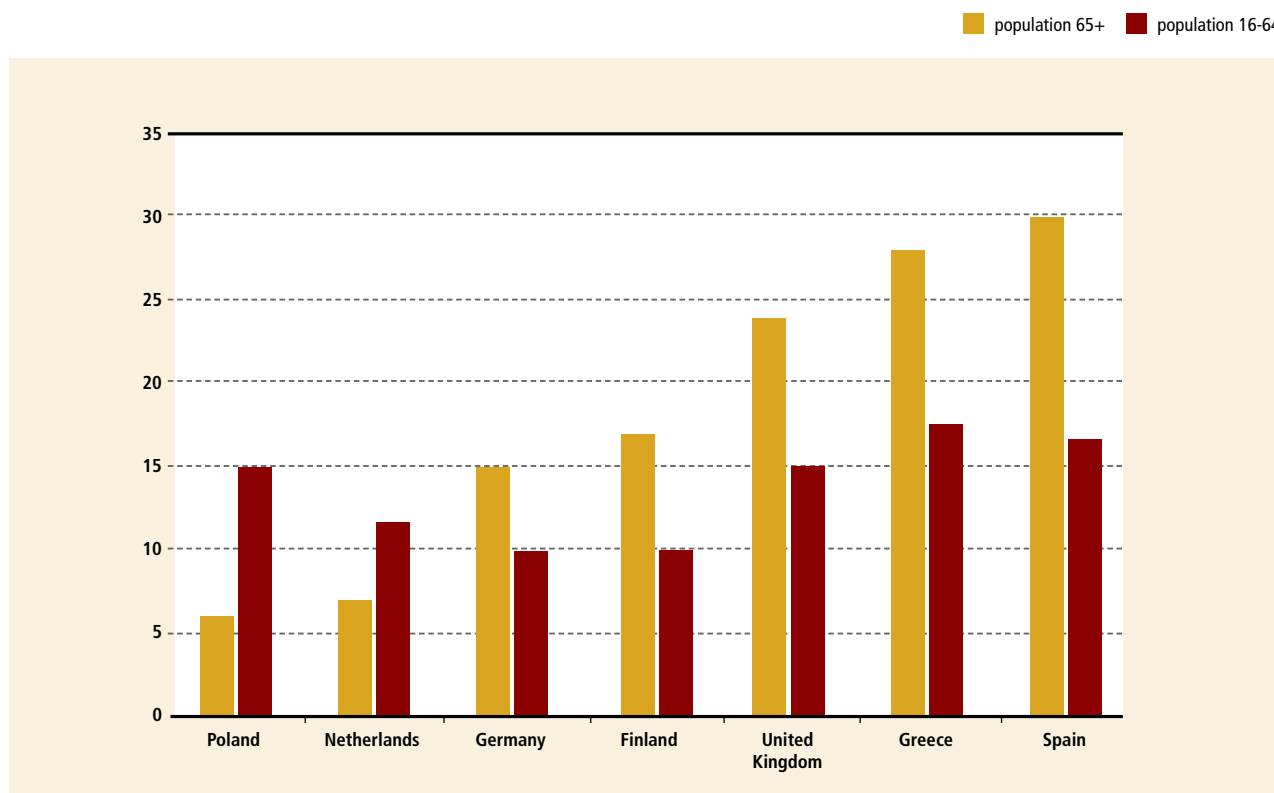
- High service needs but often limited capacity to finance co-payment;
- Hurdles of access to services due to mobility restrictions;
- Low expectations and limited health literacy; and
- Bureaucratic, fragmented service organisation that can be aggravated by ageism and age discrimination in service provision.

### 5.2.1 Poverty, deprivation and dependency

According to data from the European Union household survey (Figure 5.2), the risk of poverty for people aged 65 and over is elevated compared to the working-age population. There are, however, two notable exceptions among the sample of countries studied in HealthQUEST that have also been explained in HealthQUEST country reports. In **Poland**, elderly people (including those with disabilities) enjoy relatively high retirement incomes from public programmes, which provide an efficient safety net against poverty

**Figure 5.2: Poverty risk of older people and working age population, 2003<sup>(1)</sup>**

Source: Eurostat New Chronos Database, 2007



<sup>(1)</sup> Percentage of people at risk of poverty, with income below 60% median income.

among the elderly. Poverty rates for people at working age are in fact higher, mainly due to high long-term unemployment rates and a high number of long-term unemployed who do not receive unemployment benefits (some 85%). In the **Netherlands**, low-income levels are also under-represented in the age group of 65 and older and this older population has to face less material deprivation when compared to the younger population (de Boer, 2006). However, poverty is relatively more prevalent among women.

Poverty risks are higher for older women than for men, but, again, this is more pronounced in some countries (Figure 5.3). Gender differences in poverty risk are relatively large in Finland, Germany and Poland. For women, this is mainly due to lower incomes while in employment, and to interrupted careers, notably for care given to dependent relatives – either children or parents and parents-in-law (European Commission (2007) SEC(2007)329).

SHARE data also show that men and women with a lower socio-economic status are considerably more likely to experience limitations with activities of daily living (ADLs) than individuals with a higher socio-economic status (Börsch-Surpan et al., 2005). They are also more likely to face limitations with instrumental activities of daily living (IADLs) such as preparing hot meals and making telephone calls. This further reflects the higher burden of physical limitations among those with a lower socio-economic status.

Country reports provide several examples of the implications of this. For example, despite the equality of the **Finnish** pension system, it is a challenge to ensure sufficient pensions for women. In particular, women in older age groups may be at a risk of poverty if they receive no earnings-related pension and have to rely solely on the national pension or on a combination of the national pension and a small employment pension, due to divorce or the death of the breadwinner (Ministry of Social Affairs and Health, 2006).

## 5.3 Barriers to access

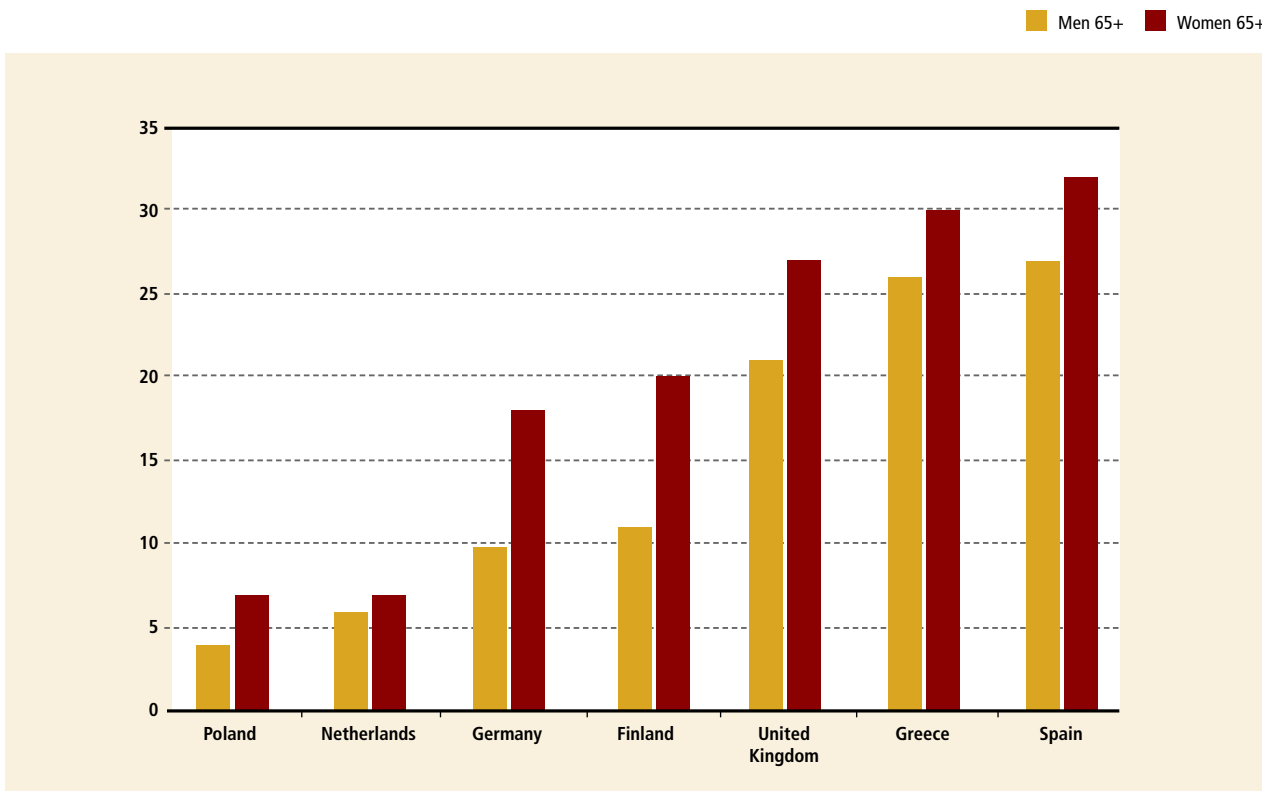
### 5.3.1 Introduction

Older people with functional limitations often find it difficult to organise the resources required for receiving treatment due to a number of factors that are studied in this section. Among these are cost-related barriers, poor mobility, lack of availability of public transport and bureaucratic hurdles. Health literacy may also play a role for this group of patients as older people may have lower education levels.

Moreover, there is evidence from some studies that they may have lower expectations and health beliefs that leave them hesitant to request support (see 5.3.8 below).

**Figure 5.3: Poverty risk of older people by gender, 2003<sup>(1)</sup>**

Source: Eurostat New Chronos Database, 2007



<sup>(1)</sup> Percentage of people at risk of poverty, with income below 60% median income.

Common health problems of older people are often not adequately addressed, putting people with dependencies at special health risks. For example, there are recognised and widespread deficits in the treatment of malnutrition. This has been highlighted as one of the biggest problems for the population of frail elderly people – with important health consequences. Other deficits have been found in the treatment of sleep disorders, depression, fall prevention, and in providing adequate pain management. Moreover, health systems often do not recognise nor accommodate sufficiently the problems created by co-morbidities. In particular, mental health needs of older people are often not properly diagnosed and addressed.

Age discrimination in access to health services also seems a particular severe problem affecting a broad range of services, including rehabilitation and prevention. For the latter services, there is now growing evidence that this creates lost opportunities for public health of older people because many of these services have the potential to prevent or mitigate dependency among older people and the corresponding risk of social exclusion.

### 5.3.2 Cost-related barriers

As frequent users of healthcare services, dependent older people often have high financial burden from cost-sharing requirements of healthcare – both for

essential services and for pharmaceuticals and other medical goods, such as glasses and hearing aids. In some cases, out-of-pocket payments for essential services that the public system does not cover, or does not deliver in a timely fashion, may contribute to this financial burden.

As several of the country studies argue, existing caps on cost-sharing requirement or exemption rules are often not sufficient to protect dependent older people, in particular those who depend on small pensions or on social assistance. But the financial burden of social care needed for older persons with severe dependency can even for middle-income pensioners pose a high risk of poverty, in particular when publicly funded long-term care is means tested or unavailable.

On average, women have lower retirement incomes but are likely to have higher out-of-pocket payments (**Germany**) as they tend to use more healthcare services.

The high poverty risk of older people in **Greece** (see Figure 5.3) makes the amount that older people have to spend on healthcare particularly burdensome. Co-payments of 10–25% for multiple essential prescription drugs is a high financial burden for older people on limited pensions (“We receive our pensions to pay for our pills!”). Moreover, there is often limited supply and it can be bureaucratically difficult to obtain cover for essential equipment (catheters, oxygen, pharmaceuticals

for bedsores prevention and treatment, disposable incontinence napkins, etc.). In addition, as a result of staff shortages of nursing personnel in hospitals, many dependent older people in Greece need the constant help of another person, usually a family member or paid 'special nurse aid' during their stay at the hospital. If informal family help cannot provide this, it is a major expenditure on hospital care for private households. Even in cases where insurance funds cover part of this cost, older persons or their families first have to pay for these out of their own pocket.

In addition, informal payments to doctors (and other healthcare staff) may be expected in return for speedier, better and more personal services, to a greater or lesser extent throughout the healthcare sector (Triantafyllou et al., 2006). Another factor that can add to the cost burden are the problems in financing the network of Home Care Services (see 5.4 below for more detail) or institutionalisation, when care at home is no longer an option (and this is in some countries, though not necessarily those of the analysis, virtually private or provided by non-profit and sometimes religious organisations).

In the **Netherlands**, the income-related premium for standard coverage amounts to 4.4% of pensioners' income. However, this premium is automatically withheld and therefore people reliant on more than one pension pay twice. This problem has been recognised by both the government and parliament, as a result of which excess premium payment will be reimbursed (see, [www.kiesbeter.nl](http://www.kiesbeter.nl)). Nevertheless, payment does take place in advance and may cause short-term cash-flow problems for people at lower income levels.

A survey in **Poland** among elderly people showed that 40% of those aged 65+ with low income stated they could not purchase needed medicine. Around 30% made this statement for services.

### **5.3.3 Geographical and physical access barriers**

The SHARE survey found that for many people with severe functional limitations it is not possible to use public transport, go shopping, find their way outside their home or even communicate over the phone. This can severely limit their capacity to access healthcare services in a timely fashion (Avendano, Mauricio et al., 2005). Several of HealthQUEST's country reports have confirmed that physical access problems are among the main barriers to access and use of health services for dependent older people.

One aspect is the question of access to transport. In particular, a study among older people in **Finland** found that a number of groups among older people

were making fewer trips to see a health professional due to mobility restrictions (Siren and Hakamies-Blomqvist, 2004). Among the groups affected were: women in general; the oldest old people; those older people without a driver's licence; and those with a lower educational level. Another group affected by transport problems were the residents of rural areas. Transport costs and a lack of access to healthcare services due to the low incomes of many older people have also been reported in **Greece**.

Women who do not drive seem to be more affected by age-related mobility barriers, such as the physical decline associated with increasing age, than men. For those older women who do not drive and live in areas with insufficient public transportation, or who cannot walk, support in transportation becomes crucially important (Siren and Hakamies-Blomqvist, 2006).

As some commentators have argued, for disabled elderly people the car's importance might lie in its compensatory qualities: the car is used as a tool and an aide in maintaining independent mobility in old age. However, women give up driving earlier than men (Hakamies-Blomqvist and Siren, 2003). A second facet to the question of physical access lies in the distance to health services. Important physical and geographical barriers have been reported for **Greece**. In rural areas with a high proportion of older people, distance from the nearest health centre is a frequent barrier to access to full primary healthcare services.

This leads to critical delays in investigating symptoms, diagnosing and managing effectively potentially treatable diseases. This is further exacerbated, particularly in rural areas, by the lack of health promotion and disease prevention programmes, including information, screening and early diagnosis of conditions common in older people such as diabetes, glaucoma, breast and prostate cancer.

Distance from appropriate and accessible primary healthcare services in both urban and rural areas may also force older people to make 'inappropriate' use of hospital outpatient and inpatient services (Triantafyllou, Mestheneos, 1994). There are long waits for publicly funded ambulance transport to primary healthcare.

In the **UK**, an interaction between age and distance was reported to affect the use of specialist services, such as renal services. These tend to be provided at central settings and create difficulties for older people living far away, who tend to 'under-use' services (Haynes, 2003). It is also difficult to organise practical resources for attending treatment due to poor mobility, inability to use public transport easily, and the cost of other transport.

### 5.3.4 Deficits in mental health services for dependent older people

It is now widely recognised that there is a range of common mental health problems of older people that are often not adequately addressed, putting people with dependencies at special health risks (Dewy and Prince, 2005). A number of country studies have illustrated this point. The main issues for which chronic under-treatment were identified in HealthQUEST's country reports (see, in particular the **Finnish** report) include treatment of sleep disorders, depression, alcohol and other substance abuse. In particular, depression often goes unrecognised and is frequently under-treated, seen mistakenly as a 'natural' aspect of ageing. Depression has also been reported as a potential sign of burnout in the role of informal caregiver of a dependent relative. The HealthQUEST country reports also demonstrate that dementia often goes unrecognised, and that many older people do not get the services they need, putting many people and their families at major health risks and risks of social exclusion. Poor case management and shortage of services for people suffering from dementia is a specific problem that calls for better cooperation between health and social care boundaries, as section 5.3.9 will argue.

A public health problem that has only recently received more attention is the treatment and prevention of alcohol -and drug- related harm in the older population, which contributes to the risk of dependency and social exclusion. Specific programmes targeted at older people are currently largely missing (see, for example the discussion in the **Finnish** country report).

Evidence on lower than expected levels of consultations for depression among older people has also been reported from the **UK**.

The specific and often precarious situation of people with dementia is a growing concern in a number of countries (Moise, OECD, 2004). However, the magnitude of the challenges is again in stark contrast with the lack of reliable data to scope the problem and to monitor policies. For example, the uncertainty and difficulty of definition is also highlighted by the range of country estimates (in **Germany**, for example, the range is reported from 5% to over 10% of people at age 65+).

A mismatch between rates of GP consultations and presence of dementia has also been reported from the **UK**, together with evidence about low levels of diagnosis and subsequent low levels of treatment.

