



Training packages for health professionals to improve access and quality of health services for migrants and ethnic minorities, including the Roma
MEM-TP

SYNTHESIS REPORT

Work package 1

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Migrants & Ethnic Minorities
Training Packages



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Table of contents

Table of contents	2
Executive Summary.....	6
Introduction.....	17
Chapter 1: Migrants and ethnic minorities in Europe.....	21
1.1. Definition of a migrant.....	21
1.2. Different types of migrants	23
1.3. Development of migration in Europe	24
1.4. Statistics on migration	29
1.4.1. Total migration.....	29
1.4.2. Asylum claims	29
1.4.3. Irregular migrants.....	30
1.4.4. Proportion of EU migrants and ‘Third Country Nationals’.....	30
1.5. Demographic characteristics of migrants.....	31
1.5.1. Gender.....	31
1.5.2. Age	31
1.5.3. Socioeconomic position	32
1.6. Ethnic minorities.....	34
1.6.1. Definitions	34
1.6.2. Vulnerable minority groups.....	37
1.6.3. Which countries collect data on ethnicity in census forms and population registers?	39
1.6.4. Main types of research on health and ethnic minorities in Europe.....	40
1.7. Descendants of Migrants.....	44
1.8. The Roma population in Europe.....	46
1.9. Statistics on the Roma population	47
1.9.1. Age	48
1.9.2. Social position	50
Chapter 2: State of health and health determinants	51
2.1. General issues.....	51
2.1.1. Gaps in the data	51
2.1.2. The relation between poor health and shortcomings in health service provision	52
2.1.3 Changing assumptions regarding the importance of different determinants of health.....	53

2.2. Health inequalities affecting migrants and ethnic minorities and their determinants	56
2.2.1. The 'healthy migrant effect'	56
2.2.2. The lack of main effects.....	57
2.3. Differences found.....	57
2.3.1. General measures of health.....	57
2.3.2. Non-communicable diseases	59
2.3.5. Communicable diseases.....	62
2.3.6. Maternal and child health	66
2.3.7. Mental health.....	67
2.3.8. Occupational health and safety.....	68
2.4. Health inequalities affecting the descendants of migrants.....	70
2.4.1. Findings from the UK.....	70
2.4.2. Findings from the Netherlands.....	71
2.4.3. Findings from other countries	72
2.5. Health determinants.....	73
2.5.1. Location of determinants	73
2.5.2. Nature of determinants.....	74
2.6. Health inequalities affecting Roma and national ethnic minorities, and their determinants	79
2.6.1. General issues	79
2.6.2. Differences found	80
2.6.3. Health determinants	82
Chapter 3: Legal and policy framework relating to migrant and ethnic minority health in the EU	84
3.1. Importance of the international dimension.....	84
3.1.1. Inherent weaknesses of international laws and initiatives	84
3.1.2. Constructive versus coercive power of legal instruments	86
3.1.3. The complex nature of governance in health systems	86
3.2. International, regional and national legal frameworks.....	86
3.2.1. International level.....	86
3.2.2. Regional (European) level	88
3.2.3. National level.....	90
3.3. International and regional policy initiatives	93
3.3.1. International level.....	93
3.3.2. Regional (European) level	94
3.3.3. National level.....	98

3.4. Legal instruments and policy initiatives specifically addressing health inequalities of ethnic minorities, including the Roma.....	99
Chapter 4: Barriers to accessing health services and good practices addressing them	99
4.1. Dimensions of access.....	99
4.1.1. General issues concerning access.....	104
4.2. Examples of barriers to access and good practices to address them	107
4.2.1. Lack of information, poor ‘health literacy’	107
4.2.2. Practical barriers	110
4.2.3. Language barriers	112
4.2.4. Discrimination and mistrust.....	112
Chapter 5. Factors undermining the quality of health service delivery and good practices addressing them	114
5.1. What is meant by ‘quality’?	114
5.2. Factors undermining quality and good practices addressing them.....	115
5.2.1. Cultural barriers	115
5.2.2. Language barriers	118
5.2.3. Barriers between the health system and migrant or ethnic minority communities	120
Chapter 6. Developing a European framework for collaboration on migrant and ethnic minority health.....	124

Appendix I: Migrants and Ethnic minorities in Europe: Demographic data,

Appendix II: Migrants and Ethnic minorities in Europe: State of health

Appendix III: Legal and policy frameworks relating to migrant and ethnic minority health in the EU

Appendix IV: Utilisation of health services, barriers to access and good practices addressing them

Appendix V: Good practice in cultural competency training for health professionals - literature and EU funded projects

Appendix VI: EU funded projects addressing migrant and ethnic minorities' health

List of figures

<i>Figure 1 Economic growth and immigration in Europe beginning in the 1950's and 1960's</i>	24
<i>Figure 2 Economic growth and immigration in Europe beginning in the 1980's and 1990's</i>	25
<i>Figure 3 Economic growth and immigration after the 2000's in Europe</i>	26
<i>Figure 4 Variation in asylum claims lodged in 44 industrialized countries 1990-2012</i>	28
<i>Figure 5 Percentage of migrants who are third-country nationals (2013)</i>	29
<i>Figure 6 Age structure of the national and non-national population, EU-27, 1 January 2012 (%)</i>	31
<i>Figure 7 At-risk-of-poverty rate among migrants, by region of origin, 2010 income year</i>	32
<i>Figure 8 EU member states with largest Roma and Traveller populations (2010)</i>	46
<i>Figure 9 Population pyramids in Europe: Roma community and the European Union</i>	47
<i>Figure 10 Roma and non Roma Households with severe material deprivation in Europe, 2011</i>	48
<i>Figure 11 Different exposures during the life course on the health of migrants</i>	71
<i>Figure 12 'Rainbow' diagram showing social determinants of migrant health, WHO 2010</i>	74
<i>Figure 13 Conceptual framework for migrant and ethnic minority health in Europe</i>	121

List of tables

<i>Table 1 Risk factors for migrants' health</i>	75
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Executive Summary

1. Brief overview of the report

This report was compiled by the University of Copenhagen's Research Centre for Migration, Ethnicity and Health (MESU), in collaboration with experts from the University of Amsterdam based at the Academic Medical Centre (AMC) and the Amsterdam Institute for Social Science Research (AISSR). It forms part of the first work package of the project MEM-TP (*Training packages for health professionals to improve access and quality of health services for migrants and ethnic minorities, including the Roma*). The title of WP1 is *Review of the migrant and ethnic minorities' situation in the EU and identifying common challenges and best practices to provide an overview of the issues of relevance to the development of training for health professionals*. This WP resulted in two deliverables: firstly the present report, and secondly a series of Appendices providing detailed information to accompany it. The report has the following components:

Introduction. This outlines the challenge presented to health systems by steadily increasing migration to the European Union, as well as by the existence of substantial ethnic minorities in many Member States. Inequalities in health and health care affecting these groups have recently been exacerbated by the financial and economic crisis. These inequalities call for concerted action at European and national levels, including the development of training programmes to further capacity-building.

Chapter 1 provides definitions of the terms used in the report and outlines the way in which migration has developed in different Member States from World War II to the present, in order to illuminate the divergent national approaches to migrants and ethnic minorities and their health problems that have arisen in each country. It describes basic demographic characteristics of the current migrant population. In relation to ethnic minorities, the chapter discusses the concept of 'ethnic groups' and singles out for particular attention the Roma, describing briefly their history and demographic characteristics.

Chapter 2 is concerned with the state of health of migrants and ethnic minorities in Europe, as well as the main factors affecting their health. It analyses the shortcomings of the present knowledge base and presents a brief overview of the most important research findings, as well as introducing the theoretical frameworks developed to analyse the determinants of health problems.

Chapter 3 describes the development of the legal and policy framework within which notions of 'good practice' in this area have developed, distinguishing international, European and national levels. It traces the gradual shifts that have taken place in the way problems are formulated and solutions proposed.

Chapter 4 focuses on the problems that migrants and ethnic minorities (in particular, Roma) may encounter in trying to access health services and identifies a number of good practices from literature and EU projects to address these problems.

Chapter 5 analyses the ways in which health service delivery may need to be adapted to ensure a better match between the services and the needs of migrants and ethnic minorities.

Chapter 6 provides an outline for a proposed Framework for European collaboration for training health professionals, which will be further elaborated on in subsequent work packages.

To supplement the report, the following information has been provided in the Appendices.

Appendix I. Detailed statistics on the distribution of the migrant and Roma population in Europe and their demographic characteristics (Chapter 1)

Appendix II. Epidemiological findings on the main diseases and health problems affecting migrants and ethnic minorities in Europe (Chapter 2).

Appendix III. Legal and policy frameworks relating to migrant and ethnic minority health in the EU at international, European and national levels (Chapter 3).

Appendix IV. Information about the utilization of health services by migrants and ethnic minorities; barriers to accessing health services and good practices developed to address them (Chapter 4).

Appendix V. Improving the matching of health service delivery to the needs of migrants and ethnic minorities (Chapter 5).

This report draws heavily, though not exclusively, on the body of knowledge that has been built up by the substantial number of EU funded projects that have been carried out in recent years, particularly in the last decade.

Appendix VI provides a list of these projects and analyses their content.

The methodology used for this project was based mostly on desk research. For the literature reviews contained in the Appendices a number of databases listing scientific publications were searched (e.g. PubMed, Science Direct, Elsevier), as well as grey literature. The report also draws on material developed in the course of the COST Actions IS0603 (*Health and Social Care for Migrants and Ethnic Minorities in Europe - HOME*) and IS1103 (*Adapting European health systems to diversity - ADAPT*).

2. Summary of findings in each area

Introduction

This section outlines the background and context of the current project. As the proportion of migrants and ethnic minorities in Europe grows, so does the need for health systems to adapt to increasingly diverse populations with diverse needs. The health of migrants has come to the

attention of health systems in different ways, with approaches differing according to the region in Europe, the number and type of migrants involved, their countries of origin and other factors.

Migrants and ethnic minorities represent a wide range of groups. The category 'ethnic minority' can refer to migrants and their descendants as well as to national and indigenous minorities, who, though distinct, are often affected by many of the same issues. Although few generalizations can be made about this very heterogeneous population, there is, for example, a consensus regarding the overall lower economic status held by most migrant and ethnic minority populations in comparison to the majority population. Research also points to an increased risk of developing a number of chronic as well as acute health conditions in this population when compared to the national averages. Mortality and life expectancy rates vary too: for the Roma, for example, data on life expectancy across Europe is estimated to range from 7-20 fewer years than for non-Roma.¹ In the case of migrants, even if many are healthy upon arrival, lifestyle factors and living conditions may over time lead to a variety of health problems.

Moreover, many of these inequalities in health are on the rise. Migrants and ethnic minorities tend to suffer from multiple forms of disadvantage, and this is a major factor influencing their health. In times of crisis when socioeconomic inequalities are increasing, they face even greater inequalities in health. Under 'austerity' policies, the most vulnerable groups in society absorb the main impact of spending cuts in the public services sector – in particular when these policy measures limit access to key services such as health care.²

In order to properly address the health inequalities experienced by migrants and ethnic minorities in Europe, there is a growing consensus that the increased health risks to which they are exposed have to be identified and the underlying causes investigated. This requires changes in the way health data are routinely collected, as well as increased research efforts. The determinants of ill-health that are discovered need to be tackled through prevention, health promotion and the implementation of an intersectoral "health in all policies" approach focused on the social determinants of health. A further challenge lies in the fact that legal entitlement to health care does not by itself ensure access to good quality services. Here, a key concern is identifying the problems migrants and ethnic minorities may have in gaining adequate and timely access to health services, as well as the shortcomings that exist in the quality and appropriateness of the services they receive. These groups all too often provide an illustration of the "Inverse Care Law" formulated in 1971 by Julian Tudor Hart³: "the availability of good medical care tends to vary inversely with the need for it in the population served".

All these tasks require substantial capacity building concerning knowledge and expertise on the challenges posed by increasingly diverse populations and the health problems they face. Health systems must improve their understanding of how best to protect the health of migrants and ethnic minorities and meet their needs for adequate care. Through effective dissemination and

¹ Matrix Consulting. *Roma Health Report*. European Commission, Health and Consumers. http://ec.europa.eu/chafea/documents/health/roma-health-report-2014_en.pdf (accessed on 23rd of September, 2014)

² Eurofound (2013). *Impacts of the crisis on access to healthcare services in the EU*, Dublin.

³ Hart, J.T. (1971). The inverse care law. *The Lancet*, Volume 297, Issue 7696, Pages 405 – 412.

training programmes, they must also ensure that this understanding is shared by health workers of all kinds and at all levels. However, focusing exclusively on front-line professionals ignores their need for back-up and support from all levels of the organisation. This implies that systematic training and education, not only of health workers, but also of policy-makers, managers and researchers, is required to bring about change. In this review we will attempt to summarise the most important issues in the study of migrant and ethnic minority health, and to review the current 'state of the art' in regard to our knowledge about these issues. The review will highlight in particular issues to which attention needs to be paid in training courses aimed at health professionals in mainstream organisations.

Chapter 1. Migrants and ethnic minorities in Europe

This chapter gives a brief sketch of post-war migration to Europe and discusses the ethnic minorities present in the region. The number of migrants in the EU has been on the increase since the Second World War, amounting in 2013 to just over 10% of the total population⁴. Approximately half of these migrants are women, while in general, both migrant and ethnic minority populations tend to be younger than the majority populations.

The terms 'migrant' and 'ethnic minority' are complex and definitions often vary from country to country. Regarding migrants, this report starts from the definition used by the UN, World Bank, OECD and EU, which define an (international) migrant as "a person who changes his or her country of usual residence". Migrants may be classified in terms of the grounds on which they receive a residence permit, for example labour migrants, students, migrants arriving for family reunification or formation or asylum seekers. Most irregular (or 'undocumented') migrants have at some time held a valid permit.

Migration to Europe has developed in very different ways in different countries – firstly in terms of the period during which it started to increase, secondly in terms of its volume, and thirdly in terms of the types of migration involved. Patterns of migration are constantly shifting, so that stereotypical assumptions about migrants formed in one period may be quite misleading in another.

Beginning in the 1950's and 1960's, North-western European countries saw the arrival of large numbers of 'guest workers' from Southern Europe, Turkey and North Africa, as well as migrants from European colonies or ex-colonies. These migrants helped to power the economic growth that Europe enjoyed until the oil crisis of 1973. Large numbers of 'guest workers' in fact remained in North-west Europe, and many of them were also joined by family members. Given the initial expectation that they would return home, no efforts had been made to encourage their integration. When economic growth slowed down in the 1970's, severe restrictions were placed on labour migration from non-Western countries; family reunion or formation and asylum-seeking became the main grounds for migration from these countries.

⁴ Source: Eurostat [migr_pop3ctb]

In the 1980's and 1990's net migration started to increase in a number of other countries, namely those who had recently transitioned to democracy and subsequently joined the EU (Spain, Greece and Portugal), as well as a few of the countries formerly under Soviet occupation (Bulgaria, the Czech Republic and Slovakia) and Finland.

The issue of migrants' health gained importance in different countries in different ways. Initially, attention focused mainly on 'guest workers' because of the increased health risks many of them faced, as well as the linguistic and cultural barriers experienced in their encounters with health services. In response to concern voiced by health professionals, the first conference on Migrant Health was organized in The Hague in 1983 by the Dutch Government and the WHO Regional Office for Europe⁵. Some countries (including France, Germany and Austria) adopted a 'passive' approach to the problems, expecting migrants to adapt to the existing health systems, while countries with a more 'active' policy (such as Netherlands and Sweden) made considerable efforts to address the issue of migrant health within the framework of their 'multicultural' integration policies.

In the second wave of migration in the 1980's and 1990's, Spain, Portugal and Italy responded actively by granting all migrants (including irregular ones) access to their health system and by collecting data on and adapting services to the needs of migrants. Others, such as Greece, relied on NGO's to address many of these needs.

The complex political, demographic and economic changes since 2000, including the addition of 13 new member states to the EU, have led to an increasingly positive migration balance (except in Slovenia, Poland and the Baltic States). Concerning asylum seekers and irregular migrants, worsening economic, climatic and political conditions in many non-European countries have led to an increase in recent years. These developments, as well as the increasingly 'circular' nature of migration and the emerging 'super-diversity' of populations in large urban areas, represent significant challenges for the health care systems of the countries involved. Training programmes must always bear in mind these differences in the history, quantity and nature of migration flows in order to effectively address the resulting challenges.

Ethnic minorities in Europe

The term 'ethnic minority' is used to cover many different kinds of groups. There are widely differing views about what ethnicity is, which ethnic groups exist, and who should be regarded as a member of them. Different types of 'ethnic group' can be distinguished: *indigenous peoples* are groups which may have lived in a country as long as, or even longer than, the majority (or dominant) ethnic group. Other ethnic minorities can result from migration, or from the redrawing of national borders (as happened on a large scale during and after the First and Second World Wars, the break-up of the Soviet Union and the Balkan Wars).

Because of the lack of shared understandings in this field, it is impossible to make a definitive list of the ethnic minorities that exist in Europe. Moreover, studies on health have only been carried

⁵ Colledge M, Van Geuns HA, Svensson PG, eds. (1986). *Migration and health: towards an understanding of the health care needs of ethnic minorities. Proceedings of a consultative group on ethnic minorities* (The Hague, Netherlands, November 28–30, 1983). Copenhagen, WHO Regional Office for Europe.

out on a few minorities (most of them 'indigenous') – although in the UK and the Netherlands the variable 'ethnicity' is commonly used in health research. In this report special attention is paid to the Roma, for three reasons. Firstly, the group is much larger than any other ethnic minority in Europe (10-12 million). Secondly, Roma experience an extreme degree of social disadvantage and discrimination. Thirdly, data on other European minorities is sparse, whereas there is a growing body of research on the inequalities in health experienced by Roma in Europe.

It is safe to say, however, that many ethnic minorities in Europe – however they are defined – experience some of the same socioeconomic disadvantages and prejudices as the Roma, leading to inequalities in health and barriers to quality health care. The Sami in Northern Norway, Sweden and Finland provide an example of this. Health professionals should be trained to understand the particular socioeconomic conditions, health risks and barriers to health care experienced by the ethnic minorities present in the countries where they practice.

Chapter 2. State of health and health determinants

Despite significant efforts to collect information on the health of migrants and ethnic minorities over the last decade, limitations in the data persist. What we do know is that those with the greatest need for good health care are often those who are least able to access it. Health services need to ensure that the needs of migrants and ethnic minorities, with their known health vulnerabilities, are met.

Increasing focus on the role of socioeconomic determinants of health

Over the last two decades a shift in focus has taken place amongst researchers and policy makers. Increasingly, the emphasis has moved 'upstream', i.e. focusing on fundamental determinants of health, such as those described in the 'Marmot Report' on the social determinants of health.⁶ Epidemiological research into the causes of ill-health, especially the role of social disadvantage, has become more central. Furthermore, there is growing emphasis on the need for macro-level policies to improve the social, economic and legal situation of migrants and ethnic minorities.

Health inequalities affecting migrants, their descendants, and ethnic minorities

While migrant status may have a positive association with health (the so-called 'healthy migrant effect'), migration tends to have a negative effect on an individual's health. The main findings identified in our abbreviated literature review include the following:

- **General measures such as mortality and life expectancy, and self-perceived health:** while no overall generalisations can be made, many (but not all) studies show higher mortality rates for migrants, and that migrants assess their own health less favourably than do the host population.
- **Non-communicable diseases, such as cardiovascular diseases, diabetes and cancer:** Research studies indicate an overall increase in incidence in migrants with age for the first two diseases, and an often lower risk of developing cancer.

⁶ CSDH (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final report of the Commission on the Social Determinants of Health*. Geneva, World Health Organization

- **Communicable diseases:** Despite data limitations, research sometimes shows a higher risk of HIV, tuberculosis, and other diseases such as Hepatitis B, amongst migrants and ethnic minorities.
- **Maternal and child health:** Migrant women experience a higher risk of maternal mortality, and newborns less favourable outcomes, for example in terms of low birth weight, premature birth, and perinatal mortality.
- **Mental health:** Research has identified an overall higher incidence of depression, anxiety disorders, schizophrenia, and PTSD (post-traumatic stress disorder).

Many different kinds of factors may underlie the prevalence of disease among migrant and ethnic minority groups. The origin of health problems, in the case of migrants, may lie in the country of origin, the journey or in the host country. Given the increasing tendency in studies of migrant and ethnic minority health to focus on more 'upstream' risk factors underlying health problems, the strategies for combating them should involve intersectoral interventions going beyond the health sector itself, e.g. education, housing and the labour market.

Chapter 3. Legal and policy framework relating to migrant and ethnic minority health in the EU

Because the ability of migrants and ethnic minorities to influence national legislation is restricted, legal instruments and policy initiatives aimed at protecting their health often originate at the international level. For a number of reasons, however, international laws and conventions are of limited effectiveness when it comes to changing realities on the ground in the field of health. Yet legal action may not be the best way to get things changed anyway. Beyond the sphere of legislation, many policy initiatives have been launched since the 1990's to promote constructive changes in health systems that will enable them to respond better to the needs of increasingly diverse populations. Most of these policy initiatives have been focused on migrants, though some also relate to ethnic minorities such as Roma. Concerning Roma, since the end of the 1990's there has been a sustained effort at European level to promote policies that will support integration and better health for this group.

A gradual shift of perspective can be discerned in all these policy initiatives. Firstly, whereas early initiatives tended to involve short-term, localised, 'one-off' interventions and categorical (separate) provisions for migrants and ethnic minorities – a sort of 'first-aid' approach - the accent has come to lie on 'mainstreaming' of provisions. This promotes their sustainability and universal availability. In keeping with this, a 'whole organisation approach' has been adopted, stressing that not just individual health workers but entire organisations have to learn to adapt to diversity. This includes measures on the individual as well as the organisational level to eliminate discrimination in access and quality of health care against migrants and ethnic minorities. Intersectoral collaboration between different agencies concerned with social protection and policy-making is also required.

At the same time, within the field of Public Health 'upstream' causes of illness have come to be increasingly stressed by epidemiologists, while policy-makers have sought remedies at the macro-social level using the 'health-in-all-policies' (HiAP) principle to tackle the social

determinants of health. This type of thinking, which emphasises legal, political and economic inequalities, has yet to gain a firm foothold in approaches to 'vulnerable groups' such as migrants and ethnic minorities.

However, one promising sign is the adoption of an 'intersectional' approach to health care delivery. Whereas diversity was traditionally viewed through the narrow lens of 'cultural differences', health workers are now urged to take account of *all* aspects of a person's social context and position in society. In this way, work tackling migration- and ethnicity-linked inequities can form a common front with work on other kinds of inequity, such as those linked to socioeconomic disadvantage, social exclusion, gender, age, education, disability, sexual orientation etc.

Chapter 4. Barriers to accessing health services and good practices addressing them

Access to and quality of health services are expressions that refer to two different steps in the process of using health services. The first, access, refers to the process of getting through the door, so to speak, while the issue of quality arises once a person has got inside the door, i.e. after overcoming any barriers to access. However, the relation between the two concepts is often blurred, as, for example, when perception of poor quality of services acts as a barrier for individuals seeking access. Moreover, factors such as language play a role both in gaining access and in ensuring the quality of communication between patient and health professional.

Whether and how effectively migrants and ethnic minorities access health services (and subsequently, the quality of care they receive), is important for a number of reasons, not least of which is the fact that ill health may negatively affect participation and outcomes in education, work, and society in general.

A significant body of research and a good number of EU funded initiatives have aimed to identify barriers to access and good practices for overcoming them. Below is a short summary of key findings.

Typical barriers to access include the following:

- Lack of information or low health literacy: both professionals and health service users may not know about or understand the relevant entitlements to accessing health services. Also, stigma surrounding certain health issues such as mental health, may act as barriers amongst certain groups, e.g. Roma.⁷
- Practical barriers, such as distance and transportation, opening hours, ID and insurance, complicated registration procedures, limited health services in migration detention centres, etc.
- Discrimination and mistrust: both factors may limit access, both by direct acts of discrimination and by perceptions or expectations of such acts.

⁷ *ibid.*

- Language barriers: inability to understand printed forms and folders, or to communicate adequately with health professionals, may lead to potentially disastrous misunderstandings when access to health services is sought.

Good practices in tackling barriers to access:

- Overcoming information barriers – e.g. strategic translation and distribution of information about health and health services, innovative health education models, cultural mediators working to reach populations.
- Overcoming practical barriers – e.g. use of mobile health units to overcome geographical barriers, educating health professionals at all levels about entitlements, and introduction of structural flexibility to enable health professionals to take care of patients whose entitlement may be in question, or who can't afford eventual fees.
- Overcoming language barriers – e.g. translating material regarding gaining access to health care, such as registration forms, information about how the health system functions, etc., as well as interpretation at entry points, such as reception.
- Overcoming discrimination and distrust – e.g. participation of migrant and ethnic minority groups in different aspects of health service design, delivery and evaluation, community-based approaches aiming to mobilise the health resources already existing within communities, cultural mediators who can narrow the gap between health providers and communities.

Chapter 5. Factors undermining the quality of health services and good practices addressing them

The *quality* of health services refers to user and health professional satisfaction, as well as the extent to which the treatment process is properly carried out, avoiding noncompliance and dropout, and leading to optimal outcomes. In order for health services to be able to do their work most effectively, individual needs and context, i.e. a patient-centred approach, should be a prime consideration.

Some of the most frequently encountered factors undermining the quality of health services include:

- *Difficult and ineffective interactions* – The view that ‘cultural differences’ are the primary cause of problems in the interactions between migrants and ethnic minorities on the one side, and health professionals on the other, has in recent years given way to a more complex vision in which many other aspects of a patient’s social and personal situation need to be taken into account.
- *Language barriers* – As we saw in relation to access, language barriers do not simply undermine quality but constitute a substantial threat to patient safety.

Good practices addressing factors undermining the quality of health services:

- *Teaching cultural competence or 'diversity sensitivity' to health professionals* - In order to improve the capacity of care providers to meet the diverse needs of their diverse users, experts have suggested that cultural competence has to be redefined. They propose the

development of an improved 'sensitivity to diversity', encompassing gender, age, religion, disability, sexuality and socioeconomic position.^{8, 9} However, focusing exclusively on front-line professionals ignores their need for back-up and support from all levels of the organisation. This implies that systematic training and education, not only of health workers, but also of policy-makers, managers and researchers, is required to bring about change.

- *Language barriers* – a number of tools have been developed and implemented for overcoming oral and written language barriers, ranging from the translation of key forms and health information, to different interpreter tools, such as face-to-face and telephone interpretation, and bilingual health professionals. Cultural mediators have been used successfully as interpreters for Roma who only speak Romani. Generally, using relatives as interpreters should be avoided.

Conclusions

This Work Package has attempted to give an overview of the inequalities in health and health care for migrants and ethnic minorities across Europe. In training health professionals to equip them with the skills, knowledge and understanding to better meet the needs of migrants and ethnic minorities, the following factors need consideration:

1. Increasingly, researchers, policy makers and service providers are recognizing the multiple layers of diversity in these groups, and looking 'upstream' in terms of the determinants of health. This means that any interventions to tackle health inequalities needs to take into consideration socioeconomic factors such as education, labour market participation, and housing, as well as legal situation, migrant status, ethnicity, gender, religion and sexual orientation.
2. The numbers and types of migrants in Europe vary from country to country, and this implies different priorities for initiatives addressing their needs. "One size fits all" is unlikely to be a good formula for developing training programmes in the European area. Health professionals at all levels should keep the nature and specific needs of migrant and ethnic minority populations in mind when designing and implementing interventions. This means that they need to receive background information for their country on the number and nature of migrants and ethnic minorities, as well as their health needs.
3. While legislation and policy may guarantee some form of entitlement to health services for migrants and ethnic minorities, it does not guarantee the actual access to, appropriateness, and quality of these services. This also applies to preventive and health promotion interventions. If services and interventions are not specifically targeted to migrant and ethnic minority populations, research demonstrates that their success may be limited. This is especially the case for very vulnerable groups such as the Roma, who

⁸ Chiarenza, A. (2012). Developments in the concept of 'cultural competence.' In: Ingleby, D. et al (eds.). *Inequalities in health care for migrants and ethnic minorities*, Vol. 2. COST Series on Health and Diversity. Antwerp: Garant Publishers

⁹ Renschler, I., Cattacin, S. (2007). Comprehensive 'difference sensitivity' in health systems. In. Bjorngren-Cuadra, C, Cattacin, S. (eds). *Migration and Health: difference sensitivity from an organizational perspective*. Malmo: IMER: 37-41 (<http://hdl.handle.net/2043/4289>, accessed 28/7/14).

experience a great number of barriers to accessing health services compared to non-Roma, despite the fact that most of them are national citizens of a Member State and thus should be entitled to these services.

4. In order for health professionals at all levels of an organisation to be able to ensure equitable access to and quality of health care, they should be aware of the barriers that migrants and ethnic minorities face. Organisations should be structured in such a way that they can equip health professionals with the training, support and flexibility to tackle these barriers. However, the primary responsibility for removing barriers to access must lie with the organisations themselves and with the health system they are part of, and improvements in the quality of care cannot be made by individual health workers without the support of the whole organisation.
5. In training health professionals to work more effectively with migrants and ethnic minorities, training materials should reflect and describe the shift towards 'diversity sensitivity' (an *intersectional* approach) rather than continuing to teach a curriculum exclusively focused on 'cultural' differences.
6. Health care systems are just one of a number of health determinants, though a significant one, impacting the health outcomes of migrants and ethnic minorities. Other social determinants also play a significant role. Therefore, in order to tackle health inequalities, health professionals should work in an intersectoral way wherever possible, promoting a 'joined-up' approach to the different factors at play in the lives of migrants and ethnic minorities. In practice, this could, for example, imply close collaboration with social services, schools, families, and community organisations.
7. Developing a European framework for collaboration on migrant and ethnic minority health could encourage countries to mainstream the adaptation of health systems to the needs of these groups. Through the use of standardised tools and indicators, such as the C2ME assessments, MIPEX and Equi-Health's Country Reports (the last two from the 'Big Picture' project), countries could, for example, more easily identify gaps in training, deploy the appropriate training curriculum, evaluate training results across different indicators, and compare experiences and results with other countries in the framework.

Introduction

The challenge

Global migration is increasing and accelerating: according to the United Nations¹⁰, in 2013 there were 232 million international migrants in the world, comprising 3.2% of the total population. As a result, societies are becoming more and more diverse – culturally, ethnically, and linguistically. For Europe, as a region of destination for many migrants, this trend presents many challenges and opportunities. Absorbing these newcomers and integrating them into society has become a key priority.

Media and politics often treat the subject of migration and ethnic minorities in a negative way, and especially in the recent EU elections anti-immigration parties have made considerable gains. The fact remains, however, that many European countries have come to rely on migrants to counteract falling birth rates and ageing societies. For sender countries, remittances often make up a large share of their GDP and play a vital role in their development.

While migrants make up a part of the increasing diversity of European countries, the offspring of migrants as well as national and indigenous ethnic minorities are other groups that, though distinct, are affected by many of the same issues. For example, as we shall see below, migrants and ethnic minorities in general are more likely to live in poverty than non-migrants and the majority population. The Roma, as Europe's largest ethnic minority of approximately 11 million, experience the highest levels of deprivation in Europe. According to a 2006 United Nations report¹¹, 40% of Roma in Europe live in poverty, and 15 % in extreme poverty.

Extensive research also points to the fact that migrants and ethnic minorities face an increased risk of developing a number of chronic as well as acute health conditions, when compared to the national averages. In some countries, for example, the Roma have a life expectancy that is on average ten years less than that of non-Roma.^{12,13} In the case of migrants, while a "healthy migrant effect" is sometimes observed among newcomers, any such differences tend to be short-lived, as other factors related to life-style and living conditions may lead over time to a variety of health problems such as elevated rates of obesity, diabetes and heart disease. Although few generalizations can be made about this very heterogeneous population, when looking in detail and disaggregating age, gender and specific groups, notable differences in health patterns emerge compared to the non-migrant and majority population. Chapter 2 discusses the epidemiological findings in more detail.

¹⁰ United Nations, Department of Economic and Social Affairs, Population Division (2013). *Trends in International Migrant Stock: The 2013 Revision*. New York: UN.

¹¹ United Nations Development Programme (2006). *At Risk: Roma and the Displaced in Southeast Europe*. Bratislava: Regional Bureau for Europe.

¹² Matrix Knowledge (2014). *Roma Health Report*. Consumers, Health and Food Executive Agency and DG SANCO.

¹³ Simko, V., Ginter, E. (2010) Short life expectancy and metabolic syndrome in Romanies (Gypsies) in Slovakia. *Central European Journal of Public Health*, 18 (1): 16-18.

Moreover, many of these inequalities in health are on the rise. Migrants and ethnic minorities tend to suffer from multiple forms of disadvantage, and this is a major factor influencing their health. As a result, especially in times of crisis when socioeconomic inequalities are increasing, they face even greater inequalities in health. As a result of 'austerity' policies, the most vulnerable groups in society absorb the main impact of spending cuts and privatisation in the public services sector – in particular when these policy measures limit access to key services such as health care.¹⁴ Recent research on the state of public health services in EU member states hardest hit by austerity, such as Greece, confirms that it is the most vulnerable populations who are most exposed to the adverse effect of public spending budget costs on health.¹⁵

With regard to irregular or 'undocumented' migrants, the global economic crisis has led to greater inequalities between countries at an international level, while restrictions on migration have also increased because migrants are seen to compete for scarce jobs. As the 'push' factors for migration get stronger, and the restrictions on migration are tightened, the number of irregular migrants goes up. Such migrants, because of the precariousness of their situation as well as the perilous journeys many have made to reach the EU, are often found to be in ill-health and to experience difficulties and poor quality when accessing health services.^{16, 17}

Health service providers and health professionals in the front line may not always be prepared or feel knowledgeable enough to be able to take into account the differences in culture, religion, language, socioeconomic status embodied by some of the patients they come into contact with. Research strongly suggests that the work practices of a great number of health professionals continue to be informed by stereotypical perceptions of migrants and ethnic minorities, and to include questionable methods such as using family members as interpreters.¹⁸ An EU funded project entitled 'Best Practice in Health Care Services for Immigrants in Europe' (EUGATE) (see Appendix VI for more details) found that health professionals, to a great extent, consider training and knowledge about cultural sensitivity, entitlements to health care, and collaboration with interpreters and social services, to be necessary to improve the quality of health services delivered to migrants and ethnic minorities.¹⁹

¹⁴ Eurofound (2013). *Impacts of the crisis on access to healthcare services in the EU*, Dublin.

¹⁵ Kentikelenis, A. et al. (2011). "Health Effects of the Economic Crisis: Omens of a Greek Tragedy." *The Lancet*: Volume 378, Issue 9801, 1457 – 1458.

¹⁶ Cuadra, CB. (2011). Right of access to health care for undocumented migrants in the EU: a comparative study of national policies. *European Journal of Public Health*, Vol. 22, No. 2, 267-271.

¹⁷ Suess, A. et al. (2014) The right of access to health care for undocumented migrants: a revision of comparative analysis in the European context. *European Journal of Public Health*, 1-9.

¹⁸ Durieux-Paillard, S. "Differences in language, religious beliefs, and culture: the need for culturally responsive health services." In Rechel, B. et al (Eds.) (2011). *Migration and health in the European Union. European Observatory on Health Systems and Policies Series*. Maidenhead: McGraw Hill.

¹⁹ Priebe et al. (2011). Good practice in health care for migrants: Views and experiences of care professionals in 16 European countries. *BMC Public Health*, 11:187.