For **Germany**, the draft reform of long-term care insurance explicitly seeks to improve services for dementia, better coordinate services at the local level and provide more incentives to care for older dependent people at home; (more resources/financing will be made available for this purpose).

### 5.3.5 Age discrimination in access to health services: ageism and candidacy

Several factors contribute to complicate the proper identification of health problems among older people. Their frequent co-morbidities can make it more difficult for older people to communicate their problems. Moreover, there is a tendency to report physical symptoms more readily than psychological; the interpretation of symptoms (both by healthcare consumers and health professionals) as 'age-related' may hide symptoms of mental health problems in particular. There is also evidence that health professionals also sometimes base their decisions on the concept of candidacy, favouring groups that are perceived to benefit more from treatment. Because of the many co-morbidities, older people have been reported to be less likely to be referred for surgery, including where there is no medical evidence suggesting that older people would not benefit from these (**Finnish** country report).

According to research from the **UK** there is often little evidence that older people fare less well from certain interventions, for example the use of statins for older age groups, so findings of lower use amongst older groups may be a signal of inequity (Reid et al., 2002). One of the difficulties in providing evidence of effectiveness of interventions in older groups is their exclusion from many clinical trial protocols. A review of qualitative studies on stroke care concluded that health professionals often relied on how 'motivated' they felt patients to be when assessing them for rehabilitation and stroke services – this may be mediated by age but also depended on other things such as attitudes of family members (Mold et al., 2003).

There is some evidence from **Germany** that oldest old patients in hospitals often receive less costly treatments than younger patients for the same conditions. Especially worrying is evidence from the literature and from country reports about age discrimination in the access to rehabilitation for the elderly (both for somatic as well as for mental problems) and this is reviewed separately under 5.3.6 below.

The **Finnish** report mentions widespread ageism in somatic as well as mental healthcare, particularly among the very old. Elderly patients were found to be more at risk of patient safety incidents than younger age groups and to have the highest risk of dying from a patient safety incident. An estimated 15% of the elderly receive inappropriate medications, a higher percentage compared to other groups of the population.

It has also been found that a major influence on access for dependent older people is exerted by the views and perceptions of healthcare practitioners. The existence of this form of 'ageism' has been asserted by many commentators in the **UK** and has been expressed

by many elderly in surveys of their views of NHS treatment, but has been found to often be based on rhetoric or on observation of use of services with little empirical evidence. The UK report suggests as a more useful way of analysis through the study of the basis on which decisions are made about the 'candidacy' for treatment of older people. Doctors may mistakenly believe that some groups may not benefit as much as others and the presence of many co-morbidities amongst the elderly may be one factor that reduces their chances of being referred for surgery.

### 5.3.6 Shortages in adequate rehabilitation and prevention services

The balance of evidence suggests that many complications and worsening of health and disability status in old age are preventable if adequate rehabilitative and preventive care at the boundary of health and social care were available and provided in a timely manner. This includes examples like incontinence, which is a leading cause for admission to a nursing home, and fall prevention in institutions but also at home in the community. The evidence from country reports about shortages in the access to rehabilitation for older people (both for somatic as well as for mental problems) is especially worrying given the fact that these can both have an important impact on reducing the prevalence of disability and improving the quality of life of older people and that there is now growing evidence about the cost efficiency of this type of intervention (see, for example the literature review in *Age Europe*, 2005).

As Table 5.1 shows, all countries for which data are available have made some progress and invested more in certain preventive activities, such as with immunisation against influenza for older people, an intervention particularly relevant for dependent and frail older people.

However, the lack of services aimed at health promotion and disease prevention is a common issue brought up in many of HealthQUEST's country reports. In **Finland**, for example, it has been found that more could be done to prevent osteoporosis, depression and that rehabilitation resources are overall scarce.

### 5.3.7 Deficits in geriatric knowledge and training

Evidence from the country reports demonstrates a wide acknowledgment of deficits in geriatric knowledge and training. Indeed there is a widespread consensus that training in geriatrics plays an insufficient role in medical training programmes. It may not be a mandatory field of study during general training – and may even be missing as a specialisation in its own right.

This is in stark contrast to the fact that older people are such a large group of clients for general practitioners and specialists. There are signs that policies have started to better address this and strategies on how to overcome them have been discussed and partially implemented in a number of countries, but much more remains to be done.

In **Finland**, discussions about changes in the medical curriculum in order to improve responsiveness of services for older people with functional limitations are still very limited with some progress recently (see under 5.2.9).

In **Greece**, a lack of general practitioners is reported to endanger continuity of care. This is particularly important for dependent older people. Specialist geriatric services (which are not a recognised specialty) are also largely missing and there is only limited geriatric and gerontological training for health and social care personnel.

**Table 5.1: Immunisation against influenza as % of the population aged 65+**

Source: OECD Health Data 2007, October 2007

	FINLAND	GERMANY	NETHERLANDS	POLAND	SPAIN	UK
2000	-	-	76	-	61.5	65
2001	25	55.8	76	-	61.9	68
2002	43	-	78	-	67.2	69
2003	45	48	77	-	68	71
2004	46	-	73	-	68.6	71
2005	52	63	77	41.6	70.1	65

In the **Netherlands**, both the Healthcare Inspectorate in 2004 and the Health Advisory Council in 2005 indicated the quality of medical treatment and care to older people is not optimal and the understanding of geriatric issues including co-morbidity needs to be improved in the health and care sector.

A problem that has long been recognised in the literature, but for which no solution seems to be in sight is the fact that older groups are often excluded from clinical trial protocols, limiting the evidence of effectiveness of interventions for this groups (**UK** report). This is in particular crucial for dependent older people who suffer from much co-morbidity. For example, too little is often known about the effectiveness –and risks– of the many prescription drugs taken at the same time, and this puts these groups at considerable risk.

Negative consequences of this lack of knowledge among health professions and of good evidence-based medicine for prescription drugs have also been reported for the **Netherlands**.

On an annual basis, every one in five independently functioning people over 65 is given at least one prescription that may actually be harmful to their health. The building up of new knowledge is hindered by the fact that older people are often not included in medical or pharmaceutical research (Inspectie Gezondheidszorg, 2004; Gezondheidsraad, 2005).

Meanwhile, the prolonged and multiuse of medication is common among older people. Two-thirds of people aged over 65 take at least one form of medication daily, 30% of the population of 74 years and older takes more than four different medicines each day (Raijmakers et al., 2005).

### 5.3.8 Health literacy, voice and health beliefs

Low health literacy, reading problems, and the specific health beliefs of very old people are further aggravating factors for utilisation/access problems. This is a complex issue. Poor health literacy may combine, for example, with complicated bureaucratic procedures to limit access to health services. So too, certain information sources such as the Internet are not usually accessible for the current generation of very old people. On the other hand, there is some evidence that older people may have substantially reduced expectations regarding access and quality of services.

Although the evidence is patchy, research from **Poland**, for example, has shown that older people are more satisfied with access and health services provided than other groups. According to these findings, older people seem to be by far less critical in terms of limitations and barriers in accessing the public healthcare system (only 25% notice signs of inequality, compared with 42% of people aged 35 to 44). These factors have also been relatively well researched in the **UK** (see Box 5.1).

Estimates on the number of older people with functional limitations who have access problems due to low levels of health literacy are currently rare, although this issue is a growing concern among citizens and stakeholders for the situation of older people more generally.

For example for **Finland**, the Finnish Pensioners' Federation (FPF) reported in response to an information request from this study that utilisation of healthcare is more difficult for older people with deficient health literacy, who may not understand

#### BOX 5.1: EXPECTATIONS AND HEALTH SEEKING BEHAVIOUR AMONG OLDER PEOPLE IN ENGLAND

The help-seeking behaviour of older people may be influenced by their expectations of health status as they get older. Walters et al. (2001) found that help was sought for less than a quarter of elderly people's needs in **England** because they were resigned to their situation and had low expectations of the value of contacting their doctor. There is also some research to suggest that interpretation of symptoms as being due to old age may hide symptoms of psychiatric disturbance. Even where help is sought, the existence of many co-morbidities may make it difficult for older people to get across their problems in the consultation setting and they also tend to report physical symptoms more readily than psychological or mood problems (summarised by Dixon-Woods et al., 2005).

There is evidence that older people and their informal carers try hard to maintain their identity as being healthy and fit despite having health problems, 'managing' their health accordingly (Tanner, 2003). They often also place great emphasis on their responsibilities in relation to healthcare interactions (only wanting to consult if 'really' necessary), rather than on their rights. This means that even if offers of help are made, they may be declined. A small interview study of cardiac rehabilitation care found that some older people did not want to disrupt their routine by attending rehabilitation services so ruled themselves out (Tod et al., 2002). Sociological research has shed light on the difference between perceptions of 'care' which suggest dependence and 'help' which suggest support to continue to feel in charge (Tanner, 2003).

Source: UK country report

what services they are entitled to or how to access them or whom to ask. This is associated with problems concerning information transfer, e.g. poorly designed printed material utilising small fonts (such as labels on medications) and forms that are too complicated for older people. Also the language healthcare personnel use may be difficult to understand for many old persons (Finnish country study).

For the **Netherlands**, estimates on overall literacy among older people are available that can impact on health literacy as well (de Boer, 2006). According to these estimates, around 800,000 people between 50 to 74 years old could be qualified as having low literacy levels and many are still not used to using a computer or the Internet. Moreover, approximately 16% of people over 75 who live independently have difficulties filling in forms and paying bills via bank accounts.

### **5.3.9 Barriers at the service interface**

There is a growing recognition that the complexity of the boundaries between different parts of the healthcare service, especially between health and social care, present important barriers for older people. As has been argued above, very old people tend to have more difficulty navigating health and care systems in general. This can become an even greater problem for dependent people who are faced with complex choices of health and care services together. The final declaration and recommendations of the World NGO Forum on Ageing in Madrid (2002) stated that "Co-ordination between health services and social services must be guaranteed, as part of the continuum of care for the elderly." Indeed Leichsenring (2004) found in a cross-national overview that issues concerning coordination and integration of social and health services are in fact high on the agenda in many countries. Nonetheless, the HealthQUEST country reports suggest that there is still significant work to be done.

For example, access problems due to outdated and limited assessment criteria and procedures for receiving services have been reported for **Greece**. A national survey among family carers of dependent older people showed that bureaucratic procedures were a frequently encountered problem and a major obstacle to accessing and coordinating services.

In **Germany**, interface problems are reported between Social Long-term Care Insurance (SLTCI) and Social Health Insurance (SHI). SHI has strong financial incentives to shift the provision of services to the LTC insurance, (there is a complete financial redistribution of the expenses under the public LTC programme among social insurance funds, but not for expenses under the public healthcare programme organised by

the same funds). There has therefore been a constant struggle about the interpretation of 'medical nursing' versus 'social nursing'.

In the **UK**, it has also long been recognised that organisational differences between health and social care agencies work against the interests of people who require health and social care services (Lewis, 2001).

In general, the evidence suggests that older people would like to have common entry-points for service organisation that make access easier, including having complex needs assessments done in a uniform way. The evidence also suggests that they prefer to see a practitioner with whom they are familiar (e.g. Glendinning et al., 2002 for the **UK**).

Coordinating care can be particularly beneficial for the vulnerable segments of society who have difficulty accessing care due to social isolation or other barriers. This includes all socially disadvantaged groups, ethnic minorities, persons with chronic disabling conditions (of any age) and persons with mental health problems (Royal College of Nursing, 2006). However, there are a number of challenges to achieving this. Some of the most important have been listed in Box 5.2.

## **5.4 Barriers to Access – context specific**

### **5.4.1 Older people dependent on care at home**

There are specific risks for older people with continuous care needs who live at home and in the community. However, in many cases, the primary healthcare sector is not well suited to provide services at home. This is the case for general medical services and preventive therapy. Moreover, there is a concern in some countries that dependent older people find it difficult to access specialist healthcare services when they need to get these in their own homes. Specialty services (including basic dental care services) seem only rarely to be available on a home care basis. Moreover, these services may be concentrated at certain centres, making transport to these services difficult for people with serious mobility problems (as reported, for example, for the **UK**). To provide another example, 88% of dependent home care clients who would profit from these services do not receive physiotherapy or exercise therapy in **Finland**.

The situation of dependent older people rests very much on the important role played by informal care that is provided by family and friends or by the voluntary sector. It has been consistently estimated that about 80% of all care hours received at home are provided by informal care, even in countries with relatively generous formal care service systems (Huber, 2007). Health and social care systems in Member States

## BOX 5.2: CHALLENGES TO BETTER COORDINATION OF SERVICES

Despite the desirability of coordinating care, incorporating it into day-to-day practice is not simple. Neither existing care delivery systems nor the professional systems are based on principles of coordinating services. The main obstacles for implementing coordinated care are deeply rooted in the prevailing organisational and policy systems. These include:

- Insufficient public funding to provide sufficient services;
- Unequal access – the counteracting mechanisms of means testing and co-payments may influence people's access to long-term care in opposite directions, as do specific eligibility criteria for social care between local authorities and/or regions;
- Complexity of the system – multiple stakeholders may have different roles, tasks, interests and power positions;
- Lack of overall responsibility for coordinated provision of care and services and for outcomes as a barrier to decision making;
- Frictions in collaboration between organisations and professionals that usually reflect the fragmentation of the various systems involved;
- Human resources – staff shortages, shortcomings in quality of staff;
- Non-corresponding cultures – there are significant differences between the social and healthcare sectors, in areas such as qualifications, ways of working and systems;
- Quality management – social services lack quality systems and policies more often than is the case in the health services. Quality definitions sometimes conflict between parties, so they are often not agreed upon.

Source: Adapted from Niels and Berman, 2004

would not be able to bring up the financing needed to replace this contribution with formal care. For example, it has been estimated that replacing the 5.2 million informal carers would cost roughly the equivalent to the total NHS budget in **England** (Glendinning and Arkesy, in press).

Informal carers not only provide much of the practical and nursing services needed for dependent older people, but they usually also act as mediators for organising the contact with the healthcare sector to ensure access to services.

To make this contribution from informal care sustainable it is essential to put the right mix of support services in place. Many informal carers are themselves older people, and there is a trend towards the ageing of carers, being themselves at health risks from their role of informal carer. For those still at working age it is often difficult to reconcile work with their role as carer. In case this leads to earlier exit from working life and results in interrupted careers, social support is needed to avoid periods spent as a carer resulting in increasing risk of poverty in old age, due to reduced retirement income.

There is a general trend in many EU countries to move towards more comprehensive services and a broader range of choice supporting informal carers (OECD, 2005b; Huber, 2007) and this is also illustrated by examples from country reports under HealthQUEST. However, systems of remuneration and formal work-leave arrangements for those taking up caring responsibilities are not in place for a number of countries, such as **Finland**.

Among the recent reforms in the **Netherlands**, the concept of 'customary care' (*gebruikelijke zorg*) was introduced, referring to the kind of care and support that can reasonably be assumed to be delivered by family or loved ones. This implies those closest to the person affected –in practice a partner where present and any available children living at home– are expected to provide the necessary care. Applications for formal care can only be granted when the need for care is prolonged and there is a lack of informal resources (Centrum Indicatiestelling Zorg, 2005).

In **Greece**, there is high reliance on care and support provided by the family with only few public services available, and the burden of care for dependent older people in Greece is born primarily by the informal care sector.

In **Spain**, as in other Mediterranean countries, families, and in particular women have been the providers of 80% of the long-term care that dependent elderly people need, and of these, the majority are women between the ages of 45 and 69. In 2004, 84% of carers were women who do not work outside the home. However, the number of carers who manage the double challenge of working and looking after an older dependent family member is increasing. Paid carers are becoming more common in families with higher earnings (Secretaría de Estado de Servicios Sociales del Ministerio de Trabajo y Asuntos Sociales, IMSERSO, 2004). Coordination between the Spanish NHS and the social system is now one of the aspects covered by the new Law to Promote Personal Autonomy and Care for People in Situations of

Dependency. Since January 2007, this law designates the National Dependence System as the fourth pillar of the Welfare State, together with the Spanish NHS, the education system and the system of pensions. The system is designed as a public network that integrates health centres and services (public and private) in a coordinated way. Support for carers includes information programmes, training, periods of respite and social security contributions. The criteria used to determine access to these services is the level of dependence of potential beneficiaries.

However, besides improving the situation of informal carers in general, other approaches towards better home care are important.

For example, it is now widely recognised that in the framework of home care services and care allowances, dementia is not sufficiently covered under public programmes in **Germany** as assessment criteria tend to have a bias towards non-mental functional limitations and for recognising rather the need for more somatic care.

For **Greece**, problems in financing the network of Home Care Services are also mainly responsible for their limited provision, which thus focuses on the poorest and most isolated older people without available family support. These services, run by the municipalities since 1998 and providing an essential free service allowing frail older people to remain in their home environment for as long as possible, have been very positively evaluated (Amira et al., 2002), but are under constant threat of reduction or closure due to a lack of clarification in their sources of financial support, i.e. between the health and social care sectors and between central and local government budgets. While there has been a recent attempt to extend the service to help working family carers, mainly women, to remain in or enter the labour market, there is as yet no evidence that this policy has been effectively implemented with positive outcomes for carers and the dependent older people they care for.

Among the policies and good practice examples to improve access to healthcare of dependent older people is the emergence of more comprehensive assessment procedures.