Responding to the challenge

In order to properly address the health inequalities experienced by migrants and ethnic minorities in Europe, there is a growing consensus (described in Chapter 3) that the increased health risks to which they are exposed have to be identified and the underlying causes investigated. This requires changes in the way health data are routinely collected, as well as increased research efforts. The determinants of ill-health that are discovered need to be tackled through prevention, health promotion and the implementation of intersectoral migrant health policies, addressing the needs of individual migrant groups, as well as the wider social determinants of health.^{20,21} A further challenge lies in identifying the problems migrants and ethnic minorities often experience in gaining adequate and timely access to health services, as well as the shortcomings that exist in the quality and appropriateness of the services they receive. As far as health services are concerned, these groups all too often provide an illustration of the “Inverse Care Law” formulated in 1971 by Julian Tudor Hart²²: “the availability of good medical care tends to vary inversely with the need for it in the population served”.

All these tasks require substantial capacity building concerning knowledge and expertise on the challenges posed by increasingly diverse populations and the health problems they face. Health systems must improve their understanding of how best to protect the health of migrants and ethnic minorities within their borders and to meet their needs for adequate care. In this review we will attempt to summarise the most important issues in the study of migrant and ethnic minority health, and to review the current ‘state of the art’ in regard to our knowledge about these issues. The review will highlight in particular issues to which attention needs to be paid in training courses aimed at health professionals who deal with migrant and minority populations in mainstream health care services.

The development of concern for migrant and ethnic minority health

The topic of migration and health did not become a significant item on the European research and policy-making agenda until the last quarter of the 20th century. However, efforts to understand these issues did not appear overnight. Since colonial times, academic centres in Europe have studied tropical medicine, medical anthropology, *Ethnomedizin* and similar topics in Third World countries. As the number of migrants in Europe increased after World War II, many of these centres started trying to apply their knowledge to issues of migrant health. Another influence came from across the Atlantic: during this period the intensive concern with minority health in the USA, ignited by the Civil Rights Movement and the Civil Rights Act in the 1960’s, also had considerable influence on European work on migrant health (especially through the notion of ‘cultural competence’). However, it is important to note that this American work dealt with ‘race and ethnicity’ rather than migration status as such. With the exception of the UK, European

²⁰ Rechel, B. *et al.* (2013). Migration and health in an increasingly diverse Europe. *The Lancet*: Vol 381.

²¹ Council of the European Union. (2010). *Council conclusions on Equity and Health in All Policies: Solidarity in Health*. 2010. http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lssa/114994.pdf (accessed Oct. 7, 2014).

²² Hart, J.T. (1971). The inverse care law. *The Lancet*, Volume 297, Issue 7696, Pages 405 – 412.

countries tend to view the term 'race' with downright disapproval, and 'ethnicity' with considerable ambivalence; on the European continent the focus has mainly been on migrants as such.

The development of knowledge and expertise in Europe concerning migrant and ethnic minority health shows wide disparities between countries. Training programmes need to take account of these differences and to facilitate the transfer of appropriate knowledge and 'good practices' from countries in which they are well-developed to those in which they are scarce (see Chapter 6 for a proposed European framework for collaboration on migrant and ethnic minority health). Moreover, two EU level initiatives, Culturally Competent in Medical Education (C2ME) and the 'Big Picture' project of ADAPT (see Chapter 3) will assist in identifying the need for training and the topics which require particular attention, given the diverse challenges faced in each country (e.g. number of migrants, nature and needs of the migrant and ethnic minority population, and the level of existing expertise and provisions). Concerning Roma, we see that the most concern about their health problems has arisen in countries with large populations of Roma. Even in these countries, however, it is only since the late 1990's that Roma health has become an important item on the research and policy agenda (see Chapter 3).

Not only does the *number* of migrants influence the attention paid to migrant health: the *type* of migration also influences the particular health issues that are focused on in each country. For example, there are striking differences between the work on migrant health found in different regions of Europe. In North-west Europe, the migrants of the 1950's and 1960's have now reached old age: many of them are particularly liable to the chronic non-communicable diseases (e.g. diabetes, cardio-vascular disorders and cancer) that are common among the elderly. As a result, the UK and Germany (for example) have built up substantial expertise on these topics. Quite different kinds of expertise are sought after in countries on the Southern borders of Europe, in particular those experiencing an influx of irregular migration from other parts of the world. Here, infectious disease, sexual and reproductive health, and the effects of destitution and detention are a greater cause for concern than the problems of old age. Another illustration is the case of Sweden, which from the 1970's onwards became home to large numbers of refugees; here, special attention has been paid to the health problems that accompany forced migration.

Chapter 1: Migrants and ethnic minorities in Europe

1.1. Definition of a migrant

The UN, World Bank, OECD and EU define an (international) migrant as “a person who changes his or her country of usual residence”.²³ ‘Usual residence’ is defined in different ways by different countries, but a person staying only a few months (usually up to three) will normally be classed as a ‘visitor’ rather than a ‘migrant’. An exception may apply to short-term migrants employed in agriculture for seasonal work.

Migrants may remain in the host country (‘settlers’), move on to another country (‘transit migrants’), or move back and forth between home and host countries (‘circular migrants’). As we will see in this chapter, such patterns of migration are constantly shifting: stereotypical assumptions about migrants, their numbers and patterns of movement formed in one period may be quite misleading in another period.

The definition of ‘migrant’ used in this report is explained below. In population registers, two criteria may be used for identifying persons who have changed their country of usual residence: *country of birth* and *nationality*.

a. ‘Foreign-born’ or ‘foreigner’?

- Nationality is an unreliable indicator because migrants may acquire the nationality of the country to which they have moved. Moreover, since not all children born to migrant parents in the EU acquire the nationality of the host country as a birthright (*jus soli*), some of these children can be natives of the host country while being denied its nationality. They are then classified as ‘foreigners’ despite the fact that they may never have set foot outside their country of birth.
- Country of birth is also an imperfect indicator of migration because it overlooks ‘return migration’ (when a person returns to their country of birth after a long period abroad). Despite this, ‘country of birth’ is generally regarded as a more reliable indicator than ‘nationality’.

UN statistics on migration relate to “the number of people living in a country or area other than that in which they were born. If the number of foreign-born was not available, the estimate refers to the number of people living in a country other than that of their citizenship”²⁴. Most epidemiological research also uses country of birth to identify migrants, only using nationality when country of birth is not available.

²³ UN (1998). *Recommendations on Statistics of International Migration – Revision 1*. United Nations Publication ST/ESA/STAT/SER.M/58/ Rev.1, New York.

²⁴ UN DESA (2010) *Migration Profiles Common Set of Indicators*.

http://esa.un.org/MigGMGProfiles/Definitions%20and%20Sources/definitions_sources.htm

Though definitions do not differ significantly between UN agencies and the EU, there are nevertheless important differences in the way migration statistics are presented.

- Whereas UN agencies combine statistics on ‘foreign-born’ and ‘foreign’ in the same dataset (cf the above quotation), Eurostat presents statistics based on the two indicators in separate datasets. We have also kept the indicators separate, but report only figures for ‘foreign-born’.
- UN agencies present mid-year estimates of migrant stock, while Eurostat presents annual totals at 1st January. This report uses Eurostat data on migrant stock.
- We do not, however, follow the convention which Eurostat introduced in 2011 for reporting the total of migrants in the EU as a whole, in which migrants from other EU member states are not regarded as coming from ‘foreign countries’. Unlike the totals for individual countries, Eurostat’s grand total for the EU27 (data set **migr_pop3ctb**) refers only to migrants from outside the EU. In effect, this convention treats the EU as a single country and regards migration within the EU as internal, not international. By contrast, the totals we give for migrants in the EU are arrived at by summing the totals in the separate member states.

b. Long-term, short-term or neither?

The 1998 UN recommendations proposed that the category of migrants should be further subdivided into ‘long-term’ and ‘short-term’ migrants. “A long-term migrant is a person who migrates for a period of at least one year. A short-term migrant, on the other hand, is a person who moves to a country other than that of his or her usual residence for a period of at least three months but less than one year, except in cases where the movement to that country is for purposes of recreation, holiday, visits to friends and relatives, business, medical treatment or religious pilgrimage. The nature of the duration measure – whether it is the expected duration of stay, the duration of the permit granted upon entry or the actual duration of stay in the host country – is not specified”.²⁵

In the global context migration statistics may be compiled in many different ways, using a one-year criterion, a three-month criterion, or other criteria based on national policies. In the past, migration statistics in EU countries were also based on varying criteria, but since the implementation in 2008 of EC regulation 862/2007²⁶ member states have been required to submit migration statistics based on the above definition of ‘long-term’ migrants. As a result, EU statistics on migration ignore ‘short-term’ migrants, though it should be borne in mind that with changing patterns of migration, substantial numbers of migrants may be overlooked in this way^{27,28}.

²⁵ Lemaitre, Georges (2005). “The Comparability of International Migration Statistics – Problems and Prospects”, *OECD Statistics Briefs*, July 2005, No. 9. Organisation for Economic Co-operation and Development, Paris.

²⁶ <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2007:199:0023:0029:EN:PDF>

²⁷ Thierry Xavier, Herm Anne, Kupiszewska Dorota, Nowok Beata and Poulain Michel (2005), *How the UN recommendations and the forthcoming EU regulation on international migration statistics are fulfilled in the*

1.2. Different types of migrants

The main classifications we shall use in this section are as follows.

Labour migrants and students

Migrants with a residence permit issued for purposes of work or study may be divided into those originating in EU/EEA countries and those from other countries ('third-country nationals', referred to from here on as TCNs). In general, EU/EAA migrants enjoy more rights than TCNs, including their rights to access healthcare. However, EU national minorities with migrant backgrounds, such as the Roma, often face significant barriers in accessing healthcare.

Migrants arriving for family reunification or formation

International conventions safeguard the right to family life and many migrants enter on these grounds. In the wake of the 1973 oil crisis and the subsequent recession, most European countries severely restricted labour migration from 'non-Western' countries, so that family reasons (together with asylum-seeking) became the main grounds for migration from those countries.

Prior to 1973, many unskilled labour migrants were recruited in European countries as 'guest workers' to remedy shortages of unskilled labour. For various reasons, a large proportion of them (especially those coming from outside Europe) did not return to their home countries. This group and their offspring are of particular concern today because their socioeconomic status (SES) usually remained low. Although their offspring tend to fare better, many have remained in a disadvantaged position²⁹.

Asylum seekers

Asylum seekers are persons applying for refugee status under the 1951 Geneva Refugee Convention. Those not granted this status may be awarded another (generally weaker) form of 'subsidiary' or 'humanitarian' protection; otherwise they will be required to leave the country. An unknown number, however, do not do so and continue to live in the country as irregular migrants.

There are wide variations in the number of asylum seekers coming to any given country, reflecting changing patterns of international humanitarian crises, the country's readiness to grant asylum or subsidiary/ humanitarian protection, and the country of origin of arriving asylum seekers. In 2013, Germany, France, Sweden, the United Kingdom and Italy registered

25 EU countries. Paper presented at the XXV International Population Conference-UIESP, in Tours, 18th-23th July 2005, 24 p.

²⁸ EU definitions of 'migrant' can be found at the following locations:

http://ec.europa.eu/dgs/home-affairs/e-library/glossary/index_m_en.htm

http://ec.europa.eu/dgs/home-affairs/what-we-do/networks/european_migration_network/glossary/index_m_en.htm

²⁹ Liebig, T., Widmaier, S. (2009). "Children of Immigrants in the Labour Markets of EU and OECD Countries: An Overview." OECD Social, Employment and Migration Working Papers no. 97.

70% of all applicants³⁰. In Section 1.4 we will describe changes in the influx of asylum seekers to Europe.

Irregular migrants

This term is coming to be favoured over the term ‘undocumented migrant’ (UDM), since ‘irregularity’ is more often associated with having the ‘wrong’ papers than with having no papers at all. The term ‘illegal migrant’ is strongly disapproved of by international authorities, because it conflicts with the principle of equality before the law. No-one can be ‘illegal’ because of who they are.³¹ Some writers find the term ‘migrants in an irregular situation’ less stigmatising; for the sake of brevity, we refer to irregular migrants.

‘Irregularity’ may arise because of entry without a valid entry permit, or residence without a valid residence permit. However, asylum seekers are exempted from penalties by the 1951 Geneva Refugee Convention “provided they present themselves without delay to the authorities and show good cause for their illegal entry or presence”³². In some situations, *either working or being unemployed* may invalidate a residence permit; estimates of irregular migration will therefore vary according to the extent to which they take violations of labour regulations into account³³. Bureaucratic delays and errors may also result in ‘irregularity’.³⁴

In the following sections we shall describe the development of post-war migration to Europe and present a number of statistics relating to migrants. We then examine briefly the demographic characteristics of migrants (sex, age and socioeconomic position).

1.3. Development of migration in Europe

In order to quantify migration, several different measures can be used. Firstly, we can consider either the annual rate of immigration to a country, or the total of ‘migrant stock’ (foreign-born residents) in that country at a certain point in time. If the rate of immigration is studied, this may also be expressed as a ‘net rate’, i.e. after subtracting the number of emigrants each year. In this report we focus on migrant stock, because this gives an indication of the size of the challenge for health systems.

Development of post-war migration to Europe

Migration to Europe has developed in very different ways in different countries – firstly in terms of the moment at which it started to increase, secondly in terms of its volume, and thirdly in terms of the types of migration involved. Training programmes must always bear in mind these differences in the history, quantity and nature of migration flows. In what follows we give a brief sketch of the main changes since World War Two.

³⁰ Eurostat (2014). *Eurostat Newsrelease 46/2014 – 24 March 2014*. Luxembourg: Eurostat.

³¹ PICUM Policy Brief. “Symptom, not the problem.” April 2007.

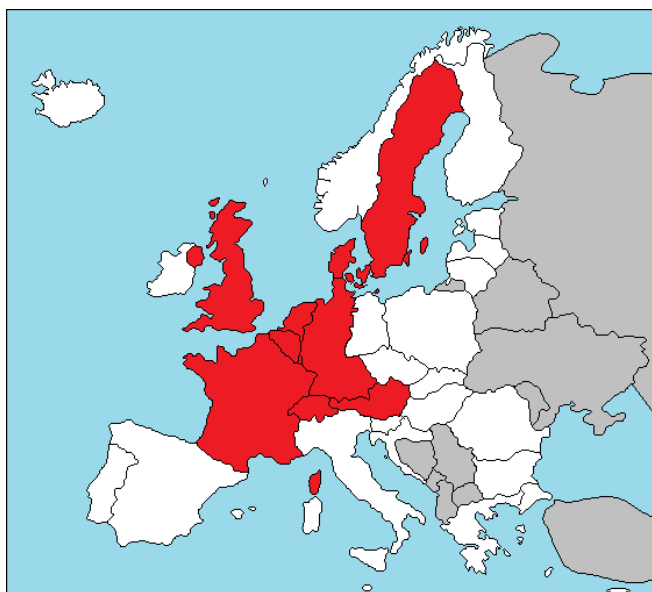
³² 1951 Geneva Refugee Convention, Article 31 (1).

³³ Vogel, D. (2009). *Size and development of irregular migration to the EU*. Athens, Hellenic Foundation for European and Foreign Policy

³⁴ *ibid.*

Labour migration, in particular, tends to follow economic growth: a basic ‘pull factor’ for migration is the need for labour in a given country. Economic growth in Europe has not taken place uniformly, but has proceeded in phases. Figure 1 identifies (in red) the countries which experienced rapid economic growth and net immigration in the first phase (the 1950’s and 1960’s)³⁵.

Figure 1 Economic growth and immigration in Europe beginning in the 1950’s and 1960’s



This phase of European immigration mainly involved ‘guest workers’ from Southern Europe, Turkey and North Africa, as well as migrants from European colonies or ex-colonies. Migration to Sweden was primarily from other Scandinavian countries. Labour migration to these countries helped to power the phenomenal economic growth that took place in them from the 1950’s until the oil crisis of 1973. ‘Guest workers’, as the name implies, were only meant to stay temporarily, so no effort was made to help them integrate, for example through integration programmes or language courses. However, many of them never returned to their country of

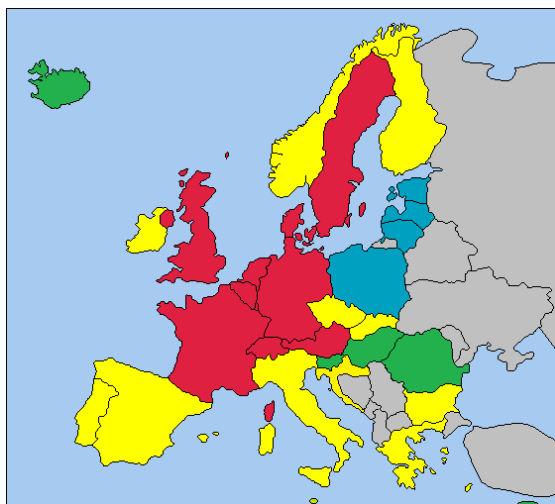
origin, but instead settled down and were joined by their families.

Another component of migration to Europe in this period was ‘post-colonial’ migration. As a result of decolonisation, many settlers, administrators, military personnel and their families returned – sometimes in great haste, sometimes gradually – to Europe. Many were returning to their country of birth and were thus ‘return migrants’. However, in the wake of decolonisation many citizens of former colonies also migrated to Europe, often making use of citizenship rights or favourable visa arrangements they enjoyed as former colonial subjects. The boundary between post-colonial and labour migration is therefore very indistinct. Of course, this type of migration is confined to former colonial powers such as the UK, France, Netherlands, Belgium, Spain, Portugal and Italy. Such migrants generally enjoy an advantage in terms of familiarity with the culture and language of the host country.

³⁵ Countries outside the present EU28/EEA and Switzerland are shaded grey. Internal immigration within the former Soviet Union is not considered. Sources for Figures 1-3: Gropas, R. & Triandafyllidou, A., Eds. (2012). *European Immigration: A Sourcebook*. Farnham: Ashgate; Wanner, P. (2002). *Migration trends in Europe. European Population Papers Series No. 7*. Strasbourg: Council of Europe; UN DESA (2013). *Trends in International Migrant Stock: The 2013 Revision*.

When economic growth slowed down in the 1970's – a process exacerbated by the 1973 oil crisis – severe restrictions were placed on labour migration from non-Western countries; as noted earlier, family reunion (or formation) and asylum-seeking became the main grounds for migration from these countries. During the 1980's and 1990's, however, a new group of European countries (marked in **yellow** in Fig. 2) experienced increasing immigration.

Figure 2 Economic growth and immigration in Europe beginning in the 1980's and 1990's



Almost all these countries had previously been characterised by *emigration*. Economic growth and immigration in Greece, Portugal and Spain was stimulated by these countries' transition to democracy in 1974-1975 and accession to the EU in the 1980's. Finland (like Sweden) joined the EU in 1995, while net migration to Norway also increased in the 1980's and 1990's. In the 1990's, after these countries gained independence from the Soviet bloc, a positive migration balance was recorded in Bulgaria, the Czech Republic and Slovakia.

How did these developments affect the growth of concern for the health of migrants? There were, and still are, great differences in the amount of attention paid to this issue. In the first period, attention focused mainly on the 'guest workers': their work was typically accompanied by increased health risks³⁶ and their encounter with the health services was complicated by linguistic and cultural barriers. In response to concern voiced by health professionals, the first conference on Migrant Health was organized in The Hague in 1983 by the Dutch Government and the WHO Regional Office for Europe³⁷.

However, some countries were very slow to realise the importance of these issues. In a pioneering article published in 1992, Bollini³⁸ found a sharp contrast between countries adopting a 'passive' attitude (expecting immigrants to adapt to the health system designed for the 'native' population) and those with an 'active' policy (acknowledging the problems and

³⁶ Bollini, P., & Siem H. (1995). No Real Progress Towards Equity: Health of Migrants and Ethnic Minorities On The Eve of the Year 2000. *Social Science & Medicine* (41)6, 819-828.

³⁷ Colledge, M., Van Geuns, HA., Svensson, PG., eds. (1986). *Migration and health: towards an understanding of the health care needs of ethnic minorities. Proceedings of a consultative group on ethnic minorities* (The Hague, Netherlands, November 28–30, 1983). Copenhagen, WHO Regional Office for Europe.

³⁸ Bollini, P. (1992). Health Policies for Immigrant Populations in the 1990s. A Comparative Study in Seven Receiving Countries. *International Migration*, Vol. 30 (Special Issue: Migration and Health in the 1990s), 103-119.

undertaking action). In the first category (e.g. France, Germany and Austria) very little was done, apart from a few local and temporary initiatives. Among the 'active' countries, the Netherlands and Sweden adopted 'multicultural' integration policies in the 1970's and, in keeping with these policies, devoted much attention to migrant health. At the same time the UK, with its strong postcolonial and transatlantic ties, developed its own approach to diversity in health care based on 'race' and 'ethnicity'. We can conclude that having large numbers of migrants may be a necessary condition for the development of interest in their health, but it is not a sufficient one.

In the countries marked in yellow in Fig. 2, the response to an increase in migration was in some cases very prompt. Spain and Portugal granted all migrants – even irregular ones – access to their health systems; data on migrant health were collected and targeted policies were introduced. Norway and Finland also showed concern for the health of migrants, but in some countries the problem is left in the hands of the NGOs.

To conclude this brief review, countries which have experienced an increasingly positive migration balance since 2000 are shown in **green** on the map in Fig 3, while countries whose balance has remained (or become) negative are shown in **blue**.

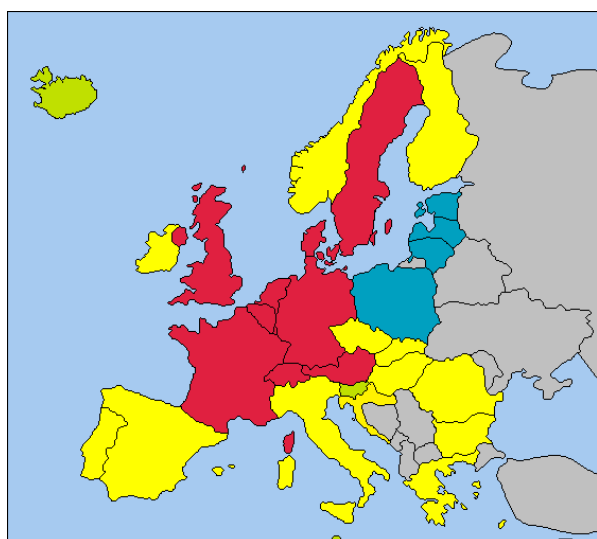


Figure 3 Economic growth and immigration in Europe after 2000

Many political, demographic and economic changes have taken place in this period. Thirteen countries, most of them in Eastern and Central Europe and the Baltic region, joined the EU between 2004 and 2013. This had complex effects on migration. It made these countries more attractive for asylum seekers and irregular migrants, many of whom hoped to move on to Western Europe; it encouraged more of their nationals to emigrate to other EU countries; and in some cases it led to a certain amount of immigration from other

EU countries. Iceland and Ireland enjoyed dramatic economic growth, followed by equally dramatic crashes resulting from the 2007 financial crisis. These developments were mirrored in those countries by a sharp influx of migrants, followed by a (less pronounced) outflow. In the entire European area, the crisis has affected migration in complex ways.

Concerning asylum seekers and irregular migrants (so-called 'mixed migration flows'), worsening economic, climatic and political conditions in many non-European countries have led to an increase in recent years. The most conspicuous illustration of this is the large number of 'boat people' crossing the Mediterranean to Southern Europe. At the same time – often in response to measures to deter the boat traffic – mixed migration over land across Europe's Eastern borders has increased. This has presented new challenges to the health systems of the countries involved.

As we mentioned in the Introduction, the prolonged economic crisis which hit the EU after 2007 has had far-reaching consequences for the health of migrants. In many countries, policies have been adopted which have simultaneously weakened the social position of migrants and limited their access to health care. Anti-immigration sentiment has increased, health and social services have been cut, while already since the turn of the century 'multiculturalism' has been under attack from politicians of all persuasions.

All this would provide a serious setback to efforts to increase attention for migrant health, but it has been countered by another important development: the growth of international initiatives to promote 'health equity' in general, and better health for migrants and ethnic minorities in particular. Since 2000 increasing efforts have been made to link up initiatives in different countries and to further the exchange of knowledge and expertise about migrant health on a European level. In Chapter 3 we will describe these initiatives in more detail.

The changing nature of international migration

Two recent trends in international migration are highly relevant for the issue of migration health. Firstly, whereas most migrants traditionally tended to be 'settlers', there has been an increasing shift toward 'circular' or 'transient' migration³⁹. Circular migration may involve regular trips back and forth between the host country and the home country: improved transportation facilities play an important role. This pattern is particularly characteristic of EU migrants and has major consequences for policies concerning integration and social protection. Ties with the home country may remain very strong. The EU Directorate General for Home Affairs published a report on the assessment of integration outcomes, using a series of indicators (the 'Zaragoza' Indicators) in the areas of employment, education, social inclusion and active citizenship that are meant to facilitate the evaluation and improvement of integration policies.⁴⁰

The other phenomenon to note is what Vertovec⁴¹ calls 'super-diversity'. Whereas fifty years ago the numbers of countries sending and receiving migrants was fairly limited, today there is hardly a country in the world which is not affected by migration. In the major capitals of Europe, hundreds of different languages may be spoken. Within each migrant nationality there will also be a great deal of diversity in (for example) educational levels, skills, ages, religions, ethnicities, and many other characteristics that have traditionally been assumed to be homogenous. Approaches to migrant health developed in the previous century may need radical revision in order to encompass 'super-diversity'.⁴² We will return to this topic in Chapter 5.

³⁹ Newland, K. (2009). *Circular Migration and Human Development*, Human development research paper 2209/42, UNDP

⁴⁰ Huddlestone, T., Niessen, J., Tjaden, J.D. (2013). Using EU Indicators of Immigrant Integration. DG HOME Final Report. http://ec.europa.eu/dgs/home-affairs/e-library/documents/policies/immigration/general/docs/final_report_on_using_eu_indicators_of_immigrant_integration_june_2013_en.pdf (Accessed on 20 February, 2015).

⁴¹ Vertovec, S. (2010). Towards post-multiculturalism? Changing communities, conditions and contexts of diversity. *International Social Science Journal*, 61: 83–95.

⁴² Chiarenza, A. (2012). Developments in the concept of 'cultural competence.' In: Ingleby, D. et al (eds.). *Inequalities in health care for migrants and ethnic minorities*, Vol. 2. COST Series on Health and Diversity. Antwerp: Garant Publishers

1.4. Statistics on migration

In this section we will mention some important statistics at European level concerning migration. More detailed figures are given in Appendix I.

1.4.1. Total migration

At the beginning of 2013, the total of migrant stock in the EU27 was 50,872,674, i.e. 10.1% of the total population⁴³. (Figures for the EU28, i.e. including Croatia, relate to the period after 1st January 2014 and are not yet available). Maps presented in Appendix I show the variations in the percentage of migrants in each country.

1.4.2. Asylum claims

Figure 4 Variation in asylum claims lodged in 44 industrialized countries 1990-2012



Figure 4 shows fluctuations in asylum claims between 1990 and 2012.⁴⁴ Figures for 2013 (not shown) continued the increase that started in 2010 and reached the highest level in Europe for a decade⁴⁵. (Note that the definition of 'Europe' in this graph includes 38 countries). The main countries of origin of asylum seekers were Syria, Russian Federation, Afghanistan, Iraq and Serbia/Kosovo .

⁴³ Source: Eurostat [migr_pop3ctb]

⁴⁴ UNHCR (2013). *Asylum Trends 2012. Levels and Trends in Industrialized Countries*. New York: United Nations High Commissioner for Refugees.

⁴⁵ UNHCR (2014). *Asylum Trends 2013. Levels and Trends in Industrialized Countries*. New York: United Nations High Commissioner for Refugees.

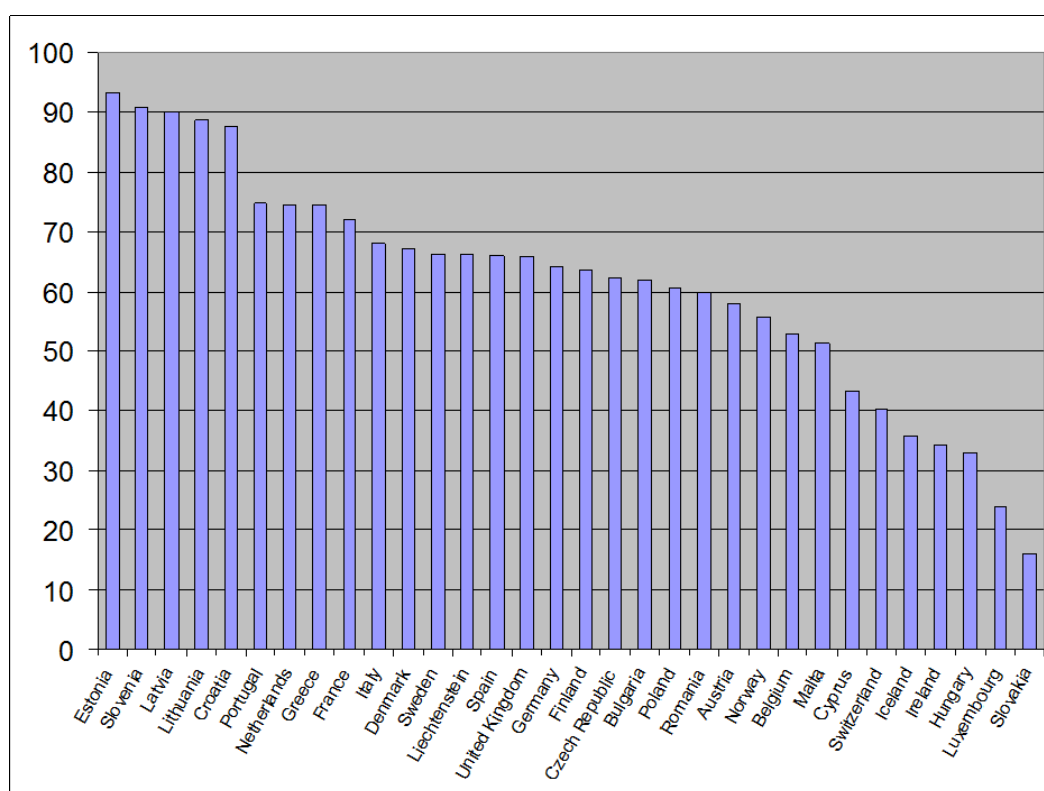
1.4.3. Irregular migrants

Contrary to popular assumptions, only a small proportion of irregular migrants are ‘unauthorized entrants’. Of the estimated 5 to 8 million irregular migrants in Europe, most have overstayed their visas or remained in the country after their asylum application failed.⁴⁶ Numbers of irregular migrants are intrinsically hard to estimate, but this group is estimated to make up approximately 1% of the population of the EU⁴⁷. In certain countries, regularization campaigns reduce the total numbers from time to time.

1.4.4. Proportion of EU migrants and ‘Third Country Nationals’

In the EU27 as a whole, 6.7% of migrant stock comprised persons born in another EU country in 2013, while 3.4% were third-country nationals. Detailed figures are given in Appendix I. The following figure shows the relative proportions of EU migrants and TCN’s in 2013, in EEA countries and Switzerland as well as the EU27.

Figure 5 Percentage of migrants who are third-country nationals (2013) ⁴⁸



⁴⁶ <http://picum.org/en/our-work/who-are-undocumented-migrants/>

⁴⁷ Düvell, F. (2009). *Irregular migration in northern Europe: overview and comparison*. Oxford, University of Oxford Centre on Migration, Policy and Society

⁴⁸ Source: Eurostat [migr_pop3ctb]

It can be seen from Fig. 5 that in 25 countries third-country nationals (TCN) predominate, whereas in 7 countries most of the migrants originate from other EU countries.

Regarding the first group, one reason for the high percentage of TCNs in Estonia, Latvia and Lithuania is the inclusion in the category 'migrants' of many people born in other former Soviet republics who were living in the country at the time of the break-up of the Soviet Union after 1989. Within the Soviet Union they had been 'internal migrants'; suddenly they found themselves reclassified as 'international migrants'. From a scientific point of view, there may be a case for reclassifying these so-called 'statistical migrants' as members of a national minority rather than migrants; however, scientific considerations do not always coincide with political ones.

1.5. Demographic characteristics of migrants

1.5.1. Gender

Women make up approximately half of the migrants in Europe (50% in 2013 according to Eurostat).⁴⁹ However in some countries, female migrants outnumber males, e.g. Cyprus, Italy, Spain and Ireland. Research has shown that a great number of female migrants are domestic workers or personal care workers, and that these forms of employment often expose the migrants to exploitation and abuse from employers, leading to possible health inequalities. The vulnerability of domestic labour migrants is compounded by the fact that in many countries, domestic work is not classified as a form of employment for the purpose of obtaining a work permit, thus forcing domestic workers into irregular conditions without a legal residence permit. As such, they are more vulnerable to face exclusion from access to health services and other social welfare services.⁵⁰ In Chapter 2 we present more detailed findings showing the role gender plays in health outcomes for migrants and ethnic minorities, as well as gender specific health and health care access issues affecting certain migrant and ethnic minority groups, e.g. maternal and child health, and female genital mutilation and cutting (FGM).

1.5.2. Age

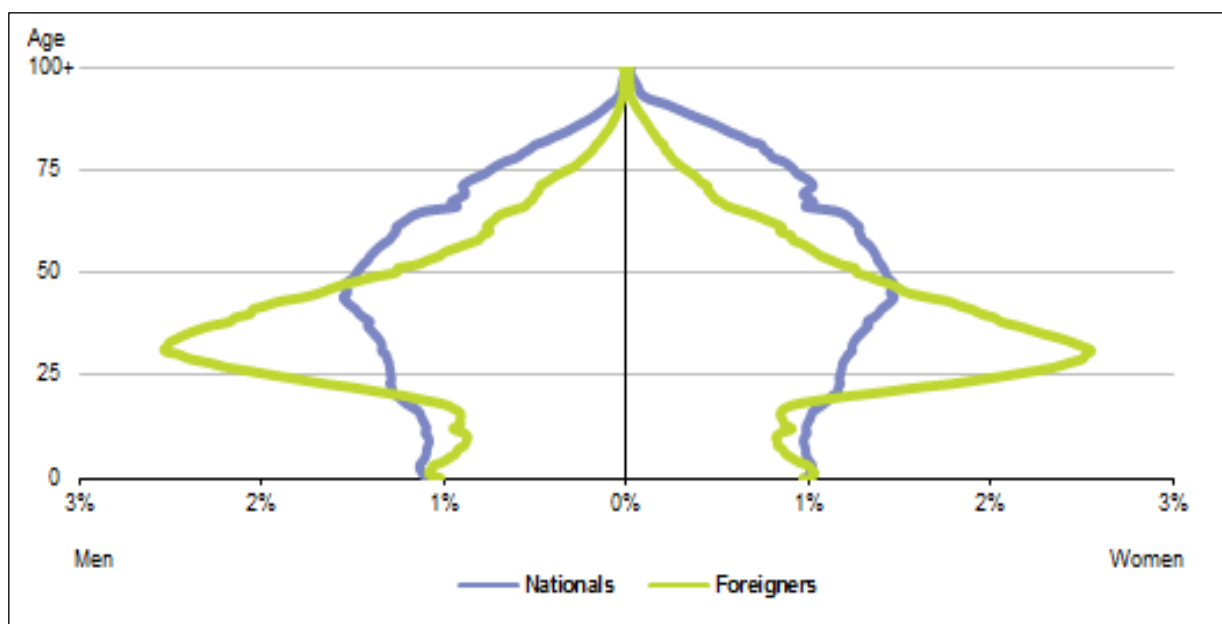
In general, migrants tend to be younger than the native population. This phenomenon is especially pronounced in the EU, with its rapidly ageing 'native' population. Indeed, without migration there would be steadily fewer younger people working and paying taxes to support the elderly and retired (whose need for social support and healthcare is much greater). Moreover,

⁴⁹ Flanders, O.A. (2011). Immigration to EU Member States down by 6% and emigration up by 13% in 2008. Eurostat, available at <http://bit.ly/1tRsWGm>

⁵⁰ Kouta, C., Kaite, C. (2012). Health issues among female migrant domestic workers. In: Ingleby, D., et al (eds). *Health inequalities and risk factors among migrants and ethnic minorities*, Vol. 1. COST Series on Health and Diversity. Antwerp: Garant Publishers.

migrants themselves will tend to consume less health care than natives: the highest costs⁵¹ are incurred in early childhood and old age - categories in which migrants are under-represented. The following 'population pyramid' shows the distribution of age differences.