In **Finland**, for example, the obligation to arrange a comprehensive service needs assessment with special procedures for accessing services is an important element towards better cooperation and more integrated service provision. Moreover, a target has been set according to which 25% of the 75+ should have home care by the end of 2007.

For people depending on care at home it is also essential that social services are provided sufficiently early and some countries have enforced time limits for signing up for key services (e.g. **Finland** and **England**).

Moreover, a number of countries have implemented programmes and policies to support informal carers, which can also be important for enabling carers in their support role to help dependent people with their access to healthcare, although this specific aspect of home care support seems to be less researched.

**Finland** provides another example of an active policy to support carers. Informal carers may receive financial support from the local authority. The system has been in use since 1984, and has been amended several times, the last time being at the beginning of 2006. The minimum amount of support for informal care is €300 per month. If the carer is unable to be gainfully employed during a transitional stage with the nature of care being heavy, the support for informal care is at least €600 per month. The support is classified as taxable income. A carer with an agreement with the local authority is covered by earnings-related pension provision for his or her work, provided that he or she is not already retired.

The local authority also provides accident insurance coverage for the informal carer. In the care and service plan, support services for the carer are also specified, in addition to the services provided for the patient. The person receiving support for informal care is entitled to have at least two days off in any month during which the nature of the care provided is extremely demanding. The local authority provides for the care during the statutory time off. The local authority may also provide recreational time off without reducing the amount of support for informal care.

#### **5.4.2 Dependent older people in nursing homes**

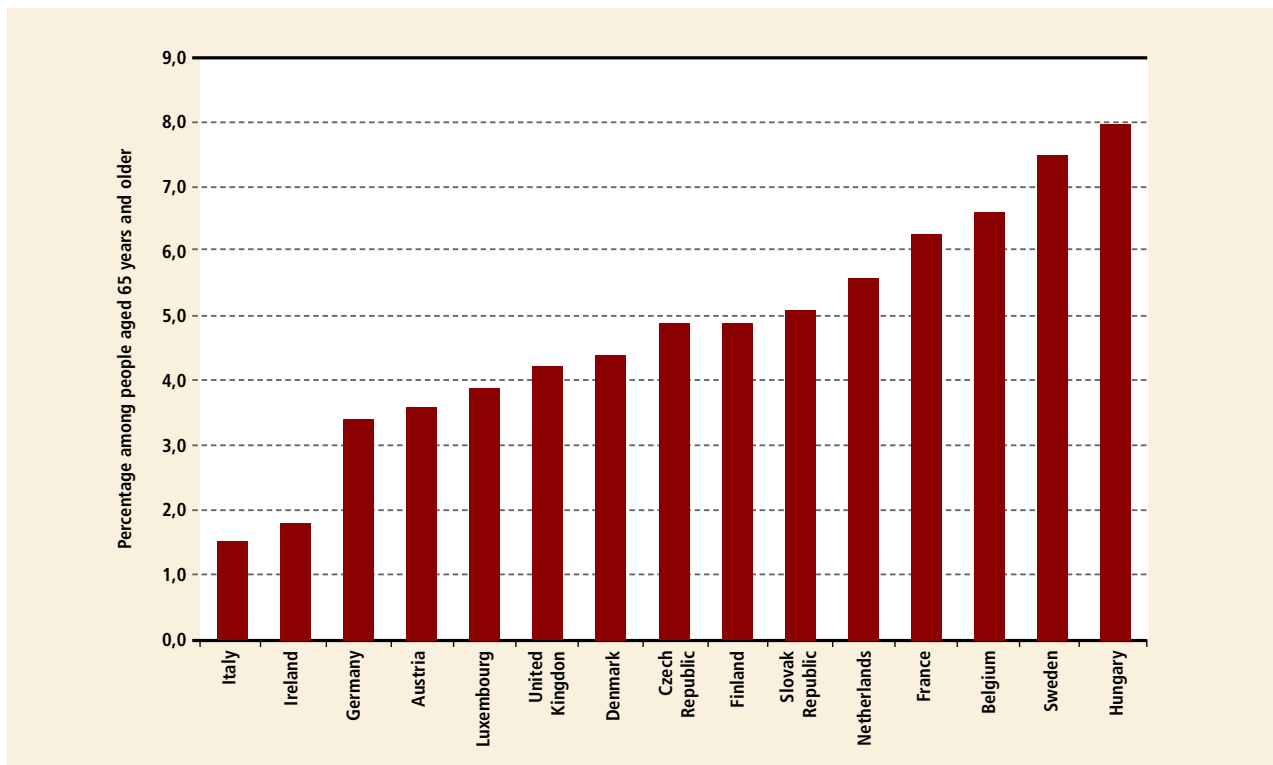
There is evidence from the research literature that the access of older persons to mainstream health services (from foot care to dental care, but also basic mental care) can decrease significantly at the moment a person is admitted to a nursing home.

Care of dependent older people takes place in various institutions in EU countries that can differ largely in the severity of average residents' needs, and in the scope and type of services provided. This has to be taken into account when numbers of older dependent people who receive care are interpreted. As Figure 5.4 shows, the share of dependent older people who are cared for in institutions can vary from below 2% to over 8% of people aged 65+.

In interpreting Figure 5.4, one needs to keep in mind that the access to long-term care institutions and for institutions at the interface between acute and treatment, rehabilitation and social care can be unequal across regions, as has, for example, been reported for long-stay institutions in **Spain**. Moreover, waiting lists

**Figure 5.4: People receiving long-term care in institutions, 2004**

Source: OECD Health Data 2007, October 2007



for long-term care institutions are reported for a number of countries at different overall spending levels on long-term care.

For example, waiting lists (for both home care and care in institutions) are reported for the **Netherlands**, with average waiting times of between 4–13 months (in 2003), which considerably varies between regions. Waiting lists for LTC institutions are also frequent in **Poland**, and patients usually spend their waiting period in a hospital.

For nursing home residents, the health risks from access problems are in addition to risks to health as a direct consequence of poor care. Problems found in some nursing homes include malnutrition and starvation, dehydration, decubitus and harm from being physically restrained. Moreover, around half of Europeans are of the view that poor treatment, neglect and even abuse of dependent elderly people are widespread in their country, according to a recent special Eurobarometer on *Health and long-term care in the European Union* (European Union, 2007).

In spite of these broad problems that affect a relatively large number of people towards the end of their lives, the situation of those living in institutions has been characterised as “seriously under-researched” (UK report), and this is also the case for other countries. The evidence and examples from country reports are therefore rather limited.

The reported lifetime risk basis for receiving nursing home care depends to a larger degree on the design of national care systems (such as available supply and the division of labour with informal family care) than on the age structure of the population per se.

In **Germany**, for example, this lifetime risk is about 35%. However, the age of entry has increased over time, while the average length of stay in a nursing home has decreased. Of the age group 70 to 74 years, only 5% need help, while in the age group above 90 years, dependency on help reaches 57%. Similar trends have been observed in other countries; however, not uniformly (Huber, 2007).

For a number of countries where provision of long-term care for dependent older people has evolved into a more balanced mix of services between care at home versus institutions, the trend is towards shorter average stays in nursing homes, with nursing home patients, who usually have severe functional limitations, being in nearly constant care need (**Finland**). This means that the typical nursing home resident needs an increasingly more complex mix of services from both social and medical care facilities and this should be reflected in the staff available on site.

There is evidence from some countries that the current rigid boundaries between health and social systems do not allow for optimal cooperation in this respect for a good mix of services for this highly vulnerable group of

older people. In **Germany**, for example, nursing homes are not legally recognised work places for physicians, leaving most of the burden of care to other professionals.

There is also some evidence about the lack of access to services and their poor quality. Dixon-Woods et al., looking at the **UK** have summarised the evidence and suggest that there are indications that these groups may receive poor access and lower quality care because of the way in which their access to GP services is handled within the care homes. In the UK, a recent Help the Aged study found 21% of care homes had no regular visits from a GP. Some reports suggest that some care homes even pay for GP services for their residents, despite the fact that they are nominally entitled to free care (Glendinning et al., 2002). Moreover, there is evidence about poor quality of primary care for dependent older people in nursing homes and this may also be the case for other health services, such as chiropody, dental care, speech and language therapy and physiotherapy, as well as management of prescription drugs that may also be poorer for those living in institutions compared to those in the community.

## 5.5 Policy initiatives

This section documents the variety of policy responses to the access problems faced by dependent older people. They have been ordered by the main type of barrier that they are intended to tackle, keeping in mind that many initiatives are relevant for more than one aspect of the often highly interrelated access problems.

The evidence from country reports about policy initiatives to address the access barriers identified in chapter 5 is uneven. For example, few targeted policies to improve problems with transport or regional barriers have been described. For the interface of health and long-term care needs, initiatives are often piloted or implemented at the local level, therefore not necessarily addressing regional (geographic) variations.

An important example for a policy that addresses variations in care is in the **UK** and aims to improve quality of services is the *National Service Framework (NSF)* for older people. Introduced in 2001, this framework sets out a 10-year programme for service improvement.

Moreover, it is important to keep in mind that the following sections on policy initiatives should all be seen under the special perspective of the situation of dependent older people, not of older people or of the population in general. Some policy initiatives for improving access for the general population, such as,

for example, the increasing role of Internet-based information may in fact put older dependent people at a disadvantage compared to the general population<sup>9</sup>.

### 5.5.1 Cross-cutting initiatives

Among the major initiatives launched to address many of the access problems reviewed in this section in an integrated way is the *National Service Framework for Older People* for the NHS in the **UK** (England). This was published in 2001 and sets out a 10-year programme for service improvement. A review of progress in 2003 found that attitudes to ageism were changing and that availability and uptake of a number of interventions have increased for older people. Among these are procedures important to prevent dependency, such as cataract surgery and hip replacement. Progress is also reported, among other areas, with strategies to reduce falls.

### 5.5.2 Cost-related barriers

There are a number of ways to mitigate the financial consequences of high health (and social) services use of dependent older people.

An effective strategy, although not frequently chosen, is to exempt older people in general from cost sharing. This approach has been taken in **Spain**. Exemption rules in other countries tend to be more complex, with caps and exemptions regulated by type of disease, or maximum annual spending. The effectiveness of these measures will, however, depend on how complex the corresponding bureaucratic procedures are and on whether spending limits are not too high for older people living in or close to poverty.

### 5.5.3 Lowering organisational barriers

As a response to the inadequate bureaucratic assessment procedures for social service needs, there are now plans in **Greece** to radically simplify and update assessment procedures for assessing functional status to determine social care needs of dependent older people.

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<sup>9</sup> There are, however, examples of the use of technology for dependent older people that have been termed 'smart technology' or 'e-care' that provide promising examples of improving access to community care and also allowing older people living alone to stay at home as long as possible. These have been shown to be cost-efficient ways of providing care in some examples (e.g. Bowes and McColgan, 2006) and systematic research both on their benefits and the reasons for their unequal spread in the EU seems to be a high-priority area for future research.

In **Spain**, the Law of Guaranteed Rational Use of Medication and Healthcare Products (Law 29/2006) was recently passed to facilitate access to medication that does not require a prescription. It allows people who cannot go to a pharmacy to purchase medication by Internet, as long as the medication is dispensed through an intermediary – a pharmacy and pharmacist who provide personalised advice. This measure has been taken to improve access to medication among people with functional limitations, and could help people in more disadvantaged socio-economic groups, provided they have the necessary support to access the Internet.

#### 5.5.4 *Better access to rehabilitation and prevention services*

Under the 2007 health reform in **Germany**, geriatric rehabilitation became a mandatory benefit under social health insurance, both for somatic and mental indications and this now also includes ambulatory geriatric rehabilitation, provided by mobile services to reach people at their places of living.

Two initiatives from the **UK NHS** are mainly aimed at older people: health checks for those aged 75+, although this has not yet been sufficiently evaluated; and all people aged 65+ are entitled to annual vaccinations against influenza (see Table 5.1 above on a comparison of uptake rates with other countries).

#### 5.5.5 *Investment in geriatric knowledge and training*

Discussions about changes in the medical curriculum in order to improve responsiveness of services for older people with functional limitations are still very limited. In **Finland** there is a degree programme in Elderly Care, which aims to promote health, well-being, functional capacity and social participation of elderly citizens. The programme combines multidisciplinary gerontological knowledge with practical elderly care qualifications and with the supervision and development of services for elderly people.

#### 5.5.6 *Coordination of care*

An interesting example from **Finland** refers to the development of a more extensive and harmonised assessment of service needs for people aged above 80 years. This system is expected to improve equality of access to services for older people. Since March 2006, all people over 80 years of age and those receiving a special care allowance from the Social Insurance

Institution of Finland (The Social Insurance Institution of Finland, 2007) may have an assessment of their non-emergency service needs if they so require by the seventh working day from the day of contact. In urgent situations, the need for all services must be assessed at once, regardless of age. After the assessment of service needs has been carried out, the client must be given a written decision on the acceptance or non-acceptance of services if the client so requires. The client may appeal the decision. If the decision on the arrangement of services is positive, a care and service plan must be drawn up.

#### BOX 5.3. GERMANY: MODEL PROJECTS ON HEALTH AND SOCIAL CARE FOR FRAIL ELDERLY

In **Germany**, 20 model projects on health and social care for frail elderly were launched in 2000 and later evaluated.

Another initiative that has helped to clarify the interplay of different health and social programmes in providing support and services to dependent older people is the Germany Charter of Rights for People in Need of Long-term Care. This was developed to summarising existing rights from various regulatory documents; distributed to providers and stakeholder organisations. An evaluation of its impact is planned in 2008.

Source: German country report

In **Greece**, a number of initiatives have been undertaken that foster better coordination of care for older people. There are now plans to introduce electronic health records during 2007–2013. Currently families and patients keep their own records, such as test results, diagnoses etc. and are responsible for informing and coordinating care between different service providers.

More prominent are the more than 1,000 KAPI centres that have now been installed on a local level (Box 5.4).

A major element of the 2001 *National Service Framework for Older People* from the **UK NHS**, is the Single Assessment Process that provides a person-centred, thorough assessment of health and social care needs as a single process, although limited to services governed within local authorities.

The experience from this reform shows that the special professional expertise required for this task is crucial. The 'LinkAgePlus' pilot programme and the 'Partnerships for Older People' extend the principles of joined-up working to improve access to the full range of health, social care and other services for older people.

## BOX 5.4: THE EXAMPLE OF KAPI CENTRES IN GREECE

The KAPI centres (Open Care Community Centres for Older People), piloted in in Greece in 1978 and adopted into policy from 1984 onwards, represent the main axis of health and social care provision for older people in Greece, based on the aim of maintaining older people as active, independent citizens participating in their local communities and living in their own homes for as long as possible. Financial support, including staff salaries, is provided by the Local Municipal Authorities and the popularity of the centres has ensured their continued support by successive governments and the steady expansion of the number of centres to its present day total of over 1,000, with some municipalities having several KAPIs.

From the outset these centres were pioneers in their understanding of and focus on the social aspects of health, together with health promotion and disease prevention programmes aimed at maintaining physical and mental health amongst the older members. Membership of and participation in the centres' activities is voluntary and a nominal fee is paid yearly, which is frequently waived in cases of need. Staff is a mixture of health and social care personnel, usually with a full-time social worker, health visitor or visiting nurse, physiotherapist, occupational/ergo therapist, visiting doctor and other part-time specialists and volunteers. Services offered are primarily recreational, social and limited health programmes, with the major problem that the health services are not integrated into mainstream health services and remain a 'Cinderella' service dependent on the enthusiasm and commitment of individual practitioners. The potential for their expansion and integration into the PHC sector, with benefits to

both older patients and practitioners, cost reduction and the relief of the overburdened hospital outpatient departments, has never been realised by any government so far and the health services and integrated health and social care provision of the KAPIs remain under-exploited. Another initial deficit of the KAPI centres, their lack of provision for the frail and dependent section of the elderly population, was partly remedied through the attachment to many of the centres of the Home Care programmes which often run in parallel with the KAPIs. The KAPI centres represent an example of partially integrated health and social care services for older people – it is the only service designed specifically for older people, is developed into a comprehensive network and has the potential to relieve overstretched and often inappropriately used primary and secondary healthcare services by offering a complementary and appropriate service for older people in their local environments. The main barrier to the more effective functioning of the KAPIs is the non-integration of their healthcare services into the mainstream services, a barrier which could be easily removed by minor modifications to the NHS law, but which requires political vision and commitment to improving the service to this vulnerable segment of the population. There is also a lack of evaluation of the KAPI services and the effectiveness of the KAPIs in improving health amongst older members (Kyriopoulos et al., 2000).

A more recent planned development is that of the KIFIs – Day Care Centres for dependent older people with 54 being listed in 2006 ([www.50plus.gr](http://www.50plus.gr)) but with no evaluation on their real usage and operation (Ministry of Health and Social Solidarity, 2005).

Source: Greek country report

## 5.6 Conclusions

### 5.6.1 *There are strong inter-linkages between cost, physical, other access problems for dependent older people*

The interplay of poverty issues, organisational and geographical barriers, as well as limitations of health literacy, voice and health beliefs are compounding factors that relatively strongly affect the ability of dependent older people to access appropriate care in a timely fashion.

The country studies provide evidence that older people do not see health professions as frequently as they would need, and issues of high cost are among the reasons stated by older people themselves for why this is the case. In addition to cost as a barrier, dependent older people often face barriers of access that are due to lack of transport, and this can be aggravated by regional disparities of service availability, in particular for those living in rural areas.

### 5.6.2 *Older people often face significant problems in accessing quality care*

Arguably as important as problems of getting access per se, and of being able to pay for it, are the limitations of quality of care that dependent older people often face.

There is now a growing number of studies that show that mainstream healthcare is often not well prepared to respond adequately to the high co-morbidity that is frequently present with dependent older people, putting them at high health and safety risks. An important example is inadequate treatment with prescription drugs.

Even for countries with relatively high public spending on health and long-term care there is evidence of serious deficits in access to good quality care of dependent older people and this is clearly illustrated by the HealthQUEST country studies analysed in this chapter.

As this chapter has argued, this is both due to genuine deficits of mainstream healthcare services that are often not taking the specific needs and risks of older people sufficiently into account, but also due to the complex interplay of broader social issues with health access problems, such as poverty of older people, organisational and geographical barriers and problems at the interface between health and social services.

For mental health in particular there are many issues of under-diagnosis and of under-treatment of common problems, such as depression and sleeping disorders. Dementia patients are one of the groups of dependent older people who are at the highest risk of not getting adequate attention by health and social care systems.

### ***5.6.3 Important opportunities for early intervention are often lost***

In all countries, opportunities for early interventions to prevent, postpone or slow down disability 'careers' of older people are frequently lost.

This is all the more worrying because the balance of evidence suggests that many of these interventions (actions to prevent falls, general community activities for physical exercise, early and intensive rehabilitation after major injury and the like) are win-win strategies that are both efficient and often cost effective.

### ***5.6.4 There are significant problems at service interfaces***

Tackling interface problems at the boundary between health and social services is key to improving access of dependent older people, and it is what most people wish. The problem is often not a general lack of access to general healthcare for dependent older people, such as hospitalisation. But there is evidence that more could be done to improve the mix of health and social services to prevent frequent hospitalisation (for example by preventing injuries or other adverse effects of placement in nursing homes). This includes, e.g. the need for having sufficient capacities and mixed teams of practitioners (health and social services) available to avoid 'bed-blocking' by dependent older people in hospital settings.

## **5.7 Recommendations**

### ***5.7.1 Coordinating policy approaches***

The inter-linkages of barriers of access for dependent people call for integrated policy approaches, in particular to prevent high health and care demand

resulting in poverty of the elderly. Because older people with functional limitations are fast-growing groups in ageing populations, it is important that health reform and system policies always consider the impact on the situation of dependent older people. This will require, among others, better data, more stringent goal setting of public policies, and better evaluation.

### ***5.7.2 Improving rehabilitative and preventive care***

Country reports show some progress in recent years with overcoming age discrimination in healthcare provision, and more investment in healthcare has helped expand the provision of some types of care that are crucial for older people and for the prevention of dependency, such as with reducing waiting time for hip fracture or cataract surgery.

But there is also ample evidence about opportunities that are not realised. A point that cannot be emphasised enough is the need to increase versatility and timeliness of preventive and rehabilitative activities in order to improve functional capacity of older people and to prevent or postpone the onset of dependency. Policies towards barrier-free public spaces for all would help older dependent people in particular, such as with the help of national guidelines for barrier-free public spaces.

### ***5.7.3 Investment in gerontology and in better care guidelines***

Because many of the problems of poor quality of care are due to a lack of sufficient understanding and knowledge of elderly health and care issues among health and care professions, there is clearly a point for more investment in geriatric medical knowhow. Because of current demographic trends, this investment is now urgently needed as well as more training of staff in gerontology, including in the social aspects of older people.

More comprehensive geriatric care recommendations and guidelines should be prepared, involving the cooperation of providers and stakeholder organisations.

### ***5.7.4 Dealing with the interface between health and social services***

The interface between health and social care is an area where a number of recent good practice examples and research allow for mutual learning on how to better integrate services and to provide improved access in the community. However, more consideration of this interface is needed.

### **5.7.5 Investment in research**

Although older people have received much attention in the literature in past years, many of the challenges of improving access to better quality services remain seriously under-researched. Besides more investment in gerontology (as mentioned above), it is important to step up research on the health access and quality of life issues of people depending on care at home and in institutions, in particular to tackle the serious inequities of access and quality deficits that exist for dependent people living in institutions.

Policies are needed that aim not just at increasing supply, but also at supporting people in accessing services. Better coordination, collaboration and

integration are likely to reduce the complexity of navigation through the system for dependent older people.

Finally, a culture of evaluation and systematic research monitoring of policy implementations is only emerging in some countries but should become a core principle in European health policy more generally, and this is of particular relevance for issues of access to care for vulnerable people.

For health and social policy of ageing societies it is essential that the evidence base about disability trends among older people is improved, both from surveys and from administrative sources, as the evidence about these trends is currently mixed and may misguide resource allocation.



## 6 People with mental health problems

### 6.1 General healthcare needs of people with mental disorders

Mental disorders constitute a major part of the European burden of disease. In any given year a quarter of Europeans are likely to be affected by mental disorders (Wittchen and Jacobi, 2005), while less than half of those in need of care will have had formal contact with health services (Alonso et al., 2007). Many EU Member States are experiencing increasing numbers of sickness spells and early retirements due to mental disorders and problems (Järvisalo et al., 2005). The economic consequences of mental health problems –mainly in the form of lost productivity– are estimated to be 3–4% of gross national product (Gabriel and Liimatainen, 2000). Projections of disability from WHO indicate that the relative burden of neuropsychiatric disorders will grow. In 2020, depression, alcohol use, dementia and self-inflicted injuries will be among the 10 leading causes of disability-adjusted life years (DALYs), and contribute to more than one fourth of the total disability burden in developed economies (Murray and Lopez, 1997). The state of mental health in the European Union was extensively reviewed in a previous Commission report (DG Health and Consumer Protection, 2004).

Mental disorders are associated with poor physical health. Current evidence has established the need for physical healthcare in people with mental disorders. A recent literature review (Nocon, 2006a) relating to inequalities in health status amongst those with mental health problems reported the following findings:

- Higher mortality rates amongst those with mental health problems, even after accounting for deaths from suicide;
- Higher than average rates of physical illness amongst people with mental health problems, including: cardiovascular disease (ischaemic heart disease, stroke, hypertension), with rates up to 1.9 times higher than the general population;
- Diabetes, with rates of between two and four times that of the general population;
- Respiratory disease, with COPD and emphysema being more common;
- HIV/AIDS and hepatitis B and C; rates of sexually transmitted diseases are higher in people with mental health problems;
- Poor oral health;
- Cancer rates have generally been found to be similar to the rest of the population.

In understanding these poor health outcomes, it is important to note that certain groups with overlapping disadvantages are at higher risk of mental disorders and may face even greater barriers of access to healthcare than others. First, mental health problems are associated with poverty; people who are unemployed or have a low standard of living have more mental disorders (Fryers et al., 2003). Second, poor mental health is common in many vulnerable groups with low access to healthcare, such as migrants and homeless people (Bhugra, 2004). Third, in Europe people with mental and physical co-morbidity may have less access to healthcare (Alonso et al., 2007).

There is evidence to suggest a high incidence of mental disorders amongst homeless people but low rates of treatment, some of which are due to difficulties with accessing services by not having a permanent address (Nocon, 2006a). In the **UK** 30–50% of rough sleepers are estimated to have a mental health problem and two out of three have a physical health problem (SEU 1998). One in three is not receiving needed healthcare and many avoid visiting GPs due to previous bad experiences (Riley et al., 2003). In **Germany**, two out of three homeless persons suffer from a mental health disorder (Längle, 2005). Many of them have general healthcare needs (Völlm, 2004) and an under-utilisation of general healthcare (Trabert, 1995). In **Poland**, it is reported that 90% of homeless people have a mental disorder (Sidorowicz, 2000).

According to international studies and reports mental health disturbances are also common among migrants, although the pattern is highly complex and heterogeneous (reviewed by Bhugra, 2004). Migrants and ethnic minority groups, particularly refugees and asylum seekers, seem to be at risk of poor mental health. There are also indications that their mental health problems are not identified or that they are treated inadequately (Kokanovic et al., 2001). In the **UK** the prevalence of mental disorders is higher amongst African-Caribbeans, Indian and Pakistani people than amongst white people (Nazroo, 1998; Weich et al., 2004). Identification and treatment rates have nevertheless been found to be lower in some of these groups (Nazroo, 1998; Wilson and MacCarthy, 1994). Data on mental health in the **Netherlands** suggest older Moroccan and particularly Turkish migrants are at higher risk of depression, with Turkish women over 65 showing the highest depression rates (van der Wurff et al., 2004). Compared with Dutch natives, schizophrenia is relatively more prevalent among Surinamese, Antillean and Moroccan migrant communities (Selten, 2001).

Important evidence also comes from the European Study of the Epidemiology of Mental Disorders (ESEMeD). Consisting of 21,425 completed interviews from Belgium, France, Germany, Italy, the Netherlands and Spain, this study evidenced a high level of co-

morbidity between mental and physical illness in a European adult population (ESEMeD/MHEDEA, 2004). According to the study, 52% of European individuals with a 12-month need for mental healthcare had visited formal health services and 25% had visited a mental health specialist (Alonso et al., 2007). Interestingly, individuals with a physical co-morbidity reported less often that they had visited health services for their 'emotions or mental health' than individuals not reporting any physical illness. Indeed the study suggests that physical co-morbidity seems to increase risk of not accessing adequate health services by 30%, indicating that in Europe people with multiple health needs may actually receive less than people with pure mental health needs.

The individual country studies, summarised below, uniformly confirm the high degree of physical morbidity among people with mental disorders, and also confirm the existence of a major health gap evidenced by huge excess mortality due to natural causes among people with mental disorders.

### 6.1.1 Finland

Finnish research indicates that there are higher mortality rates from natural causes among people with mental disorders. A longitudinal cohort study, with a follow-up period of 17 years, indicated a 50% mortality increase for those with a diagnosed mental disorder, mainly due to respiratory and cardiovascular disorders (Joukamaa et al., 2001). An increased relative risk of death from natural or unnatural causes was verified in both sexes. For men the risk of death was 1.6-fold (95% confidence interval (CI) 1.3-1.8) and for women it was 1.4-fold (CI 1.2-1.6). In men and women with schizophrenia the relative risks of death during the follow-up period were especially high: 3.3 (CI 2.3-4.9) and 2.3 (CI 1.3-3.8), respectively. The increased mortality is only partly explained by suicides or other unnatural causes. The morbidity rate from natural causes in people diagnosed with schizophrenia was threefold compared with the rest of the cohort (Joukamaa et al., 2006). The morbidity rate remained twofold even after adjusting for somatic diseases, blood pressure, cholesterol levels, body mass index, smoking, exercise, alcohol intake and education (Joukamaa et al., 2006). The excess mortality was confirmed in a nationwide register study of nearly 60,000 schizophrenia patients, who had an increased mortality from natural causes of death (RR 2.59, CI 2.55-2.63) (Heilä et al., 2005). Taken together, these data from Finland indicate that people with schizophrenia die more frequently than other people with similar risk factors.

Further studies have identified particular subgroups with extremely high mortality. A study by Räsänen et al. (2003), for example, identified excess mortality from natural causes among long-stay psychiatric inpatients in northern Finland. Diseases of the circulatory system

were the most common single cause of death in both genders, and mortality due to that cause exceeded mortality in the general population nearly fourfold. Inadequately organised somatic care and the prevailing culture of 'non-somatic' treatment in psychiatry were suggested to, at least in part, explain this phenomenon. A study by Sailas et al. (2006) demonstrated that within a nationwide cohort of prisoners, there was a sevenfold increase in mortality compared to the general population matched for sex and age. Furthermore, the odds of death for prisoners with previous psychiatric treatment was 1.6 (CI 1.3-2.0) compared to prisoners without a psychiatric history. The study indicates that the health needs of this highly troubled group have not been met.

Other evidence also comes from the general population health examination study, *Health 2000*. This confirmed that people with schizophrenia or other non-affective psychoses, when adjusted for sex and age, evidence excess type II diabetes and metabolic syndrome and poorer visual acuity than the general population (Suvisaari et al., 2007a; Suvisaari et al., 2007b; Viertiö et al., 2007).

### 6.1.2 Germany

In Germany, mental disorders are also associated with excess mortality. Indeed somatic diseases contribute substantially to the excess mortality of psychiatric hospital patients. In a study of seven psychiatric hospitals with defined catchment areas (Hewer et al., 1995), the standardised mortality rates (SMR) for inpatients with functional psychoses was 4.55 and for non-psychotic inpatients 3.25. In a later study (Hewer and Rössler, 1997), the inpatient mortality from all causes (SMR 4.3,  $p < 0.001$ ), as well as from natural causes (SMR 2.6  $< 0.01$ ) were significantly raised in psychiatric hospitals.

The *Federal Interview and Examination Survey on Mental Health* in 1998/1999 also evidenced a significant association between poor somatic health and mental disorders.

It is interesting to note that a somatic disorder is diagnosed in 33% of psychiatric hospitalisations, with diseases of the heart and the circulatory system being most frequent (Hewer et al., 2002).

### 6.1.3 Greece

The health status of people with mental disorders has not been well documented in Greece. However, Kossioni and Karkazis (1999) reported that oral health is worse in those elderly with a concurrent

mental health disorder. In addition, there is one historical report on the crude mortality rate of people with mental handicap admitted to Leros PIKPA asylum over the period 1961–1991 (Perakis et al., 1995). This data gives a figure of 59.2 deaths per 1,000 person-years, more than 20 times the rate for the general population at that time.

#### **6.1.4 The Netherlands**

A broad epidemiological overview of the health status of people with mental disorders in the Netherlands is not available, but there is some information on the increased somatic health risks of people with schizophrenia, anxiety disorders and depression.

Through a disease management programme within the mental health sector, increased somatic risk factors were identified among 28% of patients with schizophrenia. This included metabolic disorders with an increased risk of COPD. Many of the somatic conditions identified via this programme had not been previously diagnosed (Planije and Smits, 2006).

Evidence from the Netherlands suggests that adults with anxiety disorders are also two times more likely to suffer from a chronic somatic illness such as chronic obstructive pulmonary disease (COPD), high blood pressure, migraine, diabetes or arthritis when compared to people without these anxiety disorders. They are also more likely to be treated for these chronic illnesses, although it is not clear whether this is in proportion to the higher prevalence of chronic illness (Neeleman et al., 2001).

Depression increased risk of dying among Dutch primary care users. The adjusted hazard ratio for death of depressed versus non-depressed subjects was 1.4 (CI 1.2-1.6) (Ensinck et al., 2002).

Underlining other studies, data on patient profiles in primary care indicates that depression may coincide not only with other mental health problems such as sleep and anxiety disorders, but also with somatic disorders like hypertension or diabetes mellitus. Anxiety disorders are reported to coincide with neck and back pain, hypertension, eczema and fatigue (Cardol et al., 2004).

#### **6.1.5 Poland**

The research on physical co-morbidity in mental disorders in Poland is limited and restricted to people with schizophrenia. It is reported that two of three patients with schizophrenia have more than two somatic diseases. Physical co-morbidity is more

frequent (46–80%) among inpatients than in outpatients (25–43%). People with schizophrenia evidence a higher incidence of cardiac diseases, hypertension, type II diabetes, infectious diseases, including HIV, than the general population (Dereszek-Kazanecka, 2005).

#### **6.1.6 Romania**

No Romanian research on general healthcare needs of people with mental disorders was identified by the country study.

#### **6.1.7 Spain**

In Spain, few studies have addressed physical co-morbidity or excess mortality among people with mental disorders.

However, in a Catalan health survey of 15,000 members of the general population, psychological distress was most consistently related to the presence of one or more chronic physical conditions. The number rather than the type of declared chronic physical conditions was the most important factor associated with mental distress: with an OR from 1.1 for one declared condition to 5.6 in persons with over five chronic conditions (Gispert, 2003).

Excess mortality, 1.44 times greater than that in the general population, has also been shown in psychiatric patients living in an urban area of Valencia. In the analysis of mortality according to psychiatric diagnosis and cause of death, patients with organic psychoses presented an almost eightfold increase over the general population regarding the risk of death due to cardiovascular disease, an almost fivefold increase in the case of respiratory pathology, and an 11-fold increase in the risk of death due to suicide or accidents. Schizophrenia, alcohol or drug abuse and neuroses/personality disorders involved a higher risk of death from liver disease. No psychiatric disorders were found to be associated with increased risk of cancer death (Salazar-Fraile et al., 1998).

A significant association between psychiatric morbidity and mortality has also been reported among a community sample (N=1080) of Spanish elderly people (65+) in a 4.5-year follow-up study. Both pure organic (i.e. dementia) and pure depressed cases had higher mortality when compared with people from the same community sample without mental disorders (Saz et al., 1999).