Figure 6. Age structure of the national and non-national population, EU-27, 1 January 2012 (%)



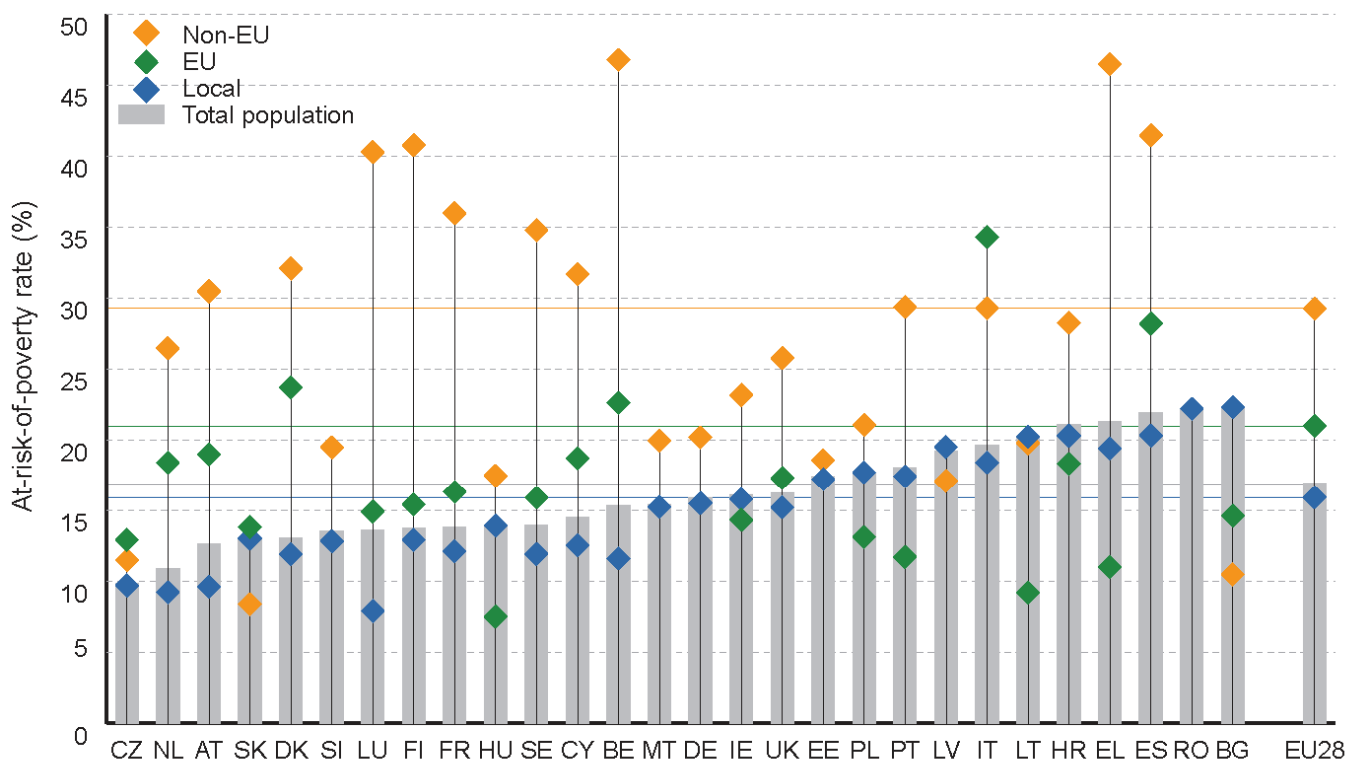
Source : (Eurostat, <http://bit.ly/1qfH8dC>)

1.5.3. Socioeconomic position

On average, the socioeconomic status (SES) of migrants is lower than that of 'native-born' people, though it may actually be higher in some groups and there are marked individual differences⁵². The following graph shows migrants' risk of poverty in 2010.

⁵¹ Yamamoto, D.H. (2013). *Health Care Costs – From Birth to Death*. Schaumburg, Illinois: Society of Actuaries. http://www.healthcostinstitute.org/files/Age-Curve-Study_0.pdf

⁵² Eurostat, (2011). *Migrants in Europe. A statistical portrait of the first and second generation*. Luxembourg: Eurostat.

Figure 7 At-risk-of-poverty rate among migrants, by region of origin, 2010 income year⁵³

Note: Estimates are based on a low number of observations (20-49) in Slovakia (for non-EU) and Bulgaria (for EU). Estimates for Romania (for EU and non-EU) are omitted due to a very low number of observations (<20). Data for Ireland refers to EU-SILC 2010.

Source: European Commission, Eurostat, cross sectional EU-SILC 2011 UDB August 2013

EU Social Situation Monitor

A large proportion of the health disadvantages experienced by migrants is related to their generally unfavourable socioeconomic position. However, this factor does not explain all the differences found; moreover (as we shall see) there are some respects in which certain migrant and minority groups actually enjoy lower (age-corrected) health risks.

⁵³ Source: EU Social Situation Monitor, <http://bit.ly/1x1mhgh>

1.6. Ethnic minorities

1.6.1. Definitions

The term 'ethnic minority' is used to refer to a wide range of disparate groups. Whereas the term 'migrant' can be defined quite precisely for scientific purposes, there are widely differing views about what ethnicity is, which ethnic groups exist, and who should be regarded as a member of them. For these reasons alone, it is in most countries harder to find useful data on ethnic minorities than on migrants. An additional problem is that in many countries, the collection of data on ethnic minorities is controversial. Insight into these competing conceptions, as well as the historical and political issues that underlie them, is essential for anyone seeking to understand the relationship between health and ethnicity, so we begin with an introduction to this topic

Social scientists distinguish between two contrasting approaches to ethnicity⁵⁴. The classic ('primordial') approach maintains that people can be accurately classified as members of an ethnic group on the basis of objective characteristics. 'Instrumental' approaches, by contrast, regard ethnicity as a social construction and/or an individual choice, the boundaries of which are negotiated in a pragmatic way. Within the latter approach, the views of the Norwegian anthropologist Fredrik Barth⁵⁵ have been particularly influential. For Barth, the boundaries of ethnic groups are the *outcome* as well as the *cause* of confrontations. "Rather than taking identities and boundaries for granted, Barth is concerned with understanding how difference is organized during and arises out of interaction.....thus, collective identification is inherently political".⁵⁶

One or more of the following characteristics are typically used to define the boundaries of an ethnic group.

- **Race.** Because of its association with Nazi doctrines of racial supremacy, the concept of 'race' fell into discredit after the Second World War. However, it is still used as a census category and in health surveys in the USA and UK⁵⁷. In both countries, the racial categories 'Black' and 'White' are used alongside other terms referring to geographical origin such as 'Caribbean' or 'African', or (in the USA) language community ('Hispanic'). Since 1970 in the USA and 1991 in the UK, respondents have been allowed to decide for themselves the census category to which they wish to be assigned ('self-definition'). The

⁵⁴ Scott, J.G.M. (1990). A resynthesis of the primordial and circumstantial approaches to ethnic group solidarity: towards an explanatory model. *Ethnic and Racial Studies*, (13)2, 147-71.

⁵⁵ Barth, F. (1969). *Ethnic groups and boundaries. The social organization of culture difference*. Oslo: Universitetsforlaget.

⁵⁶ De Anca, C. (2012). *Beyond Tribalism: Managing Identities in a Diverse World*. London: Palgrave Macmillan, p. 39.

⁵⁷ The EU subtitled *Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin* as the 'Racial Equality Directive'. However, no definition is given either of race or ethnic origin, and the two terms are used interchangeably

same procedure is currently followed in most European countries, though it is not uncommon for census enumerators to 'correct' the categories people choose⁵⁸.

- **Ancestry or 'heritage'**. Defining ethnicity in these terms implies not only a genetic component, but also a cultural one. A shared cultural heritage is often seen as central to an ethnic group, and its maintenance may be regarded as a question of human rights.
- **Region or country of origin**. Some ethnic groups are referred to by the area from which they or their ancestors originated. For example, migrants may be designated as 'ethnic Chinese' if they come *either* from Chinese-speaking countries *or* from one of the many countries to which Chinese have been emigrating for centuries.

Some migration is not voluntary but forced, as in the case of groups that are displaced in wartime to other countries and are subsequently unwilling or unable to repatriate. In Europe after World War Two, an estimated 11 million 'displaced persons' remained in countries to which they had fled or been transported for slave labour or extermination in concentration camps⁵⁹. Until it was amended in 1967, the 1951 Geneva Refugee Convention⁶⁰ related only to these people, many of whom settled in other countries rather than returning to their homeland.

Another type of minority may be formed by citizens of a country who are left behind when its borders are redrawn, or when – as in the case of Yugoslavia, the Soviet Union or the Austro-Hungarian Empire – it ceases to exist altogether. Still more examples are provided by colonial settlers who remain in a country after it obtains independence. All these groups may remain together and continue to speak their original language, but over time they may also be incorporated without much friction into the host society.

- **Religion**. Ethnic boundaries may be drawn in terms of the faith that a group adheres to (e.g. Jews, Muslims, Christians, Hindus).
- **Language or dialect**. Within a country, language may be regarded as the defining characteristic of an ethnic group (e.g. French-speaking Canadians or Walloons and Flemish in Belgium).
- The term **indigenous minorities** refers to groups that have been present in a country as long as the majority ethnic group – or, in the case of 'Native Americans' and 'Aboriginals', even longer.

From the above it is clear that in theory, ethnic groups can arise in a great variety of different ways. In addition, ethnic identities can intersect, giving rise (for example) to religious or linguistic subgroups within populations of a given national origin. Given the continual movement

⁵⁸ Ahmed, P., Feliciano, C. and Emigh, R. J. (2006). *Internal and External Ethnic Assessments in Eastern Europe*. On-Line Working Paper Series, California Center for Population Research. <http://escholarship.org/uc/item/7r9331q0>

⁵⁹ McDowell, L. (2005). *Hard Labour: the forgotten voices of Latvian migrant 'volunteer' workers'*. Portland: Cavendish Publishing.

⁶⁰ UNHCR, (2011). *The 1951 Convention relating to the status of refugees and its 1967 Protocol*. Geneva: Office of the UN High Commissioner for Refugees.

of peoples and national boundaries throughout history and the vast number of different religions, languages and dialects that exist, it is clear that in practice, far fewer ethnic groups are recognised as such than the number which is theoretically possible. One reason for this is that whereas some groups hold tightly together, others become incorporated relatively quickly into the mainstream.

It is therefore important to realise that although persons migrating from one country to another may form an identifiable *statistical* group, this does not mean that they also form a distinct *social* group. Though it is possible to classify people in terms of their genetic or cultural characteristics, area of origin, religion, or language, this does not necessarily mean that those who are classified in the same way are members of anything resembling a 'community', with individuals belonging to a specific social context characterised by meaningful interrelations. A great deal of health research on so-called 'ethnic groups' therefore does not study the membership of a social group at all – only the variable 'country of birth'. As Barth implies, it is mainly when struggles arise over power and privilege that membership of an ethnic group becomes a salient issue. This typically occurs when one group is perceived as a challenge to another, provoking both groups to assert and defend their identities.

Another point concerns the extent to which findings on the health of ethnic groups may differ between countries. While the same name may be used for ethnic groups in different countries, this does not mean that they can be regarded as the same group. Their migration history may be very different, as well as their patterns of integration into the host society. For example, refugees who fled to Sweden from dictatorial regimes in Latin American countries during the 1970's are unlikely to have much in common with people from the same countries who came to Spain as labour migrants during the economic boom starting in the late 1990's. In general, people migrating from former colonies to the old colonial power may be familiar with the language, education system and customs of the host country, while acculturation can be a much harder task for the same group migrating to a different European country. For example, Turkish immigrants in one European country may differ from those in another with regard to their region of origin in Turkey and the associated background characteristics and experiences.

Studies across European countries on health issues related to ethnicity are therefore difficult and methodologically challenging due to differences in definitions and available data, as well as variations in the determinants of health across 'similar' ethnic groups in different countries and within ethnic groups in each country. However, if the methodological challenges can be successfully dealt with, such cross-country studies can provide new insights into important determinants of health and the quality of health care. The Migrant Health Observatory project (MEHO)⁶¹ (2007-2009) pioneered this approach with studies of five health conditions in ethnic groups across Europe.

Results from such studies show that although country of birth predicts some of the variation in health outcomes, there are important variations between different countries of residence. These may reflect differences in the background characteristics of the ethnic minority populations in each country, their socioeconomic position, and in health policies affecting them. A cross-national study of neonatal outcomes in mothers of Turkish origin revealed differences according to whether national integration policies were 'active' or 'passive'⁶². International comparative studies on comparable ethnic groups may produce important new hypotheses on the role of

⁶¹ Main website (temporarily unavailable): <http://www.meho.eu.com>. Summary: <http://ec.europa.eu/chafea/news/news137.html>

⁶² Villadsen, S.F. *et al*, (2010). Cross-country variation in stillbirth and neonatal mortality in offspring of Turkish migrants in northern Europe. *European Journal of Public Health*, 20(5):530–535.

cultural, social and environmental factors and provide insight in the most effective organization and provision of culturally sensitive health care. Confirming hypotheses generated by such research, however, will require more in-depth studies – often based on qualitative methods in local settings⁶³.

1.6.2. Vulnerable minority groups

During the past two centuries, but mainly since 1945, a body of international human rights law has been developed to protect the rights of ethnic minorities who are nationals of the country in which they live and occupy vulnerable, disadvantaged or marginalized positions. Alongside the UN Conventions defending the rights of children, women and refugees, a number of conventions and other legal instruments have been created to protect such ‘national minorities’ from persecution and further their emancipation.

The definition of ‘minority’ used by the United Nations since 1979⁶⁴, which is also shared by EC agencies such as the FRA⁶⁵, is a group which is

numerically inferior to the rest of the population of a State, in a non-dominant position, whose members – being nationals of a State – possess ethnic, religious or linguistic characteristics differing from those of the rest of the population and show, if only implicitly, a sense of solidarity, directed towards preserving their culture, traditions, religion or language.

In line with these conventions, some countries formally recognise the existence of certain minorities living within their borders and take policy measures to protect their rights. Perhaps the most large-scale recent example of this is the ‘Decade of Roma Inclusion’, a policy initiative implemented by a group of 11 countries between 2005 and 2015 (see Appendix III).

However, recognising a group as a national minority remains the prerogative of individual States: moreover, it is not a step governments take lightly. In the words of Dieter Kugelmann:⁶⁶

States are reluctant to acknowledge rights of minorities because they try to avoid risks for their territorial integrity. The fight of minorities for their rights has given rise to armed conflicts. These dangers and experiences made minority protection one of the most complicated subjects of international law.

One reason why governments may refuse to recognise such groups is the perceived threat of separatism. As Kugelmann reminds us, the breakup of a country is often a bloody affair; it may also carry grave disadvantages for all concerned. Traditionally, the nation most resistant to the

⁶³ Salway, S., *et* (2011). Contributions and challenges of cross-national comparative research in migration, ethnicity and health: insights from a study of maternity experiences and outcomes. *BMC Public Health*, 11:514.

⁶⁴ See Caportori, F., (1991), *Study on the Rights of Persons Belonging to Ethnic, Religious and Linguistic Minorities*. New York: United Nations, para. 568.

⁶⁵ <http://fra.europa.eu/en/joinedup/about/glossary?title=m>

⁶⁶ Kugelmann, D. (2007). The protection of minorities and indigenous peoples respecting cultural diversity. In Bogdandy A.V. and Wolfrum, R. (Eds.). *Max Planck Yearbook of United Nations Law*, Vol. 11: 235.

recognition of ethnic groups – indeed, to the concept itself – has been France, on the grounds that ethnicity *in itself* threatens the ‘unity and indivisibility of the Republic’.⁶⁷

A second kind of danger which governments may perceive in ethnic minorities concerns social cohesion. The ‘cultural heritage’ of the group in question may be seen not as an enrichment, but as a threat to what the dominant majority perceives as its own culture. As political support for multiculturalism has declined in Europe⁶⁸, so has the climate for minority rights become increasingly sceptical.

Finally, it should not be assumed automatically that an ethnic minority is disadvantaged or vulnerable. Like migrants themselves, ethnic minorities resulting from migration vary greatly in their demographic characteristics. At one extreme, large numbers of poorly educated labour migrants have been recruited in certain periods and countries, for example as ‘guest workers’ during the 1960’s in Northwestern Europe. The social position of these workers was unfavourable and because they were not expected to stay permanently, little or no effort was made to help them integrate. The disadvantages of this group may persist into the second or third generation. At the other extreme, other groups (such as Indians in the UK and recent Chinese migrants in many countries) may reflect positive selection biases and have higher levels of ‘social capital’, so that they achieve even better results in terms of education and occupation than the native population. This diversity is also reflected in health outcomes, which can be better as well as worse than those of the majority population⁶⁹. On balance, however, ethnic minorities – like migrants – tend to be more often socially disadvantaged than privileged.

From the above it should be clear why there is no consensus about how many ‘ethnic minorities’ exist in Europe and how they should be defined. The answer to these questions is political rather than scientific, and it is hard to collect systematic data using concepts which by their very nature are contested.

Another tension in this field is that identifying a group as an ‘ethnic minority’ and collecting data on its members can be seen either as an instrument of oppression or of emancipation. In the worst case, registration of ethnicity can be a potential instrument of genocide or ‘ethnic cleansing’. During the Second World War, population registers in many countries made it easier for the Nazis to round up and deport Jews, Roma and other groups for extermination. After the war ended this led to widespread revulsion against the practice of ethnic registration, and in some countries the opposition continues to this day.

Supporters of ethnic registration argue, however, that without collecting ethnic data there is no way to develop evidence-based policies to help the groups in question.⁷⁰ In addition, they argue that the laws that are alleged to prohibit the collection of ethnic data are not really as far-reaching or strict as is often claimed. In 2007 the Council of Europe’s ‘European Commission against Racism and Intolerance’ (ECRI) published a survey among member states which

⁶⁷ “Unité, indivisibilité de la République, Liberté, Égalité, Fraternité ou la mort”. Motto adopted by the Republic, 22 September 1792.

⁶⁸ Joppke, C. (2007). Immigrants and Civic Integration in Western Europe. In Banting, K.G., Courchene, T.J., and Seidle, F.L. (eds.), *Belonging? Diversity, Recognition and Shared Citizenship in Canada*. Montreal: Institute for Research on Public Policy, 321–350.

⁶⁹ Bhopal R (2009). Chronic diseases in Europe's migrant and ethnic minorities: challenges, solutions and a vision. *European Journal of Public Health*, 19:2:140–143.

⁷⁰ McDonald, C., Negrin, K. (2010) *No Data No Progress – Country Findings*. Open Society Institute: Roma Initiatives Office.

concluded that such a strict interpretation of the law was ‘exaggerated’;⁷¹ the EU has adopted the same position⁷².

However, the opposition to collecting ethnic data is not purely legalistic, nor is it solely based on anxieties from the past. Today, data on ethnic minorities can be used by xenophobic and populist politicians to incite hostility against them, for example by presenting misleading statistics on health, unemployment or criminal convictions. Moreover, health workers may resent having to collect such data: this activity is sometimes seen as intruding on patients’ privacy and undermining the professional relationship with them^{73,74}

1.6.3. Which countries collect data on ethnicity in census forms and population registers?

A 2007 Council of Europe report⁷⁵ classified European countries into three main categories regarding the collection of information on ethnicity and/or language⁷⁶.

1. Most western and southern European countries are classified as ‘state-centred’, “since they make the link with the state a criterion for (political or geographical) identification.” These countries tend to register only nationality or citizenship, not ethnicity.
2. A second group comprises “the countries which emerged from the wreckage of the former Austro-Hungarian and Soviet empires (sometimes both) or which are in the Balkans”. These countries often collect ethnic data, focusing mainly on minorities formed by geopolitical upheavals.
3. A third group, ‘post-migration multicultural’, uses classifications “designed to reflect the recent history of immigration, whether post-colonial or, more traditionally, labour migration”. This group overlaps with the first one: within it, only Ireland and the UK identify ‘ethnicity’ directly using census categories. In other countries, country of birth is used as an indicator of ethnicity. When this is done, however, studies of ‘ethnic groups’ are in fact no more than studies of migrants disaggregated by origin. Only ‘first-generation’ migrants are included; no distinction is made between different ethnic groups originating from the same country, and there is no recognition of groups which may originate from several countries, such as ethnic Chinese.

⁷¹ Simon, P. (2007). *‘Ethnic’ statistics and data protection in the Council of Europe countries*. Strasbourg: Council of Europe.

⁷² European Commission, (2006). *Communication (COM (2006) 643) on the application of Directive 2000/43/EC*. Brussels: European Commission.

⁷³ Johnson, M. (2012). Problems and barriers in the collection of ethnicity and migration related data. In Ingleby, D. et al (eds). *Health inequalities and risk factors among migrants and ethnic minorities*, Vol. 1. COST Series on Health and Diversity. Antwerp: Garant Publishers.

⁷⁴ European Centre for Disease Prevention and Control (2011). *Improving HIV data comparability in migrant populations and ethnic minorities in EU/EEA/EFTA countries: findings from a literature review and expert panel*. Stockholm: ECDC.

⁷⁵ Simon, *op.cit.*, p. 37.

⁷⁶ Another survey of data-collection policies is provided in Mladovsky, P. (2007). *Migration and health in the EU*. London: LSE Research Note.

The unique system used in the Netherlands to define ethnicity also uses country of birth as a criterion, but in addition it includes the children of migrants. The category ‘allochtonous’ applies to people who were *either* born to non-Dutch parents outside the Netherlands, *or* who have at least one parent born outside the Netherlands. Use of this concept enables data to be collected on migrants and their immediate offspring: it therefore adds something to studies relating only to migration. A limitation, however, is that only the first two generations of each ethnic group are taken into account.

EU migration statistics collected by EUROSTAT include data on international migration, population stocks of national and foreign (non-national) citizens and data relating to the acquisition of citizenship in the EU-27 countries.⁷⁷ EUROSTAT data does not include statistics on ethnicity. A more recent study⁷⁸ gives the following overview of EU countries’ registration practices. The second group corresponds to category 1 of the countries surveyed in the CoE report:

- All EU countries register citizenship and country of birth
- Ethnicity is not registered in France, Germany, Belgium (Wallonia), Luxembourg, Spain, Portugal, Italy, Greece, Malta, and Sweden. Finland and Denmark only register ethnicity in the case of asylum seekers.
- No data on language: Belgium, the Netherlands, France, Germany, Portugal, Sweden, Italy, Greece.
- No data on religion: Germany, France, Luxembourg, Denmark, Sweden, Spain, Greece, Italy, Malta.

Within the discipline of epidemiology there is a strong tradition of research on ethnicity and health, but examination of what is meant by ‘ethnicity’ reveals several different meanings. In the USA and UK the term usually refers to ‘minorities’, operationalised in terms of racial, ethnic or linguistic census categories. Since the census categories are based on self-definition, they are capable of reflecting an individual’s identification with a group. In most other countries, however, ‘ethnicity’ usually refers either to membership of an indigenous group or to the country of birth of a migrant. As we have seen the latter variable is a poor indicator of ethnicity, since several different ethnic groups may originate from the same country, while some ethnic groups may originate from many different countries. A further objection is that ‘country of birth’ is a fixed and objectively defined variable, whereas group identification is a changeable subjective phenomenon that is better captured by using self-definition⁷⁹.

1.6.4. Main types of research on health and ethnic minorities in Europe

Broadly speaking, studies on ethnic minorities and health in Europe fall into four main categories:

⁷⁷ http://ec.europa.eu/eurostat/statistics-explained/index.php/Migration_and_migrant_population_statistics#Foreign_and_foreign-born_population

⁷⁸ Abdikeeva, A. (2014). *Measure, Plan, Act. How data collection can support racial equality*. Brussels: European Network Against Racism (ENAR).

⁷⁹ Bhopal, R. (2014). *Migration, ethnicity, race, and health in multicultural societies*. Oxford: Oxford University Press, pp. 78-79.

1) British studies based on (self-ascribed) census categories

Research on ethnicity in the UK resembles that in the USA, in that it is based on self-ascribed classification according to census categories. These categories do not distinguish between migrants and their descendants, still less between different types of migrant such as labour migrants, asylum seekers, refugees, or undocumented migrants. As a result, research on the health of migrants in the USA and UK is relatively underdeveloped⁸⁰.

There are copious findings relating to health among ethnic minority groups in the UK, but the extent to which they are relevant to other countries is not known. Firstly, the ethnic categories used in the UK are not used anywhere else, and it would be difficult to assemble health data on the same groups in other countries. Secondly, even if a group with the same geographical origin could be identified in another country, it might have come into being in a different way, at different times, and with different outcomes in terms of social position.

2) Studies using country of birth as a proxy for ethnicity

The use of 'country of origin' as a proxy for ethnicity creates *statistical* groups, but these do not necessarily correspond to any *social* groups; moreover, additional information must be collected in order to distinguish different ethnic groups coming from the same country⁸¹ or those that come from several countries. It may matter a lot, for example, whether a migrant belongs to the Christian, Sunni Muslim or Shiite Muslim population of Syria, or to the Creole or Hindustani population of Surinam.

In some studies, *nationality* is used as a proxy for ethnicity. However, this indicator has all the disadvantages associated with country of birth, as well as another very serious one: many migrants may acquire the nationality of the host country after a certain period. This will create biases of unknown magnitude in the results.

As with research from the UK, the relevance of such studies to the 'same' groups living in different countries is questionable. In essence, these studies are nothing other than studies of migration which take country of origin into account. They do not supplement or complement studies of migrants – rather, they *are* studies of migrants, but under a different name. Nevertheless, Dutch research is uniquely informative because it enables both migrants and the first generation of their descendants to be studied.

3) Studies of national minorities in the countries where these are recognised.

As we have seen, the recognition of national minorities (i.e. those not formed by recent migration) depends mainly on political considerations rather than scientific ones. For example, some research is available on indigenous minorities such as the Sami in Scandinavia, while Roma

⁸⁰ Jayaweera, H. (2011). *Health of Migrants in the UK: What Do We Know?* Migration Observatory Briefing, COMPAS, University of Oxford, UK, March 2011. However, the situation is changing: this is reflected in the change in the title of the second edition of Raj Bhopal's classic handbook *Ethnicity, Race, and Health in Multicultural Societies* (2007), now called *Migration, Ethnicity, Race, and Health in Multicultural Societies* (2014).

⁸¹ Stronks, K., Glasgow, I.K. and Klazinga, N.(2004). *The identification of ethnic groups in health research, additional to the country of birth classification*. Amsterdam: University of Amsterdam, Department of Social Medicine.

populations in Europe – after years of neglect – are now the focus of a great deal of research and policymaking. In Chapter 4 we discuss health research on both these groups.

However, the main ethnic minority singled out for attention in this report are the Roma. There are two reasons for this. Firstly, the group is much larger than any other ethnic minority in Europe (10-12 million), and secondly, Roma experience an extreme and persistent degree of social disadvantage and discrimination. In the words of a UNDP Human Development Report⁸², “the situation of Gypsy, Roma and Traveller groups must be seen as a scar on the human development record of European nations”. Their disadvantage extends across the fields of education, health, employment, housing and political participation.

A point we have stressed for all ethnic groups applies equally to the Roma. There may be considerable variations within and between countries in the populations studied, reflecting differences in both their historical origin and their current social position. ‘Roma health’ is therefore no more than a convenient shorthand term bracketing together results from many different groups.

4) Studies of ethnic minorities in the Baltic States, Central and Eastern Europe and the Balkans.

These countries correspond to category 2 in the Council of Europe report summarised above. In the less prosperous of these countries, emigration is much more common than immigration: few immigrants settle long enough to form significant ‘ethnic minorities’. Many of these immigrants may be unauthorised entrants in transit, hoping to reach more wealthy EU Member States. However, larger numbers of migrants settle in the more prosperous countries in this group (particularly Austria, Hungary and the Czech Republic).

Alongside the ethnic minorities formed by recent migration, and numerically often more important than them, are those which were created by geopolitical upheavals in the twentieth century.

- **Austria** recognises Croatian, Slovenian, Hungarian, Czech and Slovakian minorities (the historical origins of which lie in the Austro-Hungarian Empire), in addition to the Roma population. However, such recognition is a politically controversial issue. Separate data on the health of these populations does not appear to be collected.⁸³
- In **Latvia** and **Estonia**, large minorities were formed by former citizens of the Soviet Union who were left stateless when that nation broke up. These groups are counted by UN DESA as ‘migrants’, which explains the high percentage of migrants attributed to Latvia (13.8% in 2013) and Estonia (15.0%). However, the number of Russians who have moved to these countries since 1991 is far lower (in Latvia probably only 1-2%⁸⁴). The social position of these Russian-speaking minorities is not necessarily disadvantaged or

⁸² Stewart K. (2010). *Human Development in Europe*. New York, United Nations Development Programme (Human Development Research Paper 2010/7)

⁸³ Personal communication by Dr. Ursula Trummer, Center for Health and Migration, Vienna, 2nd January 2015.

⁸⁴ Personal communication by Mr. Ilmars Mezs (Head of IOM, Latvia), 27th October 2014.

vulnerable (their former social position was in fact relatively privileged), but Russian authorities often intervene on their behalf⁸⁵.

- In the **entire Balkan region**, large population groups were displaced by the ‘Third Balkan War’ of 1991 – 2001. While many returned to their former countries, some did not and remained to form ethnic minorities. Bosnia-Herzegovina is still divided between the Bosnian Serb republic and a federation of Bosnian Croats and Muslims.
- The Turkish minority in **Bulgaria**, which comprises about 8% of the population, could also be added to this list, although its origin lies in much earlier upheavals (the Ottoman conquest of the Balkans in the late 14th and early 15th centuries).⁸⁶

In many of these countries, very little is known about the state of health of either migrants or ethnic minorities, the health services available to them, and their utilization of these services. Where research exists, it may not be published in international journals or in English. We will not attempt to provide examples in this report: an important task for those developing training materials in such countries will be to locate such material representing issues related to their own countries.

In conclusion, we may note that research on the health of ethnic minorities – however they are defined – faces a large number of obstacles. Attention for ‘national minorities’ may be impeded by the ambivalent attitude of national governments towards the very existence of these minorities. They may be difficult to identify in official registers, while data on their social situation, health status and access to health care may simply not be collected. The fact that little is known about their situation may easily lead to the mistaken conclusion that there is no reason to be concerned about it.

The same applies to minorities resulting from migration – which include not only the migrants themselves, but also their children and later descendants. The offspring of migrants, in particular, tend to suffer from both conceptual and statistical invisibility. They do not belong in the category ‘migrants’; nor do they always satisfy the sociological criteria for being a ‘group’ or the legal criteria for being a ‘minority’. In their case, too, the fact that it is difficult to identify them and study their problems does not mean that they do not have any. When groups formed by migration remain tightly-knit and inward-looking, their integration into the host society may be impeded: but when a lack of contact, identification and solidarity with each other is combined with non-acceptance by the majority population, descendants of migrants may become marginalised – with all the problems that this entails.

The reasons why there is a such a shortage of data on the social and health situation of descendants of migrants can be summarised as follows:

- I. When ‘country of birth’ is used as a proxy for ‘ethnicity’ – as it is in most epidemiological research – the offspring of migrants are completely ignored.

⁸⁵ Immigration and Refugee Board of Canada. (2006). *Latvia: Treatment of ethnic Russians; whether ethnic Russians face discrimination; availability of state protection (January 2004 - December 2005)*. <http://www.refworld.org/docid/45f1477325.html>

⁸⁶ Can, T., Todorov, M.S.(2004). *Turks of Bulgaria: Assimilation Policy and Linguistic Oppression*. Syracuse University

- II. In the few countries where data on health are disaggregated in terms of self-ascribed ethnicity, no distinction is usually made between migrants and their descendants. This applies especially to the UK, the source of most epidemiological studies on ethnicity. In Dutch data on ethnic minorities (*allochtonen*) it is possible to distinguish migrants from specific countries from their children, but these data have several shortcomings:
- a. ethnic variations within the country of origin are ignored
 - b. the fact that ethnic groups can come from a number of different countries is overlooked;
 - c. only the first generation of migrants' offspring are included; and
 - d. only the groups which have traditionally been numerous in the Netherlands are studied.

1.7. Descendants of Migrants

As we saw in Chapter 1, large-scale immigration to Europe did not begin until the 1950's. Most of the European-born descendants of migrants are therefore either the children or grandchildren of migrants. Confusingly, the first generation of such descendants is normally labelled the 'second generation', though clearly they are not 'second generation migrants' because they have not migrated.

Several large-scale research projects were set up after 2000 in response to concern about the unfavourable integration outcomes of many of the 'second generation'. These projects focused mainly on educational attainment and labour market integration. In Europe, the project *The Integration of the European Second Generation (TIES)*⁸⁷ set up a database of more than 10,000 respondents in 8 countries to remedy the lack of data on this group. The OECD's PISA programme⁸⁸ (*Programme for International Student Assessment*) has since 2000 collected data on student attainment in up to 65 countries, devoting particular attention to children who have migrated and 'second-generation' children.

These and other projects have provided more information about the second generation, though unfortunately not much about their health status and utilisation of health care. Some important findings concerning Europe are as follows⁸⁹:

- The parents of the second generation mostly come from low- and middle-income countries, in particular Turkey and Morocco. However, migration in recent decades has become much more diverse: other countries besides those from which the 'guest workers' of the 1950's and 1960's originated are increasingly represented in the total.

⁸⁷ www.TIESproject.eu

⁸⁸ <http://www.oecd.org/pisa>

⁸⁹ Liebig, T., Widmaier, S. (2009). "Children of Immigrants in the Labour Markets of EU and OECD Countries: An Overview." OECD Social, Employment and Migration Working Papers no. 97.

- The parents' educational and occupational status is generally below the average level of the host country population. The second generation tend to do better in these respects than their parents, but still not as well as the majority population. By contrast, in non-European OECD countries (Australia, Canada, New Zealand and the United States), their achievements are at least on a par with those of native children.
- In terms of educational outcomes, the disadvantage of the second generation relative to children of natives is most marked in Austria, Belgium, Denmark, Germany, Luxembourg and the Netherlands. All of these are countries in which large numbers of 'guest workers' were recruited in the last century (see section 1.3). France, the UK, Sweden and Switzerland also recruited 'guest workers' but the second generation in those countries appears to be less disadvantaged. This may be because many immigrants to France and the UK came from former colonies and were already familiar with the language and culture, while in Sweden, temporary labour was recruited mainly from other Nordic countries. Many guest workers in Switzerland came from Italy or Spain and were subject to laws that prevented them from settling down⁹⁰. As the name implies, 'guest workers' in Western Europe were not expected to stay and so far from being helped to integrate, they were actively discouraged from doing so. It took a long time for the host countries to acknowledge their presence, and even longer for them to develop policies to promote integration.
- The fact that the second generation is socially disadvantaged in Europe⁹¹ but not in other OECD countries can be interpreted either as a result of differing policies governing the recruitment of migrants, or differing opportunities for integration, or both. Whatever the reason, it suggests that the health of this group in Europe is likely to be worse than that of the offspring of natives.
- Another indication of the disadvantaged position of the second generation in Europe concerns youth unemployment rates. In 2009 these were 1.6 times higher for children of migrants than for children of natives. Youth unemployment in Europe has increased dramatically as a result of the crisis: in 2014, according to Eurostat⁹², figures in Spain and Greece were above 50%. Figures for young people of migrant origin in these countries could thus be as high as 75%, meaning that most members of this group have no job and little prospect of ever getting one. Given the well-established negative relationship between unemployment and health this also suggests increased health problems in this group, which clearly deserves to be regarded as 'vulnerable'.