In Barcelona, a recent retrospective study reviewed medical records of patients who attended primary care centres in 2004 and analysed the cost and use of services by persons with mental health problems

(Sicras-Mainar et al., 2007). It shows that 17.4% of those who came seeking care had a mental problem, that those patients usually had a higher number of comorbidities and that costs to attend them were slightly higher than for the rest of patients (differential cost of €73 per year when adjusted for sex, age and comorbidity). The annual number of health problems attended was higher in mental health patients and the presence of mental health problems was related with a higher probability of having the following diseases: malignant neoplasias, arterial hypertension, dyslipemia, obesity and ischemic cardiopathy.

### 6.1.8 United Kingdom

A recent formal, independent investigation of the physical health status of people with learning disabilities and/or mental health problems, undertaken by the Disability Rights Commission, summarises a large amount of existing evidence relating to inequalities in health status (DRC, 2006a; 2006b).

The main findings of the national data analysis from England and Wales on the prevalence of physical health disorders among people with schizophrenia or bipolar disorder (undertaken as part of the DRC review) suggest higher rates of ischaemic heart disease, stroke, elevated blood pressure and diabetes in both these groups as compared to people without either disorder (Hippisley-Cox and Pringle, 2005). The analysis also explored cancer rates and, in contrast to published research, suggests higher prevalence of breast and bowel cancer amongst those with schizophrenia (Hippisley-Cox et al., 2006a). The clinical analysis also suggests that those with mental health problems are more likely to develop some conditions than those without such problems, that they develop them at a younger age and that once they have them they die faster than others with the conditions. The conditions include coronary heart disease, diabetes, stroke, respiratory disease (Hippisley-Cox et al., 2006b). Overall, five-year survival rates show lower survival for patients with mental health problems for almost all key conditions (Hippisley-Cox et al., 2006c). This is the case even after allowing for suicide rates.

In Scotland, a study has found that people discharged from long-term psychiatric care between 1977 and 1994 were most likely to die from circulatory problems, with a 50% higher number of deaths than expected. The second greatest cause of death, respiratory disease, accounted for four times more deaths than expected (Stark et al., 2003).

A study in Wales found that the reported prevalence of specific physical conditions was generally at least twice as high for people with serious mental health problems as for other people (Richards et al., 2005).

One partial explanation has been suggested by a UK study investigating health determinants among 102 people with schizophrenia living in the community. Compared to general population norms, this study shows that people with schizophrenia tend to have an unhealthy lifestyle. They ate a diet higher in fat and lower in fibre than the general population, took little exercise but were not significantly more obese. They smoked heavily but drank less alcohol. Most differences remained significant after controlling for social class (Brown et al., 1999).

## 6.2 Access to healthcare for people with mental disorders

### 6.2.1 Previous work

At a European level there has been some work on the connection between mental and physical health. The Commission Green Paper, *Improving the mental health of the population: Towards a strategy on mental health for the European Union* (European Commission, 2005) highlighted the close interrelation between mental and physical health. During the Green Paper consultation process the need for more responsive mainstream health services was stressed. The need to support general health screening programmes among people with mental disorders, as well as the need to integrate mental healthcare into general healthcare, was also stressed. The European Health Management Association (EHMA), for example, suggested that the OMC processes and NAPs on social inclusion should pay particular attention to overall access to mainstream services for people with mental disorders. Member State governments also noted that mental health promotion should recognise the strong relationship between mental health, physical health and general well-being (European Commission, 2006).

At a European level, the discrimination faced by people with mental disorders in health services has also been highlighted by the NGO, Mental Health Europe in a project funded by the European Commission DG Employment and Social Affairs. The project involved national partners from Austria, Germany, the Netherlands, Spain and the UK, as well as the European Network of (ex-)Users and Survivors of Psychiatry (ENUSP). The project produced a booklet with examples of best practices, a training pack for health professionals and a set of policy recommendations.

On a national level, very little previous work related to access to general healthcare services for people with mental disorders has been identified. A notable exception is the UK, where research commissioned by the UK Disability Rights Commission on the health inequalities experienced by people with mental health problems and/or learning disabilities in England and

Wales has highlighted the existing health gap (DRC, 2006a; 2006b). The HealthQUEST country reports, summarised below, report a lack of awareness in other countries on the issue of access to healthcare for people with mental disorders.

## **6.2.2 Finland**

### **6.2.2.1 Legislation**

In Finland, the health and social services for people with mental disorders are based on general healthcare legislation and on the special provisions in the Mental Health Act. The Act states that a patient (in mental health care) is entitled to treatment for physical illness according to the general Act on the Status and Rights of Patients, i.e. general healthcare should be provided on equal grounds to people with mental disorders. The mental health legislation builds on the universal principle of mutual understanding between patient and doctor when treating physical disease, and the provisions for treatment of physical disease if the patient objects to treatment are strict.

The Constitution of Finland and several other Acts guarantee equality and prohibit discrimination, although the Non-Discrimination Act, which came into force in 2004, does not specifically mention people with mental disorders.

### **6.2.2.2 Policies and programmes**

On the policy level, the goal has been to include mental health policy in general health policies, and no specific national policy document for mental health exists. This can be seen as advantageous from the point of view of inclusion policy, but this decision also includes the risk for neglect of mental health issues. In the current public health programme, 'Health 2015', mental health issues are not prominent.

On the programme level, national programmes to prevent suicides and to facilitate early interaction between mother and child have been implemented on a large scale. However, in spite of the increased mortality among people with mental disorders, there have been no policy level initiatives to increase access to general healthcare for people with mental disorders.

As a pilot programme, the 'Time Out' programme<sup>10</sup>, implemented by STAKES as a randomised trial, aims at preventing social exclusion of young men by offering

case management in connection with the military conscription at age 18. The intervention includes a needs assessment, and referral to health services if deemed beneficial.

According to a preliminary evaluation, the intervention group has evidenced a beneficial mental health effect and reduced alcohol consumption.

### **6.2.2.3 Health services**

At the level of health services, people with mental disorders in need of general health services are expected to use the same health services as the rest of the population. Very little attention has been paid to develop responsiveness of services to this special group of patients.

The issue of inadequate access to general healthcare has been raised by the users' organisation, the Finnish Central Association for Mental Health. As they have highlighted, the general public and not even all policy makers are aware of the problems in access to healthcare for people with mental disorders.

In Finland, no quantitative or qualitative studies focusing on access to general healthcare for people with mental disorders could be identified.

## **6.2.3 Germany**

### **6.2.3.1 Legislation**

Provision of healthcare for people with mental disorders is regulated by the countrywide uniform legislative framework for healthcare. The Social Code Book V stipulates that the needs of people with disability due to mental disorders shall be paid special attention in the provision of ambulatory physician care, allied health personnel services and medical rehabilitation. The countrywide Social Code Book IX on rehabilitation also highlights that the special needs of people with mental disorders shall be taken into account.

An anti-discrimination law was passed in Germany in 2006 which prohibits discrimination due to disability. While the term 'disabled' includes people disabled due to mental disorders, there are no specific provisions for people with mental disorders.

Legislation on social care and compulsory hospitalisation for mental disorders is performed at Länder level with 15 out of 16 Länder having specific mental health legislation in place.

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<sup>10</sup> For more information, see <http://info.stakes.fi/aiikalisa/EN/index.htm>

### 6.2.3.2 Policies and programmes

Policies for people with mental disorders continue to be based upon the principles of the Parliamentary Enquête Commission in 1975, that is, the establishment of community psychiatry and coordination of all care providers (and payers), as well as social and legal equalisation of the mentally ill with the somatically ill. In recent years, the policy has been refined by work in the Federal Assembly (2000), the Federal Council's Conference of the Health Ministers of the *Länder* (2003) and a working group at the Federal Ministry of Health and Social Security (2004). In addition, improved recognition and treatment of depression is a priority area of the federal health target programme, and a national suicide prevention coalition is currently developing a national suicide prevention programme.

In terms of stigmatisation, the anti-stigma campaign 'Open doors' (of the World Psychiatric Association) was implemented in Germany by the Medical Society of Psychiatry, Psychotherapy and Neurology in cooperation with psychiatry user associations from 1999. This showed an improvement of attitudes and opinions in the general population of six large urban areas at a second evaluation in 2002 compared to 1999 (Gaebel, 2004). This work has been followed by public campaigns initiated by the national competence networks on depression and schizophrenia, which will be coordinated by the newly formed Action Alliance Mental Health under patronage of the Federal Minister of Health.

However, in Germany the general focus of mental health policy is on those with mental disorders, and much less emphasis is paid on whole population mental health well-being and addressing determinants for positive mental health. There is no specific programme to promote physical health among people with mental disorders.

### 6.2.3.3 Health services

People with mental disorders are entitled to and largely use mainstream general health services. Special mobile services are provided in metropolitan areas for homeless people and for intravenous drug users.

Public health offices of municipalities provide social-psychiatric services directed particularly at the most disadvantaged among people with mental disorders. However, psychiatrists employed by social-psychiatric services are allowed to provide medical treatment in only four *Länder*.

According to the *Federal Health Survey* and the additional *Mental Survey 1998/1999*, people reporting current mental disorder utilised general healthcare

twice as often as people who never experienced a mental health disorder. No other research on access to general healthcare for people with mental disorders was identified by the German country report.

## 6.2.4 Greece

### 6.2.4.1 Legislation

In connection with the establishment of the National Health System in 1983, provisions were made for deinstitutionalisation of psychiatry and establishment of community mental health centres. The basis of the current legal framework on mental health was formed in 1992 by the Act on Modernisation and Organisation of the Health System, in which greater protection was provided for people admitted compulsorily. In 1999, new legislation (the Act on Development and Modernisation of Mental Health Services and other provisions) to support the development of sectorised community mental health services was introduced. An Office for the Protection of the Rights of the Mentally Ill and a Special Committee for the protection of the rights of people with mental disorders were established within the Ministry of Health (Constantopoulos and Yannulatos, 2004). However, there is no specific mention of the right to equity of access to general healthcare, although this would certainly be in line with the spirit of the 1999 law.

In Greece, anti-discrimination legislation was passed in 2005, although it does not make specific reference to people with mental disorders.

### 6.2.4.2 Policies and programmes

The national mental health policy and action plan, Psychoargos Phase B Programme, (2001–2006), emphasised development of community mental health services, rehabilitation of long-term psychiatric inpatients and closure of the psychiatric hospitals. The implementation is monitored and supported by the Monitoring and Support Unit for Psychoargos Phase B (MSU).

The ongoing revision of the programme for next five-year period is currently delayed, and there is a political debate regarding the future direction of mental health policy in Greece.

There is no reference to the issue of access to general healthcare in Psychoargos Phase B. However, access may be improved through the establishment of departments of psychiatry in the general hospitals and through establishment of mobile units which provide care to areas with difficult access to health services.

There are no national guidelines regarding general medical services for people with mental disorders.

There is also a national anti-stigma programme, run by the University Mental Health Research Institute, encompassing anti-stigma activities, research and educational activities.

### **6.2.4.3 Health services**

Before the mid-80s, mental healthcare was provided almost exclusively by the psychiatric hospitals, and by private clinics operating in much the same way as the psychiatric hospitals. Outpatient care, with few exceptions, was provided by private practitioners, who had been trained within the asylum system.

Several psychiatric hospitals have now been closed, and the closure of several other hospitals is foreseen. Some of the psychiatric hospitals have general medical departments, but many of these services have shrunk considerably as a result of the reform, the closure of psychiatric hospitals, and the reduction in size of the remainder. If a person's condition was serious, they would usually be referred to mainstream services in general hospitals, and nowadays, they would be encouraged to use mainstream services.

In Greece, there are no national research activities regarding equity in access to healthcare for people with mental disorders. Neither has this issue been raised by the relatively new NGOs in the area of mental health.

## **6.2.5 The Netherlands**

### **6.2.5.1 Legislation**

In the Netherlands, people with mental disorders have the same rights to healthcare access as any other person. The position of all patients and clients is protected and supported through several laws, including the Law on Contracts for Medical Treatment, the Client's Right of Complaint (Care Sector) Act, and the Participation (Clients of Care Institutions) Act.

The Psychiatric Hospitals (Compulsory Admissions) Act is specifically designed to safeguard the legal rights of persons suffering from a mental health disorder in the event of and during involuntary admission to a mental hospital. For people admitted under this Act, decisions relating to their somatic health needs are taken by their legal representative. In 2007, a new element was added to the Act: clients can now sign a formal declaration that they agree to future compulsory treatment when this is considered appropriate.

### **6.2.5.2 Policies and programmes**

There is no overarching national mental health policy in the Netherlands. Instead, issues related to prevention, care and cure of mental ill health are incorporated into overall health promotion, healthcare and social support policies. Specific objectives of Dutch mental health policy have been to improve collaboration between mental health services and other actors in social and health care, to harmonise funding arrangements of mental healthcare with arrangements for general healthcare, and to reduce waiting lists for mental health services.

For the purpose of this report it is important to note that, in spite of the recognition of co-morbidity factors, policy proposals focus almost exclusively on a more adequate response to meeting mental health needs. The question of how the somatic health needs of people with mental disorders could be met more appropriately seems to be outside policy makers' scope.

The prevention of depression is one of five priority areas in the national public health policy for 2007–2010, along with tackling obesity, smoking, alcohol abuse and diabetes. Other areas of mental health are not addressed within this strategic document.

To implement the national public health policy objective of preventing depression, a programme has been initiated by the Trimbos Institute and the Dutch Mental Healthcare Association. There are no national programmes to improve access to general healthcare for people with mental disorders. 'Making it Better', the national programme aiming to improve quality, effectiveness and efficiency of the somatic health sector has, however, broadened to include work on mental health. Five local projects to improve physical health of people with mental disorders have been implemented in areas that include Rotterdam and Eindhoven (Planije and Smits, 2006).

### **6.2.5.3 Health services**

In the community, people with mental disorders are expected to rely on general health services for their somatic health needs. For clients living in sheltered accommodation, mental health service providers may set up a formal collaborative arrangement with a local GP practice. Within mental hospitals, somatic healthcare is to be provided to resident clients up to at least primary care level standard.

A recent development is the creation of specialist somatic nursing teams within inpatient settings (Inspectie voor de Gezondheidszorg, 2004). The focus on and quality of somatic health services within

mental hospitals has increased following a Healthcare Inspectorate report in 1999 (Inspectie voor de Gezondheidszorg, 1999).

In the Netherlands, no quantitative or qualitative studies focusing on access to general healthcare for people with mental disorders could be identified.

## **6.2.6 Poland**

### **6.2.6.1 Legislation**

The legal basis of mental health protection in Poland is the Act of 1994 on mental health with later amendments. The Act emphasises that treatment for people with mental disorders should be provided with the preservation of their dignity and freedom. The Act also defines the right of people with mental disorders to psychiatric and physical healthcare, as well as the responsibility of public authorities for the provision of such care. Utilisation of treatment is voluntary and subject to the patient's consent, although in special cases so-called 'direct compulsion' can be used. The Act on education in sobriety and counteracting alcoholism of 1982 and the Act on counteracting drug addiction of 2005, which guarantee free detoxification treatment in healthcare institutions and free services for family members, are also of relevance in this context.

It is also important to note that the Act on social aid of 2004 and the Act on social employment of 2003 regulates provision of health and social care and reintegration efforts for people with mental disorders.

### **6.2.6.2 Policies and programmes**

In the long-term perspective, health policy is defined by the National Health Programme (NPZ). In 1995, the government adopted a 10-year NPZ with a broad scope, addressing tasks not only for the health sector, but also for other sectors (education, labour and social policy, transport). The next NPZ has been prepared for the period 2006–2015 and was adopted in 2007. One of the 19 priorities of the new NPZ is the reduction of health inequalities. However, even if social integration of people with chronic mental disorders is mentioned in the programme, improved access to healthcare for people with mental disorders has not emerged as a specific target within the programme.

A first ministerial Mental Health Protection Programme was created in 1994 following the adoption of the Act on mental health. It aimed at development of community care and downsizing of psychiatric hospitals, but, according to the country report, the goals often remained theoretical, the

necessary funding was never assigned, and implementation was not monitored. A new National Mental Health Protection Programme has been prepared in 2005–2006 by the Institute of Psychiatry and Neurology. It aims include promotion of mental health and prevention of mental disorders, modernisation of psychiatric care and strengthening of mental health research and information.

### **6.2.6.3 Health services**

The Polish healthcare system for people with mental disorders is separate although it is funded via the universal health insurance system. In recent years there has been an increase and a privatisation of psychiatric outpatient facilities and a decrease in beds in mental hospitals. This has been supported by a programme for restructuring of beds in psychiatric hospitals developed by the Polish Society of Psychiatrists. At the same time there has been an increase of psychiatric beds in general hospitals.

According to the Act on mental health, health services provided to people with mental disorders or handicapped people by healthcare public institutions are without charge. In the case of somatic disorders accompanying psychiatric ones a person has free access to somatic care, on a regular basis, as for other patients. In psychiatric hospitals, there are internal medicine or infectious diseases departments.

The country report concludes that in Poland, combining psychiatric care settings with somatic care ones, has improved access to somatic care for psychiatric patients. However, in Poland no quantitative or qualitative studies focusing on access to general healthcare for people with mental disorders could be identified.

## **6.2.7 Romania**

### **6.2.7.1 Legislation**

Since 2002, Romania has had comprehensive mental health legislation, covering promotion, prevention, care and involuntary treatment. In 2006, the National Centre of Mental Health was established for research and development activities.

### **6.2.7.2 Policies and programmes**

The national mental health policy is implemented in the five-year National Mental Health Action Plan, and currently reform is underway to strengthen community-based mental health services.

Anti-stigma work is among the priorities established by the mental health law. However, a negative image of psychiatric illness and psychiatric patients still persists among the general public, enhanced by stigmatising media coverage. Even institutional discrimination exists: people with a mental health disorder are not granted driving licences and are not allowed to teach by the Ministry of Education and Research. The National Centre of Mental Health has initiated an anti-stigma training programme for Romanian journalists.

### 6.2.7.3 Health services

Currently, mental health services in Romania are mainly hospital-based, and there is a lack of continuity in care between psychiatric hospitals and outpatient care. A programme for establishing community mental health centres is in progress, aiming at 140 centres in 2009. However, the development of mental health services is hampered by a shortage of psychiatrists, psychologists and psychiatric nurses and lack of capacity among general practitioners to provide services to people with mental disorders.

In Romania, no quantitative or qualitative studies focusing on access to general healthcare for people with mental disorders could be identified.

## 6.2.8 Spain

### 6.2.8.1 Legislation

In Spain, mental health legislation is mainstreamed in general health legislation due to a perception that a specific law could contribute to discrimination against people with mental health problems. The General Law on Health from 1986 establishes that people with mental disorders have the same rights as other patients.

In Spain, the Law on Equal Opportunities, Non-discrimination and Universal Accessibility for disabled people from 2003 seek to protect those with disabilities from being treated differently from those without disabilities. The law considers disabled people to be those individuals with a permanent disability degree of 33%, but no special reference is made to anti-discrimination protection of people with mental disorders.

The Law on Civil Indictment from 2000 allows the compulsory hospitalisation of people with mental health problems, dependent on previous judicial approval. It is also important to note that the Law to promote Personal Autonomy and Care for People in

Situations of Dependency, which came into force on January 2007, includes persons with serious mental disorders in the general framework of provisions for people with disabilities.

### 6.2.8.2 Policies and programmes

At a national level, the Ministry of Health launched the National Health System Mental Health Strategy in 2007 to promote prevention, early diagnosis, treatment, rehabilitation and social integration activities. Access to general healthcare for people with mental health problems is not, however, addressed in this document.

Mental health plans are also developed at a regional level. The second Mental Health Plan for Andalusia is under preparation, for example; tackling physical health of people with mental health problems will be one of the strategic lines of this plan, as well as an inter-sectorial approach to attend mental health needs of groups at risk of social exclusion. The last Andalusian Plan for Social Inclusion (2003–2006) included promoting access to healthcare for groups at risk of social exclusion among its objectives. People with mental health problems without family support were considered as a target group. In Andalusia, anti-stigma activities have been implemented by the Andalusia Health Service and under the framework agreement for social awareness.

### 6.2.8.3 Health services

Special services for provision of general healthcare to people with mental health problems do not exist. People are served by both the mainstream health services and specialist services.

In Spain, no quantitative or qualitative studies focusing on access to general healthcare for people with mental disorders could be identified. The most recent document that analyses the mental health situation in Spain is from 2002 (Observatorio del Sistema Nacional de Salud, 2002), but access to general healthcare is not included in the analysis.

However, there is raising awareness about the problem as illustrated by the initiative of the Andalusian Department of Health to create a working group composed of the coordinators of the Andalusian Comprehensive Mental Health Plan, the Andalusian Comprehensive Smoking Plan and the Andalusian Comprehensive Plan for Cardiovascular Diseases. The objective of the working group is to elaborate a document with recommendations to tackle the influence of unhealthy lifestyles on physical health of persons with mental health problems.

## 6.2.9 United Kingdom

### 6.2.9.1 Legislation

The Mental Health Act from 1983 deals with circumstances in which people may be subject to compulsory detention and treatment. Currently there are proposals for a new Mental Health Act in England that seeks to update legislation concerning the professionals who have the authority to detain patients and the categories of people who may be subject to compulsory treatment. However, the Bill has proved controversial and there is some concern that it is based more on issues to do with public order, rather than therapeutic benefit, and that it may increase rather than reduce stigma (Crichton and Darjee, 2007).

The Disability Discrimination Act of 1995 and the Disability Rights Commission Act of 1999 seek to protect those with disabilities from being treated differently from those without disabilities. Disability is defined as a physical or a mental impairment which has a sustained and long-term adverse effect on day-to-day activities. The Disability Equality Duty (DRC, 2005) came into force in December 2006 and requires all public services to actively promote disability equality. There is some concern that the focus (especially of employers) has been largely on physical rather than mental disabilities, but the legislation is intended to cover both.

### 6.2.9.2 Policies and programmes

The *National Service Framework (NSF) for Mental Health* was published in 1999. It sets out a 10-year programme for improving mental healthcare. In sections on general healthcare, the service framework focuses on reducing smoking rates and improving services for long-term physical health conditions. Subsequent policies have supported and expanded this initiative, for example, the National Institute of Clinical Excellence (NICE) guidance on schizophrenia acknowledged the need for physical health checks for those with high risk factors for cardiovascular disease. *Choosing Health* (Department of Health, 2004), the English strategy for public health, has also committed to learning from eight pilot studies on improving physical healthcare for people with mental health problems. The pilots involved specialist teams working in partnership with primary and social care providers to help support people with severe mental illness who are vulnerable to physical ill health. In primary care, financial incentives have been introduced for GPs to undertake annual health checks for people with mental health problems.

Anti-stigma activities in England are encapsulated in a number of different policy initiatives, rather than in a single policy. These include: recommendations issued in 2004 by the Social Exclusion Unit on tackling exclusion

as experienced by people with mental disorders; a Strategic Plan to tackle exclusion published by the Department of Health in 2004; and the *National Service Framework for Mental Health* from 1999 which includes sections on combating discrimination and stigma. The NAP for Social Protection and Social Exclusion mentions anti-discrimination in relation to people with mental health problems, but does not set out any specific policies over and above those contained in the above documents.

A number of initiatives integrating health literacy improvement in mental health action plans have been developed. The 2004 UK Mental Health and social exclusion report along with 'Getting the basics right' (housing, finance, transport) and 'Making it happen' implementation plans were reviewed in 2006. Nationally, most progress had been made in terms of issuing guidance to commissioners and employers, the dissemination of guidelines about treatment and services, the improvement of communication with users, carers, media, employers, and the training of staff.

### 6.2.9.3 Health services

People with mental health problems are served by both the mainstream health services and specialist services. The vast majority of people with mental health problems are managed within the primary care setting by GPs, gateway workers and mental health primary care workers. In the secondary sector, services include community mental health teams, assertive outreach teams, crisis resolution teams and early intervention teams.

In principle, mainstream services are available equally to all users without distinguishing between those with and without mental health problems. However, the reality of the situation is that those with mental health problems often face substantial barriers to access in practice. The evidence suggests that health needs of people with mental health problems are often 'off-loaded' onto specialist services rather than being addressed through primary care (Samele et al., 2006).

Over the last three years, efforts have been made to develop a flexible, responsive workforce in the area of mental health and to initiate what are termed, 'new ways of working'. A recent update suggests that substantial progress has been made (Department of Health, 2007). The key theme in this initiative is to recognise the multiagency and multidisciplinary nature of mental health services and to develop a 'Capable Teams Approach'. These are multidisciplinary teams focused on supporting service users in self-management where possible and also supporting the voluntary sector and primary care by providing assessment, treatment and care navigation for those with more severe problems.

The UK has also benefited from engagement with voluntary sector organisations. In particular, the NGO, MIND has implemented projects to train mental health service users to become 'Experts of Experience' to assist the Commission for Healthcare Audit and Inspection (CHAI) and the Commission for Social Care Inspection (CSCI) in inspection of health and social services<sup>11</sup>.

Most of available European research on access to healthcare for people with mental disorders stems from the UK. Consultation rates with GPs are three to four times higher than for the general population in the UK (Seymour, 2003), but people who use psychiatric services are less likely to be offered health promotion interventions such as smoking cessation, blood pressure checks or prescriptions for leisure (Brown et al., 1999; Burns and Cohen, 1998). Research has indicated that despite experiencing higher rates of coronary heart disease, lower rates of screening in primary care for raised cholesterol has been found amongst people with mental health problems (DRC, 2006a). Similarly people with mental health problems who have diabetes are less likely to have their body mass index checked than those with diabetes without such problems (Samele et al., 2006). People with schizophrenia and coronary heart disease had fewer blood pressure or cholesterol tests than people with coronary heart disease without such problems (Hippisley-Cox and Pringle, 2005). Slightly fewer people with schizophrenia and coronary heart disease who have had a stroke are on aspirin; and fewer people with schizophrenia who have coronary heart disease are on statins compared with those without mental health problems (Hippisley-Cox and Pringle, 2005; Hippisley-Cox et al., 2006d).

### **6.3 Barriers in access to general healthcare for people with mental disorders**

Stigma underlies many of the barriers to access, and is relatively well documented (see, e.g. Stylianidis et al., 2005; Aromaa et al., 2007). A recent in-depth review of the issues of stigma and discrimination faced by those with mental health problems concluded that on the basis of global evidence about stigma, "there is no known country, society or culture in which people with mental illness are considered to have the same value and to be as acceptable as people who do not have mental illness" (Thorncroft, 2006, p. 11).

Stigma associated with mental disorders has many consequences. Healthcare for people with mental disorders tends to be underfunded all over Europe (Knapp et al., 2007), which can be explained by stigma

and discriminatory attitudes. But stigma also affects the individual. The clinical course of the stigmatised disorder itself may be worsened and other outcomes affected, such as the ability to work and lead a normal social life. Of special relevance is the impact of stigma on access to general healthcare. Evidence suggests that stigma lessens the responsiveness of the health services, and that the fear of being labelled may cause individuals to delay or avoid seeking treatment altogether. Those already labelled by the health services may decide to distance themselves from the label, forgoing treatment or becoming noncompliant (Link and Phelan, 2006).

Individual studies from several of the participating countries (**Finland, Germany, Greece**) indicate that stigmatisation of people with mental disorders may have decreased in the general population (Madianos et al., 1999; Gaebel, 2004; Sauri, 2007). In **Greece** there is also evidence that stigmatisation has reduced in the press (Economou et al., 2006), in parallel with the development of community mental health services. In **Poland**, however, repeated population surveys indicate that stigma and stereotypes still prevail (CBOS, 2005). Trends in the **UK** in attitudes to mental illness are more mixed: some research shows signs of greater understanding amongst the general public over a 10-year period, whilst other signals are less favourable, such as greater levels of fear of, and perceived danger from, those with mental health problems (Department of Health, 2006). In Scotland, a positive trend in attitudes has been recorded over the last five years, in connection with the national anti-stigma campaign 'See me'. The author's interpretation of the difference between England and continental Europe in this respect is that it relates to the prolonged and sometimes heated debate on the government's proposal for a new Mental Health Bill, which emphasised the need to extend civil detention also to groups without benefit of treatment, in order to safeguard society from violent acts. It is possible that the English media's focus on danger, the need to protect the public and the proposed Bill has contributed to the fact that the trends in public attitudes towards people with mental disorders have been less favourable in England than in continental Europe.

#### **6.3.1 Gaps in coverage**

##### **6.3.1.1 Poverty and exclusion from labour market worsen access barriers**

Mental disorders are associated with poverty and low socio-economic status. For many people with mental disorders the only available route to access general healthcare is therefore through public services, because financial constraints mostly preclude the use of complementary private health services. Due to the

<sup>11</sup> <http://www.mind.org.uk/About+Mind/Networks/CSCI/about.htm>

disadvantage connected with poverty, people with mental disorders tend to have a more restrictive coverage than people who can afford to pay out-of-pocket for health services or can afford to join an optional private health insurance scheme.

Many people with mental disorders are not active in working life, due to unemployment or disability. In countries with a health insurance system based on employment (e.g. **Poland**), people excluded from the labour market face difficulties in access to healthcare. In many countries with universal health insurance access to general healthcare is also at least partly dependent upon being an employee (e.g. Finland) and this will exclude many people with mental disorders from one channel of easy access.

*In some cases, people with mental disorders are exempted from ordinary coverage.*

In most countries studied, people with mental disorders are covered by national health insurance schemes on equal grounds to other residents. In some countries, however, discriminatory practices regarding private health insurances exist. In **Germany**, any use of psychotherapy or psychiatric care in the past five years may lead to an increase in entry fees for private health insurance, while for physical illness the corresponding time period is three years. For special benefits, it is common that eligibility criteria are geared towards physical illness (e.g. long-term care benefits in **Germany** and medical rehabilitation in Finland).

There are also particular issues for people in residential psychiatric care. For example, in **Greece** residents in psychiatric hospitals are entitled to care outside the institution, but in **Finland** and the **Netherlands** some people in hospital residential care, (in **Finland**: long-stay psychiatric patients; in the **Netherlands**: compulsorily admitted patients), are not entitled to normal health or social security benefits. In **Finland**, people in long-term residential care are not entitled to national health insurance reimbursement for visits to private care providers such as doctors or dentists, based on the assumption that the institution will provide all the necessary medical services for inpatients. In reality, many institutions provide neither in-house specialist services, nor have sufficient funds for purchasing services for their patients from external medical or dental service providers. In the **Netherlands**, people admitted under the Compulsory Admissions Act lose their right to regular social security benefit. This has clear financial consequences for people in compulsory admission, leaving them without a financial safety net and in danger of not being able to meet essential financial commitments, including paying rent and health insurance. The Dutch government in July 2007 proposed legislative action to address this coverage gap.

### 6.3.2 Scope of health basket

In principle, people with mental disorders are entitled to the same spectrum of health services as other residents of the countries studied. Many country reports stated that the benefit baskets are more geared towards needs of people with physical illness. Health services in all countries investigated have problems in supplying adequate psychiatric treatment. Countries with devolved decision making in health services reported unequal geographical distribution of mental health services (e.g. **UK** (Beecham, 2005) and **Finland** (Harjajärvi et al., 2006)).

### 6.3.3 Cost sharing

Data from several Member States indicate that mental health problems are associated with low socio-economic status. Low income, unemployment and low education levels are all associated with poor mental health (Reijneveld et al., 1998; Trimbos, 2003).

Because of poverty, cost sharing constitutes a particular barrier of access to healthcare, which is of special concern for the group of people with mental disorders. This barrier is of particular concern in countries with a relatively high formal co-payment (e.g. **Finland**, **Germany**), widespread use of private health services (e.g. **Poland**) or common use of informal 'under the table' payment (e.g. **Greece**, **Romania**). Co-payment ceilings (**Finland**) and exemption (**Germany**) requires collection of user fee receipts and written applications, and people with mental disorders may have special difficulties in overcoming such administrative hurdles.

### 6.3.4 Geographical barriers

People with mental disorders may also be particularly disadvantaged by geographical barriers of access to healthcare because of difficulties in use of transportation.

In some countries (e.g. **Finland**) local authorities purchase out-of-town residential services for people with mental disorders. This incurs problems for the patients to reach the health services of their own municipality. In some countries (e.g. **Romania**) psychiatric hospitals tend to be located outside of urban centres, creating transportation barriers for access to healthcare outside of the psychiatric hospital. In **Romania**, the difficulties in visiting out-of-hospital health facilities are worsened because most psychiatric hospitals grant only one-day leave for patients, due to unclear regulations regarding reimbursements and responsibilities during leave from the hospital.

People with mental disorders may also experience special difficulties travelling. In particular, anxiety or phobic symptoms of psychiatric disorders may preclude use of public transport. No research on the subject was located.

### 6.3.5 Organisational barriers

Many general organisational barriers in access to healthcare, such as waiting lists, may constitute an even higher barrier for people with mental disorders because of lack of resources to use alternative pathways to care (e.g. private healthcare). As several country reports point out, articulate, well-educated and well-off people have in general easier access to healthcare than people with mental disorders, who tend to have poorer communication skills and lower socio-economic status.

In some countries (e.g. **Poland**), psychiatric care is organised separately from other healthcare. In such a split system, difficulties in providing adequate services to people with both mental and physical healthcare needs occur. Indeed the organisation of psychiatric inpatient care may promote or hinder adequate somatic care. In **Germany**, for example, most psychiatric beds are integrated in acute hospitals, which provides opportunities for interdisciplinary consultation and timely referral. On the other hand, remote psychiatric hospitals, for example in **Romania**, offer fewer opportunities for collaboration with general medical services.

Mental disorders are also often correlated with poor health literacy. In countries with complicated health insurance systems (e.g. the **Netherlands**) people with mental disorders may therefore end up being uninsured or having poorer coverage than citizens with good health literacy. In the **UK**, some people with mental health problems are not registered with GPs. There are also reports of people being struck off GPs' lists and having difficulty re-registering (Buntwal et al., 1999). In the **UK**, 30% of people with mental health problems using one mental health unit had been struck off GPs' lists at some point (Buntwal et al., 1999), and evidence suggests that permanent registration is particularly difficult for those with multiple vulnerability, e.g. refugees, asylum seekers and homeless people (Noonan, 2006a).