⁹⁰ D. Efiomayi, J.M. Niederberger and P. Wanner (2005) Switzerland Faces Common European Challenges. *Migration Information Source*, 1/2/2005. <http://www.migrationpolicy.org/article/switzerland-faces-common-european-challenges>

⁹¹ With the exception of Switzerland (*op. cit.*)

⁹² Eurostat Newsrelease Euroindicators 1/2015 (January 2015), <http://ec.europa.eu/eurostat/documents/2995521/6454659/3-07012015-AP-EN.pdf/f4d2866e-0562-49f5-8f29-67e1be16f50a>

- The disadvantage of children of migrants on the labour market in Europe is not fully explained by differences in educational attainment. It is hard to avoid the conclusion that discrimination plays a role.

Although health issues concerning the second generation are very poorly documented, we will describe in Section 2.4 some findings concerning their state of health. Section 4.1.1 examines findings concerning access to health and utilisation of healthcare.

[1.8. The Roma population in Europe](#)

Present-day Roma, described by the Council of Europe⁹³ as “a mosaic of diverse groups”, are considered to have descended from groups which left Northern India around the 11th century and migrated westwards, reaching Europe at the end of the 13th century and spreading out in many directions. In most of the countries where they attempted to settle they were subjected to systematic persecution, enslavement and exclusion, going as far as what we would now call ‘ethnic cleansing’ and genocide. The extermination by the Nazis of an unknown number of Roma (estimated at between 500.000 and 1.500.000) in 1936-1945 was thus the culmination of a virtually unbroken history of nearly seven centuries of persecution.

Although they are dispersed over the whole of Europe, the largest populations of Roma are found in Central and Eastern Europe. Under Soviet rule attempts were made to forcibly integrate Roma as well as other ethnic minorities, such as the indigenous people of the northern and Arctic territories of Russia, into the majority population (“Russification”).⁹⁴ Nevertheless, communism had certain advantages for the Roma, including the suppression of ethnic rivalries and nationalism and the introduction of a system of social protection and welfare⁹⁵. With the breakup of the Soviet Union in 1989 and the turbulent transition to capitalism that followed, their economic situation worsened and ethnic hatreds were again unleashed. Towards the end of the 20th century, international organisations promoted coordinated policy initiatives to improve the lot of Roma, leading to the ‘Decade of Roma Integration’ in 2005-2010. With the accession to the EU of several countries with large Roma populations in 2004 and 2007, the European Commission acquired an active role in influencing the policy agenda on Roma (see Chapter 3).

Unfortunately the social history lived by Roma continues into the present: many Roma still live in poverty and levels of education and employment are very low. Health-wise, these social determinants add up and lead to significant health inequalities compared to non-Roma. In addition, mutual distrust between Roma and non-Roma persists, and anti-Roma sentiments, always present, have recently flared up and reached the political level – as demonstrated by the demolition of Roma shanty towns in France and Italy in 2010, and the subsequent deportation of

⁹³ Council of Europe (undated). *Defending Roma Human Rights in Europe*. <http://bit.ly/1nUJway>

⁹⁴ Vakhtin, N. (1992). *Native Peoples of the Russian Far North*. London: Minority Rights Group

⁹⁵ Council of Europe (undated) *Factsheets on Roma History*. <http://bit.ly/1n4ktvA>

Roma EU citizens to Romania and Bulgaria.⁹⁶ Roma provide perhaps the most extreme example of Tudor Hart's 'inverse care law'⁹⁷: while their social and material living conditions lead to an extremely poor state of health, their access to good quality health services is also seriously hampered.

1.9. Statistics on the Roma population

For several reasons, it is difficult even to collect data on the number of Roma in each country, let alone on their demographic or other characteristics. In the first place, certain countries prohibit the collection of such data: this is a legacy of the Holocaust, which was greatly facilitated by population registers containing lists of Jews or Gypsies. In view of recent developments, researchers who argue that we do not need to worry about such things ever happening again would seem to be displaying a certain amount of political naiveté. The dilemma for policy-makers, however, is that as long as the situation of such groups is not monitored, it is difficult to take steps to improve it. Adequate monitoring of the social conditions and health of ethnic minority groups is considered essential to be able to respond effectively to their problems⁹⁸.

Another problem is that it is difficult to be sure of the reliability and validity of such data. Self-ascription is not considered reliable because many Roma – especially those living in mainstream society – may be reluctant to disclose their origins. Some countries use residence in a Roma settlement as a proxy for Roma ethnicity, but this will give a distorted picture of the group's situation. In this area we must be constantly aware that *all data have to be treated with more than the usual degree of caution regarding their reliability and validity.*

⁹⁶ Parekh, 2011.

⁹⁷ Hart, 1971.

⁹⁸ OSF(2010). No Data—No Progress. Country Findings. Data Collection in Countries Participating in the Decade of Roma Inclusion, 2005–2015. <http://osf.to/1uyswGX>

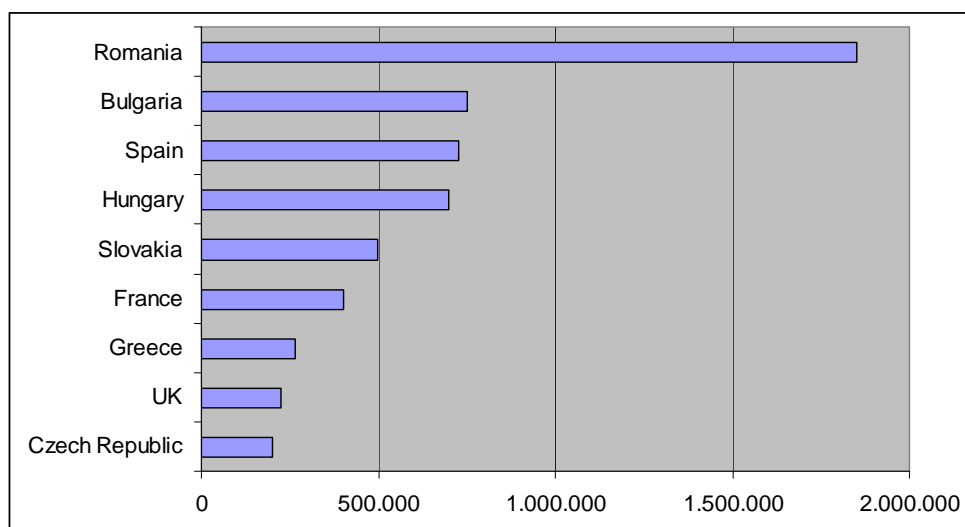


Figure 8 EU member states with the largest Roma and Traveller populations (2010)

Although these numbers are only a guideline, we can identify the main countries in the EU where Roma live. Figure 8 shows estimates of population size made by the Council of Europe in 2010: it should be noted that numbers refer to the combined category “Roma and Travellers”. The heterogeneity of the different groups which are conventionally described as ‘Roma’ is described in a Glossary published by the Council of Europe⁹⁹.

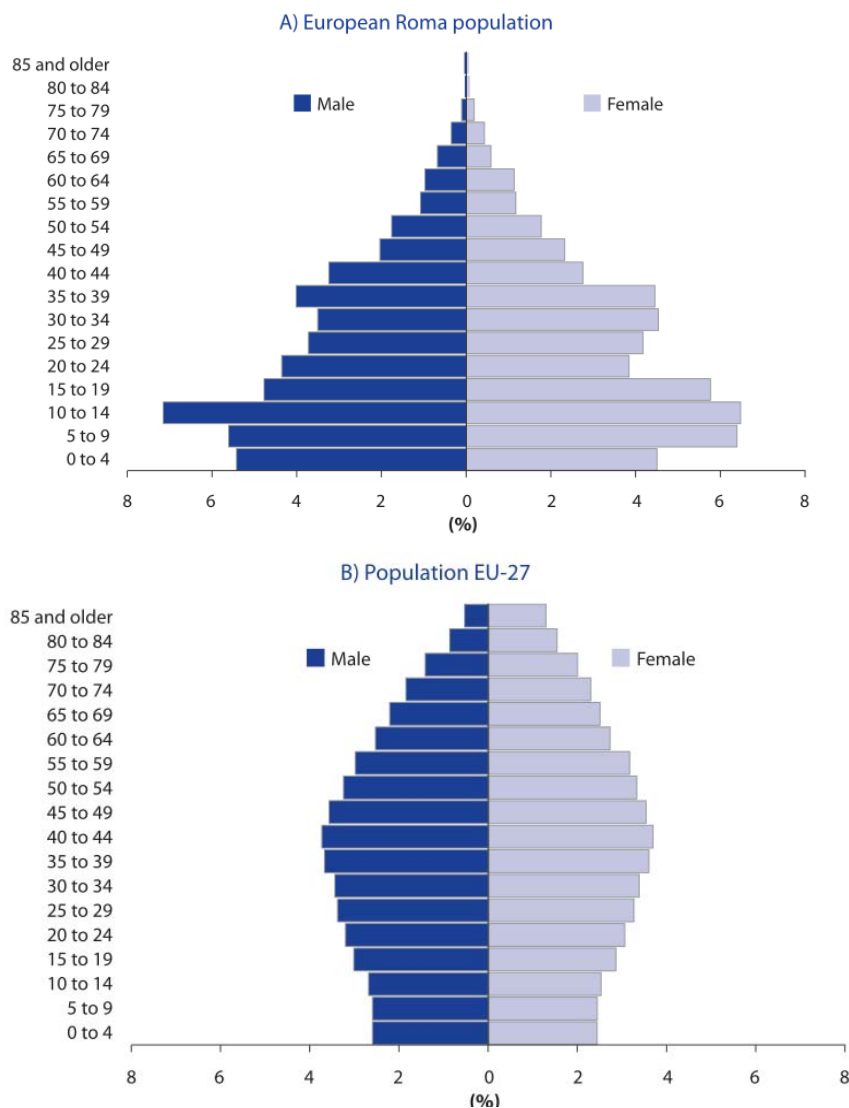
In section Appendix I, the full table is given showing numbers and percentages for each European country (source: Council of Europe, 2010), together with a map

1.9.1. Age

As the following population pyramids show (Fig.9), the age distribution of Roma differs markedly from the EU average: in some ways it resembles more closely profiles found in impoverished third-world countries (which tend to be triangular, rather than a pear-shaped distribution as in wealthier countries). The proportion of children is much higher, while at the top of the pyramid it can be seen that Roma live much shorter lives than other inhabitants of the EU.

⁹⁹ See <http://www.coe.int/t/dg3/romatravellers/Source/documents/GlossaryRoma.doc>

Figure 9 Population pyramids in Europe: Roma community and the European Union¹⁰⁰

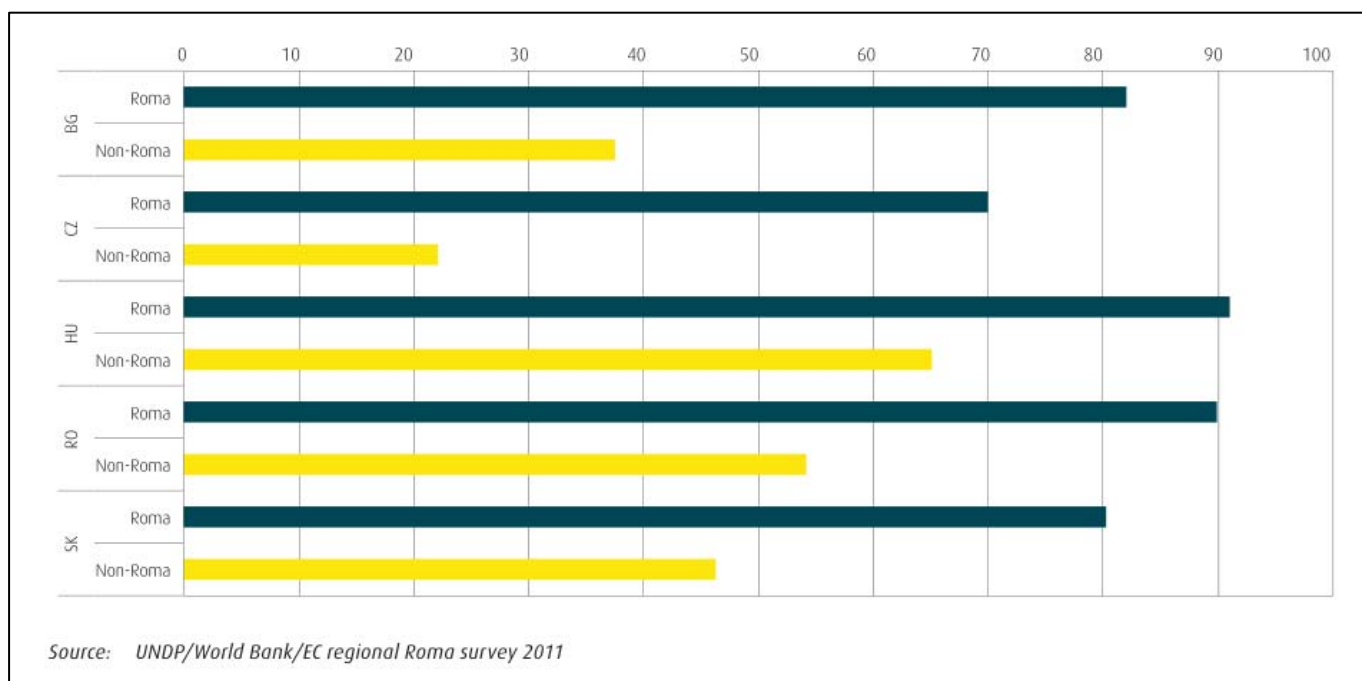


¹⁰⁰ Figures extracted from the report *Health and the Roma Community: Analysis of the situation in Europe*, 2009, p. 17. Based on Eurostat data from 2008.

1.9.2. Social position

A great deal of information has been collected in the last ten years on the social position of Roma. For reasons of space we limit ourselves to one graph¹⁰¹ (Fig. 10): it shows the percentage of Roma households classified as suffering “severe material deprivation”, compared with the non-Roma population, in five countries.

Figure 10 Roma and non-Roma households with severe material deprivation in Europe, 2011



¹⁰¹ FRA (2012). *The situation of Roma in 11 EU Member States - Survey results at a glance.*

Chapter 2: State of health and health determinants

In this section we will review the findings of research on health inequalities affecting migrants and ethnic minorities, in particular Roma, examining both the differences found and their hypothesised causes. We begin with discussion of some general issues relating to these topics.

2.1. General issues

2.1.1. Gaps in the data

Although the amount of information available on the health of migrants and ethnic minorities in Europe has increased considerably in the last decade, this information still has serious limitations. Firstly, many issues have only been studied in certain countries or not at all. Second, research is hampered by the difficulty of obtaining the necessary data: health statistics are seldom categorized according to the ethnicity or migration status of the people concerned, and often it is not possible to link them with databases that do contain such variables.

A major EU project aiming to review the adequacy of information in this field, the **Migration and Ethnic Health Observatory (MEHO)**, was completed in 2010¹⁰². Work Package 4 reviewed the data available and provided maps showing coverage in each country. Not surprisingly, the most widely available data on migrant and ethnic minority health concern dependent variables that are relatively easy to collect, such as self-reported health status, life expectancy or mortality. The availability of data on specific health conditions varies much more between countries.

As far as migrants' health is concerned, the volume of European research on this topic has increased greatly since the turn of the century, but (as the MEHO project showed) there are still many gaps. In different countries and databases, data may be disaggregated in terms of migrant status, country of birth, country of origin, ethnicity, nationality, or a combination of any or all of these. When ethnicity is recorded, the categories used and their definition may vary from country to country: moreover, research traditions do not always keep up with demographic changes, such as changes in the size and number of ethnic groups. In the UK (as in the Netherlands), a large body of research focuses on ethnicity: much of it, however, makes no distinction between migrants and their offspring^{103,104}. The recording of national or indigenous minority ethnic status

¹⁰² Migrant and Ethnic Health Observatory (MEHO). Website: <http://www.meho.eu.com/> (temporarily unavailable). See also Nielsen, S.S., Krasnik, A., Rosano, A. (2009). Registry data for cross-country comparisons of migrants' healthcare utilization in the EU: A survey study of availability and content. *BMC Health Serv Res*; 9:210.

¹⁰³ Bhopal, R. 2014. *Migration, ethnicity, race, and health in multicultural societies*. Oxford: Oxford University Press.