Access to services may also be restricted if healthcare professionals believe that specific types of interventions are not effective for people with mental health problems. This may particularly be the case for health promotion and prevention therapies where evidence of effectiveness is generally limited. There may be a belief that people with mental health problems are even less amenable than other population groups to such interventions, because they are not good at adhering to long-term behaviour

changes, for example. However, current evidence indicates that health promotion among people with mental disorders is feasible and effective. Indeed it has even been reported that health gains may be larger than among people without mental disorders (Vreeland, 2007). The **UK** investigation by the Disability Rights Commission found that some practitioners expressed doubts about the value of smoking cessation advice, even though there is emerging evidence to suggest this intervention (and structured approaches to weight management) are effective for such groups (DRC, 2006). There is also a risk of 'diagnostic overshadowing' where mental health problems obscure diagnosis of physical problems.

In working to overcome these barriers, the country reports suggest that clinical practice guidelines are one useful tool to support the recognition of physical illness in people with mental disorders. It is reported that practice guidelines for mental disorders incorporate recommendations to support improved recognition of physical co-morbidity in several countries, including **Finland**, **Germany**, and the **Netherlands**. However, a **Dutch** report points out that the implementation of practice guidelines as illness-specific treatment programmes may be at odds with individual needs as this discourages tailor-made service provision and it may lead to a situation where a patient is being treated via two –or more– parallel programmes or receives serial episodes of treatment (Schellevis, 2006).

To ensure proper identification and treatment of physical diseases of people with mental disorders, mental healthcare staff also need to be adequately trained. In several country reports staff training challenges were mentioned: in **Germany** the training of psychiatrists and specialists of psychotherapy does not include a generalist phase, but also countries which have a compulsory training period in primary care (such as Finland) report that the standard of somatic care in psychiatric institutions is unsatisfactory. In Germany, the need for capacity building to improve psychiatrists' somatic care skills has been highlighted (Hewer, 2005).

### 6.3.6 Supply-side responsiveness

In spite of recent reports of excess mortality from natural causes in people with mental disorders, there is poor awareness of the need for special measures in response to the health needs of this group. In Europe, many national clinical practice guidelines mention existing co-morbidity, but health service providers in general have not developed special programmes or services for people with mental disorders. This may in part be due to ignorance, but it may also partly be due to a conscious effort to streamline and integrate health services of people with mental disorders into the ordinary health services.

### 6.3.6.1 Negative responsiveness of care providers

Country reports from **Germany** and the **UK** indicate that people with mental disorders visit healthcare two to four times more often than people without mental disorders. In contrast, the health outcome of people with mental disorders is poor, despite the high usage of health services. This indicates a failure of the healthcare system to identify and address the health needs of people with mental disorders. In the **Netherlands**, anecdotal evidence from a telephone helpline for people with mental disorders indicates that physical problems may be too quickly attributed to psychological factors by health service providers and that prejudice exists among health professionals. From **Greece** and **Poland**, several cases of discrimination in healthcare services were reported. Patients had not been properly examined or even denied treatment for a physical condition due to their mental health disorder. The **Polish** country report mentions that in waiting lists for surgical operations those with schizophrenia are placed at the end of the list. From **Finland**, there is also some anecdotal evidence that in 'difficult cases', health centres have shown a negative responsiveness, banning certain people with mental disorders from emergency rooms for example, usually due to disturbing or threatening behaviour of the person in question.

The evidence also suggests that supply-side responsiveness to physical health problems of people with mental disorders is severely undermined by prejudices and discriminatory attitudes of healthcare staff (Levizos et al., 1983; Tripodakis et al., 1990; Mandas et al., 1994). From **Romania**, anecdotal information indicates that the attitudes of non-psychiatric physicians are even worse than attitudes of the general population. The stigmatising attitudes of healthcare staff seem to be formed early during training years, and are reinforced in clinical working life by selective exposure to seriously affected patients with a less favourable prognosis. From the **UK** it is reported that negative attitudes by reception and clinical staff may reinforce the reluctance to seek help (Nocon, 2006a), and anecdotal information from **Spain** indicates that stigma and discrimination in healthcare centres formed a barrier of access. No national efforts to improve the attitude of healthcare staff towards people with mental disorders were found in the participating countries.

It is important to note that the only national efforts to improve access to healthcare for people with mental disorders were reported from **England**: *Choosing Health*, the English strategy for public health (Department of Health, 2004) initiated eight pilot studies on improving physical healthcare for people with mental disorders. The pilots involved specialist teams working in partnership with primary and social

care providers to help support people with severe mental disorders who were vulnerable to physical ill health. In primary care, financial incentives have also been introduced for GPs to undertake annual health checks for people with mental disorders (Department of Health, 2006). These include checks related to alcohol and drug use, smoking and blood pressure, cholesterol, BMI, risk of diabetes from antipsychotic drugs, cervical cytology and accuracy of medication. Analysis of the first year of the contract shows that 76% of practices reported having carried out such checks to at least 90% of their patients with mental disorders (who had agreed to be included on the practice register) (DRC, 2006a).

### 6.3.6.2 Positive responsiveness

In some countries investigated, special integrated services have been created to care for the complex needs of people with compound mental, physical and social problems. In **Finland**, Labour Force Service Centres (LAFOS) are a successful new one-stop concept for providing employment, social and health services for disadvantaged adults. Another Finnish approach to improve access to healthcare is the establishment of occupational health services for long-term unemployed people. In **Germany**, socio-therapeutic care was introduced in 2004 to help people with severe mental disorders who have difficulties in accessing care. This has been targeted mainly at access to mental healthcare but also general healthcare. However, uptake has so far been low in **Germany**, and the concept is currently under review. In the **UK**, dedicated primary care services for homeless people do exist in some cities, sometimes involving mobile clinics (Homeless Link Cymru, 2006; Riley et al., 2003). Some of these are limited by restricted hours and not being able to offer permanent registration, which undermines the quality and continuity of care that can be provided (Pleace et al., 1999).

In **Spain**, the FAISEM (Andalusian Foundation for the Social Integration of the Mentally Ill) housing resources for people with health mental disorders are closely connected with corresponding health centres, which provide periodical visits by nursing teams to implement health promotion activities.

According to the EuroHealthNet report, some initiatives, such as the use of 'Gateway Workers' in the UK, have been shown to enable better access to health services for this particular target group. Gateway workers coordinate and ensure prompt access to care, and were found to be well embedded across the country. Furthermore, 24-hour access to crisis resolution and assertive outreach teams were found to be increasing along with training of NHS Direct advisers to deal with mental health risks.

However, the use of health mediators for people with mental health problems, linking them to mainstream health services is not widespread amongst EU Member States and a need for training and creation of link worker positions in the field of mental health has been identified as a priority in some countries (Blanchard and Costong, 2007).

### 6.3.6.3 Vulnerable groups: migrants

The preparedness within health services to handle mental health problems of migrants vary. Migrants' mental health problems are in many cases treated rigidly according to the same principles as those of the majority population. Anecdotal evidence indicates that capacity building by setting up special units may improve quality of mental healthcare provided.

In the **Netherlands**, a national expertise centre for ethnicity and health, the Mikado Centre, has been established with governmental funding. The centre is currently leading efforts to develop a 'cultural awareness annex' for multidisciplinary mental health guidelines. The **Finnish** country study reports that access to care is better in those municipalities that have a healthcare unit for foreigners or otherwise more centralised healthcare arrangements for immigrants.

### 6.3.6.4 Vulnerable groups: older people

A survey of WHO mental health counterparts in Europe in 2002 indicated that stigma and discrimination of old people with mental disorders was highly prevalent in the healthcare sector (de Mendonça, Lima et al., 2003). However, the survey did not address the issue of access to general healthcare for older people with mental disorders.

## 6.3.7 Health literacy

Poor health literacy skills among some people with mental disorders also create a special challenge for health systems. Health literacy is important to navigate the health system, and health literacy problems may exclude people from healthcare benefits or have an impact on help-seeking behaviour.

In most countries, all residents are automatically enrolled in a single obligatory health insurance scheme. However, in some countries with multiple insurance schemes based on applications (e.g. **Germany**, the **Netherlands**), deficient health literacy can exclude people with mental disorders from health insurance schemes. In **Germany**, for example, an

eligibility card is required for healthcare provision beyond emergency care. The process to apply for a new card when the old has expired or been lost includes administrative hurdles, which constitutes a particular access barrier for people with mental disorders. In the **Netherlands**, insurance is based on individual application and regular payments, which means that a high level of organisation and health literacy is required to navigate the Dutch health insurance system. Correspondingly, in **Greece** destitute people are covered by a special welfare insurance which provides free medication. However, this can be obtained only from hospital pharmacies, and in some cases authorisation by hospital medical staff is required. In effect this means that two appointments are required to obtain the medication, which requires good health system navigation skills.

An additional factor is that people with mental disorders who also have somatic health needs may present to primary care at a relatively late stage. Their mental health problems may stand in the way of verbally expressing their complaints (Planije and Smits, 2006) but the delay may also be due to perceived stigmatisation. In addition to health literacy, health beliefs contribute to care-seeking behaviour.

One insight comes from health belief models, which assume that humans act rationally in ways that diminish perceived threats (disease symptoms) and enhance perceived benefits (improved health following treatment) (Rosenstock, 1975). Of major importance in this equation is perceived stigmatisation in general healthcare. If people with mental disorders are not treated respectfully and with dignity in general healthcare services, the perceived health benefit of seeking care will weigh less than the perceived harm in the form of shame and lowered self-esteem.

In the **UK**, the 'Penumbra Youth Project'<sup>12</sup> is an example of a community-based mental health initiative that combines empowerment, development of prevention and health literacy actions and strengthening of partnerships and collaborations working to improve access to health services and promote social inclusion through increased social support services. The project offers advice, information and emotional support to young people experiencing mental health difficulties.

Indeed the evidence suggests that the health literacy of care providers may also be poor, and that care providers may have difficulty distinguishing between somatic and mental health aspects of patients' needs (Planije and Smits, 2006).

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<sup>12</sup> For more information, see

[http://www.nhsborders.org.uk/view\\_item.aspx?item\\_id=17009](http://www.nhsborders.org.uk/view_item.aspx?item_id=17009)

<http://www.kelso.bordernet.co.uk/organisations/penumbra.html>

The European task force on 'Health Promoting Psychiatric Services' has been established within the WHO network 'Health Promoting Hospitals' to improve and develop good practices for health promotion within psychiatric services.

## 6.4 Policy initiatives and their impact on access to general healthcare for people with mental disorders

### 6.4.1 Impact of general health policy initiatives

Although many general health policy initiatives may have specific impacts on people with mental disorders, the only policy evaluation targeting this vulnerable group is the **UK** formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems by the Disability Rights Commission (DRC, 2006a; 2006b).

The policy analysis presented here is thus based more on reasoning from the principles of the policy concerned than on direct evaluation.

#### 6.4.1.1 Health basket coverage

It can be assumed that a broad health basket public coverage (e.g. inclusion of dental care in the basket) benefits people with mental disorders who often live in poverty. It can also be assumed that health systems which require a high level of health literacy and consumer action may be difficult to enter for people with mental disorders, and may leave this vulnerable group without adequate health service coverage.

#### 6.4.1.2 General access to healthcare

Cuts in health and social care budgets can selectively affect people with a mental health disorder. In **Germany**, cuts in social care budgets have affected ambulatory support and access to case management for people with mental disorders, and cuts in the health budget have reduced social-psychiatric services which tend to reach the most disadvantaged.

Introduction of complex rules for health insurance coverage may also constitute a selective barrier of access for people with mental disorders.

In the **Netherlands**, the complexities of the new health insurance system is reported to constitute a real danger for people with mental disorders of losing basic health coverage, due to reduced capacity to navigate the complex health insurance system.

It can be assumed that the introduction of criteria for and maximum waiting times for public non-emergency care improves access to general healthcare for people with mental disorders. In **Finland**, the reduced waiting lists have probably improved access to general healthcare for people with mental disorders, who often lack the funds to use alternative pathways to care, such as private healthcare. However, in **Finland** advocacy groups have aired the concern that a general reduction of waiting times will shift resources from mental healthcare to surgical procedures, because waiting lists exist for surgical procedures, but often not for psychiatric treatments such as psychotherapy.

In **Finland**, the policy to use payment ceilings for user fees in public healthcare, medication spending and transportation in connection with healthcare, offers some support for access to healthcare, but the payment limits are probably insufficient for those worst off.

#### 6.4.1.3 Structure of health service provision: fragmentation vs. integration

The general pattern emerging from the country reports indicates that problems in access to general healthcare are more pronounced in countries with clear separation of mental health and general healthcare (e.g. **Poland**). Some country reports (**Germany, Greece**) reported that mainstreaming of mental health into general health had improved access to physical care.

The picture is complex. Health policies that fragment services, such as division of **Dutch** mental services starting from 2008 in three vertical sectors (i.e. acute treatment (Zvw), long-term care (AWBZ) and social integration (WMO)) with separate funding channels, may have a negative impact of service provision to people with multiple needs in cure, care and rehabilitation. On the other hand, within the care sector, collaboration and coordination of provision of mental health and general healthcare may improve. It remains to be seen whether the split **Dutch** system will improve or worsen access to general healthcare for people with co-morbid mental and physical illness.

In the **UK**, health policy strives towards integrated services with good links between primary care and secondary mental health services. Financial incentives to increase the number of physical health checks undertaken on people with mental health problems appear to be an effective approach to increasing utilisation of mainstream services. However, even in the **UK** it was reported that there has been a failure to mainstream mental health services into primary care, and that health needs of people with mental disorders often were 'off-loaded' onto specialist services rather than being addressed more appropriately through primary care (Samele et al., 2006).

#### 6.4.1.4 Responsiveness to needs of special groups

Several country reports stated that special outreach services, tailored to the health needs of people with multiple vulnerabilities, such as the homeless (**Germany, Poland**), jobless (**Finland**) or migrants (**Finland**) have proven to be beneficial in improving access to healthcare. The Finnish horizontal policies of establishing inter-service labour force service centres (LAFOS) and of providing special occupational healthcare to the unemployed may be of special importance for people with mental disorders. Among the long-term unemployed who get referred to those centres, a considerable proportion has mental disorders.

In the **UK**, financial incentives for GPs to undertake annual health checks of people with mental disorders have been introduced. An evaluation indicates that the incentive scheme has worked quite well, and the **UK** Disability Rights Commission (DRC, 2006a) recommends that further incentives should be included in the GP contracts.

#### 6.4.2 Impact of mental health policy initiatives

There is only one instance (i.e. the **UK**), where improved physical health is a clearly stated focus of the mental health strategy. In general, the mental health policies of the Member States in this study support deinstitutionalisation and aim to strengthen community care. In the worst case scenario, this could lead to leaving people with severe mental disorders unsupported, leading to poverty, marginalisation and excess mortality. Studies from some Member States (e.g. **Finland**), however, have indicated that there has been no increase in mortality among people with schizophrenia during the era of deinstitutionalisation (Salokangas et al., 2002).

**Finnish** studies also show that post-discharge suicides have decreased (Pirkola et al., 2007). The results indicate that the mental health reforms have not introduced new barriers of access to healthcare. In fact, evidence from some Member States (e.g. **Greece**) indicates that the psychiatric reform has improved access to general healthcare, perhaps due to a more individualised care. However, excess mortality among long-stay patients (data from **Finland, Germany**) indicates that barriers of access may still exist within psychiatric hospitals.

In **England**, there have been initiatives to recognise the multiagency and multidisciplinary nature of mental health services and to develop a 'Capable Teams Approach'. These are multidisciplinary teams focused on supporting service users in self-management where possible and also supporting the voluntary sector and

primary care by providing assessment, treatment and care navigation for those with more severe problems. A recent evaluation indicates that progress has been made (Care Services... 2007).

Many mental health policies also have a strong emphasis on stigma reduction, and anti-stigma programmes have been performed in all participating countries. In order to address access to general healthcare, the campaigns need to target not only the general population, but also to improve attitudes of healthcare staff.

## 6.5 Conclusions

### 6.5.1 Co-morbidity is common

Research from several participating countries (**Finland, Germany, the Netherlands, Spain, UK**) and international studies (Scott et al., 2007) indicate that physical and mental morbidity often go hand in hand. Excess morbidity from physical disease may, in part, be related to common underlying factors. These include poverty, direct disease influence (e.g. depression leads to increased risk of cardiovascular disease), adverse treatment effects and unhealthy lifestyles.

It is a challenge for general health services to recognise psychiatric co-morbidity. Likewise, it is a challenge for mental health services to recognise physical co-morbidity. Regrettably, European research on co-morbidity has tended to focus on psychiatric co-morbidity in physical disorders, and research on somatic co-morbidity in psychiatric disorders is mostly lacking.

### 6.5.2 People with mental disorders evidence excess avoidable deaths

Epidemiological research from several Member States (**Finland, Germany, the Netherlands, UK, Spain**) indicates that there is clear and considerable excess mortality among people with mental disorders. This mortality is partly due to avoidable deaths caused by physical disorders, such as cardiovascular, respiratory and metabolic disorders. Research on inpatient mortality has been performed in several countries in this study (**Finland, Germany, Greece**). The results are unambiguous, showing that there is a uniform excess mortality from avoidable natural causes in institutional settings.

The HealthQUEST study design does not allow conclusions regarding causality, but the risk of premature death may either be due to some unknown factor related to the mental health

disorder and its treatment, or it may reflect an excess of avoidable deaths due to deficiencies in access to or quality of healthcare. The pooled findings from mortality studies indicate that considerable barriers of access exist. Although only limited data is available on how people with mental disorders access and use general health services, findings from some countries (**Germany, UK**) indicating that people with mental disorders actually visit primary care more often than other people, point towards the existence of major organisational barriers to care within the health systems.

### **6.5.3 People with mental disorders are selectively affected by many common barriers of access**

Because many people with mental disorders have overlapping disadvantages, they are selectively affected by cost-related barriers, organisational hurdles and lack of supply-side responsiveness, which interrelates with demand-side barriers.

Poverty, homelessness, and lack of capacity to navigate the health system add to the burden of the mental health disorder as such.

### **6.5.4 Stigma is a major cause of access barriers**

The most significant barrier to healthcare access for people with mental disorders was unanimously felt to be the stigma and discrimination associated with mental ill health. Stigma is found in the general population, but perhaps more importantly in the health service administrative staff, the healthcare staff, and also the mental healthcare staff. Self-stigmatisation is also a factor which in combination with previous bad experiences of healthcare (e.g. compulsory admissions or humiliating treatment) makes it difficult for the person with the mental health disorder to seek help and assert his/her rights to care. Due to stigma, general health staff may be more paternalistic and use less of shared decision making than with patients without a mental disorder.

A paternalistic and derogatory health provider approach will add to previous disappointing encounters with the health system, and further decrease the user's incentives to seek help for health problems, creating a demand-side barrier of access.

Many health professionals also seem to have the false perception that health and wellness are not feasible among people with mental disorders, as a consequence of their mental illness.

### **6.5.5 Targeted actions to improve access to healthcare are mostly lacking**

In light of the documented excess morbidity and mortality, there was a striking paucity in research on access to healthcare for people with mental disorders. In the participating countries, the **UK** being an exemption, health services research and the health policy debate have hitherto largely ignored the deficits in the access to somatic healthcare for the mentally ill. In the **UK**, successful measures have been introduced to increase the number of physical health checks performed by GPs for people with mental disorders. In many countries (e.g. **Finland, Germany, UK**), clinical practice guidelines stress the need for physical health checks and health promotion efforts among people with mental disorders, but, except for the **UK**, these recommendations have not been translated into policy actions or programmes. Of special interest are two **Finnish** initiatives: the labour force service centres and the introduction of targeted healthcare for those unemployed.

### **6.5.6 Targeted health promotion actions are lacking**

Research indicates that the lifestyle of people with mental disorders is less healthy compared to the general population, especially with regard to eating habits, smoking and exercise. At the same time, research indicates that health promotion action is feasible and effective among people with mental disorders. Thus people with mental disorders constitute an appropriate target group for specific and indicated health promotion interventions. The striking lack of health promotion programmes may implicate that due to stigma the health promotion needs of people with mental disorders are not adequately recognised.

### **6.5.7 General health policy measures can improve access**

It is highly likely that general health policy measures, such as provision of a broad public health service basket and introduction of maximum waiting times for non-emergency care, improve access to general healthcare for people with mental disorders as well. Actions to reduce health inequalities, such as selectively providing health services to deprived areas, will probably also benefit people with mental disorders, because of the links between poverty and mental health. Many general health policy initiatives have most probably supported access to general healthcare for this group, as many barriers of access are shared with other groups.

### **6.5.8 Integrated care and psychiatric reform improves access**

Evidence indicates that a general health policy supporting integration of health and social services and mainstreaming of mental health services will also offer better access to general healthcare. Close links and proximity between primary care teams, and mental health services with good links between primary care staff and mental health staff is highly effective in improving the physical health of those with severe mental disorders. There is extensive evidence that multiprofessional and team-based assertive community treatment is an effective method of providing services to deprived people with mental disorders and complex problems.

Psychiatric reforms in Europe are largely built around the principles of deinstitutionalisation, mainstreaming, social inclusion and empowerment. These principles support access to general healthcare by integration of psychiatric services into mainstream healthcare and easier access to general healthcare for many people with mental disorders. It can therefore be concluded that the continuation of the psychiatric reform will support both social inclusion and users' access to general healthcare.

### **6.5.9 Barriers of access to general healthcare exist within psychiatric hospitals**

Individual studies and reports have highlighted problems in offering adequate general medical services to inpatients in psychiatric hospitals in several Member States (e.g. **Finland**, the **Netherlands**). Health system reforms have actually contributed to the challenge of providing adequate physical care in some of the countries studied (**Finland**, **Greece**, the **Netherlands**), because mainstreaming efforts have led to the closure of in-house general medical facilities of psychiatric hospitals. Efforts to address this problem by practice guidelines for somatic co-morbidity have been made in the **Netherlands**, and somatic care in mental health settings is reported to have improved.

## **6.6 Recommendations**

### **6.6.1 Raising awareness is central**

The striking lack of data on access to general health for people with mental disorders indicates a significant lack of awareness of this problem. This is also evidenced by the fact that, with the exception of UK, no national policies addressing the issue of access to general healthcare for people with mental disorders were identified.

Governments need to acknowledge the specific needs of those with mental disorders and centrally target the needs of these groups in national health inequalities programmes, incentivising providers and performance managing to ensure targets are met. Specific treatment guidelines need to be developed where needed. Awareness of the problem needs to be supported by an improved evidence base about the health and needs of people with mental health problems. Governments also need to initiate sensitisation and capacity building programmes for healthcare staff to better recognise the healthcare needs of people with mental disorders.

It should be noted that awareness-raising is best achieved in close collaboration with users' groups, building on the experiences of users.

### **6.6.2 Actions to reduce discrimination are needed**

There were also reports of clear discrimination against people with mental disorders within the health services. It is important that referral and health record systems are designed so that discrimination can be avoided. People with mental disorders should be empowered by involving users' representatives in healthcare decision making.

Regular monitoring of differences in waiting times between patients with mental disorders and other patients should be carried out to highlight any discrimination. Anti-discrimination legislation should be enforced to ensure equal access to healthcare.

### **6.6.3 Targeted health promotion action is needed**

Many models of evidence-based health promotion programmes exist, but they need to be integrated into routine health and social care. A European clearing house for health promotion actions for people with mental disorders needs to be established, to support exchange of evidence-based interventions between Member States. Health promotion has a wide spectrum of effects, not restricted to health status only, and health promotion should be seen as a valuable tool for achieving social inclusion. At the same time, it is important to note that other non-health policies may have a major impact on access to healthcare for people with mental disorders. Attention should be paid to this especially vulnerable group in all health impact assessment exercises.

As a particular example, evidence shows that people with schizophrenia tend to have unhealthy lifestyles, which probably contributes to the excess mortality of the disease. They are therefore an appropriate target group for health promotion interventions to address nicotine dependence, obesity and lack of exercise.

#### **6.6.4 *The goal should be to develop integrated and community-based health services***

Research suggests that the organisation of services is key to the success of meeting the needs of people with mental disorders, with integration, coordination, communication and seamless provision across health and social care sectors being of vital importance. A transformation of the mental healthcare system towards multidisciplinary, coordinated and holistic approaches is needed. Locating a primary healthcare team close to mental health services with good links between primary care staff and mental health staff is highly effective in improving the physical health of those with severe mental health problems. At the same time, care should be taken to develop targeted services for those with multiple vulnerabilities, e.g. for migrants with mental health problems or for homeless people.

#### **6.6.5 *Actions to reduce inpatient mortality***

The high inpatient mortality at psychiatric institutions is alarming. To reduce mortality rates, measures to improve capacity of staff to recognise and treat physical disorders are needed. However, above all a

radical change in attitudes of staff in institutions is needed. Current evidence on the effectiveness of health promotion actions among people with mental disorders needs to be disseminated, and efforts should be made to bridge the gap between mental healthcare and general healthcare by closure of mental hospitals and initiation of psychiatric care within general hospitals.

#### **6.6.6 *Investment in research***

To succeed in the above mentioned actions, a sound European research base is needed. Multidisciplinary research on stigma, anti-discrimination, health promotion, and integrated community-based services is crucial to bring the field forward. Clearly, the problem of access to healthcare for people with mental disorders is not just a problem of health services; indeed it has wider ramifications: for attitudes within the European population, for defining the fundamental rights of every European; and for social cohesion and inclusion policies. The need for broad-based, multidisciplinary research to describe, analyse and improve access to general healthcare for people with mental disorders is clear.

## **Part 4**

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## 7 Conclusion and Policy Recommendations

All Member States address poverty and social inclusion in their national policy programmes. The HealthQUEST project has studied how hurdles of access to good quality healthcare can worsen the situation of groups at risk of social exclusion and what policies countries have put in place to improve the situation of vulnerable groups in this respect.

Information provided in country reports confirms the widespread consensus both within the academic literature and the policy community that being socially disadvantaged is associated both with ill health and to barriers in accessing healthcare.

### 7.1 Conclusions

**National policies differ in the awareness of the specific access challenges of the groups studied in detail in HealthQUEST.** There are similarities as well as differences in policy frameworks to tackle the challenges that have been identified. For example, similar policies are used to protect vulnerable groups against the consequences of cost sharing requested under public healthcare programmes. The differences are here more in how comprehensive these protective measures are, and how straightforward it is for people to profit from them without having to deal with complex bureaucratic hurdles.

In some situations, barriers of access have been found to be severe but targeted policy responses are largely absent. The problem of access to somatic healthcare for people with mental disorders is a particularly striking example that was studied in HealthQUEST. Deficits of healthcare to which people in institutions have access (both mental health patients, and dependent older people) is also widespread.

The importance of **health literacy** as an access hurdle to healthcare, and how to put services in place to support people in the complex choices in increasingly competitive regulated markets of providers and financing agents has only recently received more attention.

There are also **differences in policies for the three groups studied** in HealthQUEST. Access problems of vulnerable groups have not received the same attention in national policies for the different groups studied. Most countries have in the past developed strategy documents and entered in policy discussions on how to improve the situation of the growing number of older and very old people in society. This has included recognising the need for better tailored services (both health and social) for dependent older

people, and studying the links to their living situation and challenges of poverty in old age. The situation of migrants has recently received more attention in Member States but there is still a gap in many countries between policies to support migrants with a recognised status, versus those with no official status. Access problems to somatic healthcare for people with mental disorders, finally, seems to largely escape the radar screen of healthcare policies.

HealthQUEST has also revealed that there are a number of **problems of policy implementation** and that sound evaluation, such as impact assessment of healthcare reform on the situation of vulnerable groups, seems to be the exception rather than the rule. A closer look at policy implementation has shown that there might be unintended side-effects of policies for the situation of people at risk of social exclusion. One example is the complex bureaucratic procedures that people with low health literacy will find difficult to deal with, such as the demanding administrative forms that may be needed to register with insurance funds or apply for reimbursement of cost-sharing payments.

There are other **factors that stand in the way of more effective policies** to lower access hurdles for groups at risk. While inequality in health has received much attention in recent years, the focus of policy response is often targeted more on broader population health determinants than on specific access problems of vulnerable groups. The cost of measures to improve access and concern for financial sustainability is a major policy hurdle when it comes to abolishing cost sharing, address shortages of services, or make the investments needed to improve the quality of services.

Shortages of public resources have indeed been identified as a major factor limiting access in a number of cases, and vulnerable groups tend to suffer more from these barriers than other groups because they both have higher demand in general but more restricted resources.

Work under HealthQUEST has also allowed a **stock taking of the available evidence**, and of gaps in knowledge, as well as the identification of priorities in research both for Member States and perhaps also on the European level.

Gaps in knowledge are widespread. There is a scarcity of targeted research, such as of surveys regarding access problems of vulnerable groups. In addition, population health information systems often do not show the level of detail needed for the study of social exclusion concerns. This was particularly striking for the situation of people with mental health problems.

There are also serious gaps in medical knowledge about the specific health challenges of certain groups, including adequate medical responses to the multi-morbidity that

dependent older people and people with mental disorders often present. More investment in targeted research in these areas will be key to improving quality of care and to putting in place a better mix of services. Better training of staff to allow them to better respond to the specific challenges of vulnerable groups is another factor that has been identified in country reports.

Filling these gaps in research and improving staff qualifications and training is among the **priorities identified** in the HealthQUEST study. Other actions on such a priority list could include targeting people in deprived areas, including remote and rural ones in order to improve the regional spread of resources.

There is evidence that a number of prevention and health promotion actions might lead to a more efficient use of available resources, such as for dependent older people. However, lowering a number of other access barriers for people at risk, such as reducing cost sharing or waiting lists, will most likely require additional public resources in a number of countries.

## **7.2 Policy Recommendations**

### **7.2.1 General recommendations**

***Vulnerable groups need specific policy attention to overcome the access barriers posed by the ways healthcare systems regulate population coverage, health basket and cost sharing.***

Vulnerable people are particularly at risk from cost sharing for healthcare. Member States may wish to consider putting policies –such as exemption or reimbursement rules– in place to ensure that the organisation of the health system does not unduly disadvantage vulnerable populations.

***Address issues of health literacy explicitly as part of health system reform.***

Member States should ensure that they have clear policies in place to address both supply and demand side health literacy for vulnerable populations.

Member States who are changing their healthcare systems should pay particular attention to ensuring that active ongoing measures are in place to support vulnerable populations in effectively using the system.

The European Union should ensure that there is a strong evidence base to support MS in addressing health literacy.

***Undertake specific impact assessment of major social and health policy changes on the situation of people at risk of social exclusion.***

As Member States change systems for financing healthcare including cost-sharing regulations, specific attention in routine data collection must be given to vulnerable groups to ensure that policy measures to prevent exclusion are effective.

Member States need to facilitate systematic research on the reasons why some people fail to obtain a regular insurance status. This should be undertaken for countries where this places certain vulnerable groups at risk of exclusion from regular healthcare coverage. This needs a culture of monitoring and programme evaluation to close serious gaps in research and information systems.

***Give barriers of access for vulnerable groups greater attention in the European Union policy process.***

Among issues of priority for a broader European exchange are affordability of healthcare for vulnerable groups, health literacy and patient empowerment.

***The EU might wish to consider how to address the most pressing questions for further research identified in HealthQUEST under the Framework Programme for Research of the European Union.***

Priority questions for further research include good practice of tailored prevention and health promotion for people at risk of social exclusion, integrated care models, and the situation of people with mental disorders.

### **7.2.2 Migrants, asylum seekers and illegal immigrants**

***Services for migrants and asylum seekers without papers.***

Member States may wish to consider how to improve the situation of asylum seekers and migrants with no official status. Member States may wish to consider ensuring that healthcare is in place for this group and that strategies are designed on how to deal with the specific access barriers that affect this group of the population.

***More resources should be invested in researching the healthcare needs and access problems affecting migrants, asylum seekers and illegal immigrants.***

Information on the main health problems affecting these groups is currently lacking. Member States should consider investing in more research to understand the epidemiological profile and the main access barriers affecting these groups.

### **7.2.3 Older people with functional limitations**

#### ***Older people and their families need an appropriate mix of health and social services in place.***

Member States should improve the mix of services by fostering access to prevention; rehabilitation and comprehensive care assessment as well as better care management at the boundary between health and social services.

The role of informal carers in supporting older people is underpinning services to this group in all Member States. Member States might wish to pay particular attention to creating a policy framework to support informal carers and to enable them to stay in employment.

#### ***Make improving the access and quality of services of dependent older people in institutions a priority.***

Member States urgently need to ensure that policies are in place to meet the healthcare needs for older people cared for in institutional settings. The right skill mix of staff in institutions and more seamless cooperation across the social care and health boundary needs special attention.

#### ***Invest in gerontology and in better quality assurance mechanisms and care guidelines for dependent older people.***

Member States should invest more in research on improving the knowledge of elderly health and care issues among health and care professions. Member States should step up multidisciplinary research on stigma, anti-discrimination, health promotion, and integrated community-based services.

### **7.2.4 People with mental health problems**

#### ***More research is urgently needed on the somatic healthcare needs and access for people with mental disorders.***

The lack of data on access to general health for people with mental disorders indicates a lack of awareness on this problem. This is also evidenced by the fact that, with the exception of UK, no national policies addressing the issue of access to general healthcare for people with mental disorders were identified

The EU might wish to urgently fund research to better understand the somatic healthcare needs of people with mental disorders and what effective interventions can be made to alleviate this problem.

#### ***Stigma is a major access barrier for people with mental disorders.***

The most significant barrier to healthcare access for people with mental disorder was unanimously felt to be the stigma and discrimination associated with mental ill health. Stigma is found in the general population, but perhaps more importantly in the health service administrative staff, the healthcare staff, and also the mental healthcare staff.

Member States need to acknowledge the specific needs of those with mental disorders and centrally target the needs of these groups for mainstream health service in national health inequalities programmes, incentivising providers and performance managing to ensure targets are met. Specific treatment guidelines need to be developed.

#### ***Give special attention to the high co-morbidity and health risks of people with mental disorders.***

Member States should ensure that health policy addresses the high rates of co-morbidity of people with mental disorders, particularly when people are inpatients in specialist mental health services by mainstreaming mental healthcare with general healthcare.

The EU might wish to consider how good practice examples of targeted health promotion action for people with mental disorders might be disseminated more widely.



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