¹⁰⁴ Jayaweera, H. (2014) *Better Health Briefing 19: Health and access to health care of migrants in the UK*. London: Race Equality Foundation.

depends on a number of factors, such as the integrationist tendencies of the central government (i.e. non-recording of ethnicity to promote a unified national identity, e.g. Spain and France),¹⁰⁵ and the administrative status of the territories they inhabit. For example, in the North Scandinavian region, Sami territories have their own parliaments and maintain voter registers that include ethnicity data: in the north of Sweden ethnicity and ancestry is recorded by the Sami Parliament as well as by Statistics Sweden.¹⁰⁶ However, most countries in Europe do not record ethnicity in census or other population registers (see section 1.6.3)

Data on the Roma population in Europe is particularly limited, which impacts negatively on the ability of countries to assess the situation of Roma and to monitor the effects of policies intended to improve their situation. Several factors impede the collection of reliable and comparable data on Roma populations and their health, including restrictive interpretations of legislation governing data collection and privacy protection, as well as an excessive dependence on (sometimes highly unreliable) census data. In addition, there is a reluctance to use other sources of data which may be more reliable than official national-level sources, such as intergovernmental sources (UNDP, CoE, UNICEF, etc.) and academic or NGO publications and materials based on independent data collection.¹⁰⁷

During its **2007-8 Decade of Roma Inclusion Presidency**, Hungary identified the need for a framework of indicators applicable at a transnational level by which to measure the implementation and progress of the Decade's Roma inclusion policies. In response, Decade member countries formed the Decade Indicator Working Group, which in 2009 published a report¹⁰⁸ describing mechanisms that Decade members could use to chart implementation and progress of Roma inclusion policies. While subsequent Presidencies have called for the need for monitoring and indicators, in the end, individual countries are responsible for the establishment of reliable monitoring mechanisms for collecting comparable data that is disaggregated for ethnicity.¹⁰⁹ The European Commission's 2014 **Report on the implementation of the EU Framework for National Roma Integration Strategies**, pointed out the continued lack of systematic data collection on health of Roma compared to the general population, data which is essential to the monitoring of Roma health and health inequalities.¹¹⁰

2.1.2. The relation between poor health and shortcomings in health service provision

¹⁰⁵ Morning, A. (2008). Ethnic Classification in Global Perspective: A Cross-National Survey of the 2000 Census Round. *Population Research Policy Review* 27:239–272

¹⁰⁶ Sjolander, P. (2011). What is known about the health and living conditions of the indigenous people of northern Scandinavia, the Sami? *Global Health Action*, Vol. 4.

¹⁰⁷ McDonald, C., Negrin, K. (2010). *No Data No Progress – Country Findings*. Open Society Institute: Roma Initiatives Office.

¹⁰⁸ Kahanec, M. (2009). The Decade of Roma Inclusion: A framework for progress measurement and options for data collection. Bonn: Institute for the study of labor (IZA).

¹⁰⁹ *Ibid.*

¹¹⁰ Report on the implementation of the EU Framework for National Roma Integration Strategies.

European Commission, Directorate-General for Justice (2014).

http://ec.europa.eu/justice/discrimination/files/roma_implement_strategies2014_en.pdf (Accessed 23 February, 2015).

It is often argued that shortcomings in health services for migrants and ethnic minorities (especially Roma) must be addressed because of the heightened health risks known to affect these groups. While increased health needs certainly justify increased attention to these needs, the converse is not true: if a group's state of health is not particularly poor, this does not mean there is no need to worry about the health services available to them.

The reason for this is that the majority of conditions that health services treat are the result of simply being human, rather than of belonging to a specific group. Accidents, infections, complications in childbirth, genetic defects and the natural deterioration of the body in old age can affect anybody. Poor access to good-quality care is not only a problem when groups are exposed to heightened health risks.

However, in these cases it does become *more* of a problem. Here again we encounter the 'Inverse Care Law'¹¹¹ referred to earlier: those with the greatest need for good health care are often those who are least able to get it. Migrants and ethnic minorities sometimes experience special needs and vulnerabilities which justify greater attention to the services provided - but as a matter of principle, equity in health service provision does not have to be justified by evidence of heightened needs. It is a question of rights; the universal human right to health and the unacceptability of discrimination in service provision between groups.

2.1.3 Changing assumptions regarding the importance of different determinants of health

Among researchers in this area, there has been a gradual shift during the last two decades in the emphasis placed on different types of determinant.

2.1.3.1. Health service provision

As we saw in the previous paragraph, emphasis has often been placed on the connection between inadequate health care for migrants and ethnic minorities and poor health. Improving care has been seen as the key to improving health. So, for example, efforts in the UK to improve mental health care for 'Black and Minority Ethnic' (BME) groups were regarded by many as having failed when evidence emerged of continuing elevated rates of admission for serious mental illness¹¹².

Improving service delivery, however, may not have much impact on the overall prevalence of a health problem. The impact is likely to vary greatly, depending on the context and the nature of the health problem. If we are talking about containing an epidemic which can be effectively combated by known treatments, the impact may be very high; but improvements in service delivery will have much less impact on persistent, non-communicable illnesses which are due to

¹¹¹ Tudor Hart (1971).

¹¹² Singh, S.P. and Burns, T. (2006). Race and mental health: there is more to race than racism. *British Medical Journal*, 333(7569): 648-651.

age-related degeneration or deeply-rooted environmental factors – problems that by their nature may be hard to eradicate through treatment.

In research concerning migrant and minority ethnic health, a shift of attention can be observed in the last 15 years from shortcomings in health care to more fundamental determinants of health. As we shall see in the next chapter, a corresponding shift has occurred in *interventions* aimed at improving the health of these groups. One could say that the focus has moved ‘upstream’, in the sense that more fundamental determinants of health are being studied. This has much to do with the influence of the ‘social determinants of health’ movement associated with the ‘Marmot Report’¹¹³.

In the Health Programme (2003-2013) migrants and ethnic minorities were classed as ‘vulnerable groups’. Projects for such groups (in particular the earlier ones) tended to focus on shortcomings in health service delivery (including targeted health promotion)¹¹⁴. Examples are the two **CORRELATION projects** (2005-2008, 2009-2010) which studied the need for improved access to high-quality treatment, as well as harm reduction and prevention of infection, among high-risk groups such as intravenous drug users and sex workers (including migrants). Early research on Roma also tended to focus on poor access to good quality services as a cause of health problems. By contrast, later projects, such as ***Health and the Roma Community (2007-2009)*** and ***Reports on health status of the Roma population (2012-2013)*** placed more emphasis on the need for more epidemiological research into the causes of ill-health, especially the role of social disadvantage.

2.1.3.2. Lifestyle factors and harm reduction

The importance of *prevention* has been widely emphasised in health policy-making circles since the WHO’s 1978 ‘Declaration of Alma Ata’¹¹⁵ and even before. However, preventive measures can be of different kinds. Some are targeted at individuals and aim to induce *behavioural change*. This can either have the aim of harm reduction or illness prevention (aims which are sometimes hard to distinguish from each other). Recently there has been a great increase in attention to behavioural (‘lifestyle’) factors as determinants of both communicable and non-communicable illnesses. Much importance has been attached to ensuring that health promotion interventions reach and influence migrants and ethnic minorities effectively.

From an epidemiological point of view, however, interventions targeting the behaviour of individuals may not be as effective in the long term as attention to the ‘causes of the causes’, i.e. fundamental social factors influencing illness. Whitehead¹¹⁶ distinguishes four levels at which health inequities can be tackled: strengthening individuals, strengthening communities,

¹¹³ CSDH (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final report of the Commission on the Social Determinants of Health*. Geneva, World Health Organization

¹¹⁴ Consumers, Health and Food Executive Agency (2014). *Action on health inequalities in the European Union*. European Union. <http://bit.ly/1vYIQBf>

¹¹⁵ WHO (1978). *Declaration of Alma-Ata*. Geneva, World Health Organization.

¹¹⁶ Whitehead, M. (2007). A typology of actions to tackle social inequalities in health. *Journal of Epidemiology and Community Health* 2007; 61: 473–478.

improving living and working conditions, and promoting healthy macro-policies. In keeping with the shift towards more ‘upstream’ factors in epidemiological research, there is growing emphasis on the need for macro-policies to improve the social, economic and legal situation of migrants and ethnic minorities. This has blurred the dividing-line between ‘health interventions’ and other efforts to tackle the disadvantaged situation of these groups.

2.1.3.3. Social determinants of health and the influence of SES

Despite this shift ‘upstream’, the emphasis on deeper structural determinants of health inequities has mainly been linked to the enormous differences in health and longevity between those at the top and bottom of the socioeconomic ladder. Meanwhile, most research on migration and ethnicity has continued to be preoccupied with service provision, ‘cultural’ factors, lifestyles and the immediate effects of migration. Researchers into SES differences have tended to overlook the fact that social disadvantage and migrant status (or ethnicity) are closely linked¹¹⁷. However, the poverty and social exclusion experienced by most Roma is well documented, and migrant households experience poverty with much greater frequency than native households¹¹⁸. For this reasons, researchers investigating the ‘social gradient’ need to pay more attention to stratification in terms of ethnicity and citizenship, while those dealing with migrants and ethnic minorities need to be specially aware of the role of low SES in the genesis of health problems. Although earlier studies neglected these interactions, it is becoming increasingly common to control for SES when studying migration and ethnicity.¹¹⁹ While some of the observed differences disappear when this is done, others do not.¹²⁰

However, measuring the SES of migrants and members of ethnic minorities groups is far from straightforward. It is not even clear whether the methods of measuring SES developed for majority populations are valid for migrants and ethnic minorities. As one epidemiologist put it, “conventional measures of socioeconomic position may actually serve to conceal the socioeconomic disadvantage experienced by ethnic minority groups, rather than expose it.”¹²¹

A common mistake in this area is to assume that if health differences in migrant or ethnic minority groups disappear statistically when SES is controlled for, the ‘real’ determinants of health are socioeconomic ones and policies need not take account of migrant status or ethnicity. In statistical terms, SES is assumed to be a ‘confounder’. Yet a different interpretation is possible and in fact more likely – that SES is not a confounder but a *mediator*, part of the causal chain between migration status or ethnicity and health. This will be the case if membership of these groups to some extent determines a person’s SES, which is precisely what mechanisms of social

¹¹⁷ Ingleby, D. (2012). Migration, ethnicity and the ‘social determinants of health’ agenda. *Psychosocial Intervention/Intervención Psicosocial* 21(3), 331-341

¹¹⁸ Sainsbury, D. (2012). *Welfare States and Immigrant Rights: The Politics of Inclusion and Exclusion*. Oxford: Oxford University Press.

¹¹⁹ Földes, M., Covaci, A. (2012). Research on Roma health and access to healthcare: state of the art and future challenges. *International Journal of Public Health* 57: 37-39.

¹²⁰ Nazroo, J. Y. (2003). Genetic, cultural or socio-economic vulnerability? Explaining ethnic inequalities in health. In *The Sociology of Health and Illness: A Reader*, ed. M. Bury and J. Gabe, 145-160. London: Routledge.

¹²¹ Karlsen S., Nazroo J.Y. (2002). Agency and structure: the impact of ethnic identity and racism on the health of ethnic minority people. *Sociology of Health & Illness*, 24:1:1-20

exclusion do. In addition, there may be a *direct* relationship between discrimination and poor health.¹²² In any case, measures to reduce health inequalities may need to be specially adapted in order to reach migrant and ethnic minority groups effectively.

The conclusion must be that policies to reduce socioeconomic health inequalities which do not take migrant status and ethnicity into account can only have limited success in countries where these groups are numerically significant and are not treated equitably^{123,124}. We will return to the theme of levels of explanation and intervention in Section 2.4 below.

2.2. Health inequalities affecting migrants and ethnic minorities and their determinants

We will first consider some general findings of research on the health of migrants and ethnic minorities. It should be borne in mind that in the scientific literature, these categories to a large extent overlap: much research on ethnicity is at the same time research on migration, because it uses 'country of birth' as an indicator of ethnicity (see Section 1.6.4).

2.2.1. The 'healthy migrant effect'

In some respects, migrants as a group may appear to be in better health immediately after arrival than native-born populations. Usually, their health then declines gradually to the level found in the native population. This well-known phenomenon¹²⁵ may reflect at least three factors:

- The fact that migrants tend to be younger and for that reason less likely to be ill;
- Possible selection (e.g. by countries or companies screening out migrants who are ill, or self-selection of less healthy individuals who do not migrate);
- A lower prevalence of certain illnesses in the sender country.

Whether these factors are relevant will depend on the particular group migrating, the identity of the origin and host countries, and the health condition being studied. For this reason, a 'healthy migrant effect' is by no means found in all studies. And as we shall see, many factors increase the risk of ill-health before or during migration and thus work in the opposite direction.

¹²² Pascoe, E.A., Smart Richman, L. (2009). Perceived discrimination and health: a meta-analytic review. *Psychological Bulletin*, 135:4:531–554.

¹²³ Masseria, *et al* (2010).

¹²⁴ Földes, *et al* (2012).

¹²⁵ See e.g. Fennelly, K. (2005). The healthy migrant effect. *University of Minnesota, Healthy Generations Newsletter*, 5:3 (http://www.epi.umn.edu/mch/resources/hg/hg_immi.pdf, accessed 11th July 2014). Kennedy, S., McDonald, J.T., Biddle, N. (2006). *The healthy immigrant effect and immigrant selection: evidence from four countries*. Hamilton, McMaster University (Social and Economic Dimensions of an Aging Population Research Papers 164; <http://ideas.repec.org/p/mcm/sedapp/164.html>, accessed 11th July 2014).

2.2.2. The lack of main effects

In the area of migrant and ethnic minority health, few straightforward generalizations can be made. The effects found depend to a large extent on the health problems studied, the origin and host countries involved, the sex and age of the migrants in question, as well as their reason for migration, legal status and socioeconomic position (SES). Moreover, the health problems of first-generation migrants may differ from those of their descendants.

It is not even the case that where differences are found, they are always in the direction of worse health for migrants. Bhopal¹²⁶ asserts: “We need to sustain the beneficial aspects of minority ethnic group cultures (e.g. taboo on smoking in Sikhs). Where minorities exhibit the lowest rates of disease or risk factors they should provide the goal for other groups to emulate”. However, the fact that no simple generalizations are available in no way weakens the point that the burden of ill health among certain migrant and ethnic minority groups is often unacceptably large.

2.3. Differences found

As seen above, migrant status may (statistically speaking) have a positive association with health, but the influence of migration on an individual’s health is nevertheless usually negative. Data collection in this area is still lacking in systematic methodology, which has led to a lack of high quality studies at the European level. The literature review carried out in this project (see Appendix II) gives some examples of the differences found in health outcomes between migrants and host country populations. Methodology is seldom standardised across countries, which limits the generalisability of the results. A landmark study in this respect was the MEHO project mentioned throughout this chapter and described in detail in Appendix VI, which studied the following health domains: mortality, cardiovascular disease and diabetes, infectious diseases, cancer, self-perceived health and health care use¹²⁷. Below we give a selection of important findings, gathered from the literature review and other sources¹²⁸. Of course, this quick sketch makes no claim to be exhaustive.

2.3.1. General measures of health

¹²⁶ Bhopal, R. (2009). Chronic diseases in Europe's migrant and ethnic minorities: challenges, solutions and a vision. *European Journal of Public Health*, 19:2:140–143.

¹²⁷ Migrant and Ethnic Health Observatory (MEHO). Website: <http://www.meho.eu.com/> (temporarily unavailable).

¹²⁸ Overviews on migrants’ state of health are provided by (e.g.) Rechel, B., Mladovsky, P., Devillé, W., Rijks, B., Petrova-Benedict, R., McKee, M. (2011). *Migration and health in the European Union*. Buckingham: Open University Press; Gushulak, B., Pace, P., Weekers, J. (2010). Migration and health of migrants. In: *Poverty and social exclusion in the WHO European Region: health systems respond*. Copenhagen, WHO Regional Office for Europe; Bhopal (2014, *op cit*).

Clinical data, which concern diagnoses made by qualified professionals, are seldom disaggregated by migrant status or ethnicity and may suffer from biases because of variations in care utilization and the difficulty of estimating denominators (i.e. the proportion of migrants in the underlying population)¹²⁹. For these reasons, much research on migrant and ethnic minority health focuses on variables that are relatively easy to collect for the population as a whole, such as self-reported health status, life expectancy or mortality. Such data can be collected from individuals themselves or from national 'vital statistics' (registries of births and deaths). However, these indicators of health status may also be subject to biases. Mortality rates, for example, may be underestimated because of 'salmon bias' (the tendency of some migrants to return to their country of origin as they become older and less healthy).¹³⁰ Self-reported health status is also an imprecise measure, because there are no objective criteria for 'feeling well' or 'feeling unwell'; there may be significant cross-cultural differences in the way such judgements are made.¹³¹

2.3.1.1. Mortality and life expectancy

Death certificates are not a reliable indicator of the prevalence of specific illnesses, because the causes of death are often oversimplified.¹³² Nevertheless, many studies have made use of this indicator. A Dutch study¹³³ found that life expectancy was longer than for native Dutch in seven out of ten non-Western migrant groups. The authors concluded that "migrant health could be benefiting from the favourable socioeconomic, public health and health-care conditions in The Netherlands, but not yet be affected by the higher risks of cancer and cardiovascular disease associated with prosperity." However, there are many studies showing higher mortality rates for migrants as a result of a number of different factors. For example, postpartum maternal mortality rates amongst foreign (sub-Saharan, Asia, North and South America) women in France were twice as high compared to non-foreigners.¹³⁴ This study suggests that inferior medical attention may have been a factor in these elevated mortality rates. These findings were echoed in the UK, where two major triannual studies into maternal mortality showed that women in minority ethnic groups were at significantly greater risk than the majority population.^{135, 136} In particular Black African and, to a lesser extent, Black Caribbean women had significantly higher mortality rates than White women. Potential causes for these elevated rates included the later engagement with maternity services, and migration trajectories and circumstances of some Black

¹²⁹ Ingleby, D. (2009) *European Research on Migration and Health*. Brussels: International Organisation for Migration. <http://www.migrant-health-europe.org/background-papers/research-on-migration-health.html>

¹³⁰ Bhopal, R. (2014, *op. cit*), p. 135.

¹³¹ Ramírez, M., Ford, M.E., Stewart, A.L. and Teresi, J.A. (2005). Measurement Issues in Health Disparities Research. *Health Services Research*, 40(5), 1640-1657.

¹³² Bhopal, R. (*op. cit*), p. 142

¹³³ Mackenbach, J. P., Bos, V., Garssen, M. J., Kunst, A. E. (2005). Mortality among non-western migrants in The Netherlands. *Nederlands Tijdschrift Geneeskunde*, 149(17):917-23.

¹³⁴ Philibert, M., Deneux-Tharoux, C., Bouvier-Colle, M. (2008) Can excess maternal mortality among women of foreign nationality be explained by suboptimal obstetric care? *BJOG* 115:1411-1418.

¹³⁵ Ge, L. (2007) Saving mothers' lives: reviewing maternal deaths to make childbirth safer - 2003-2005. London: CEMACH.

¹³⁶ Centre for Maternal and Child Enquiries (2011). Saving Mothers' Lives: Reviewing deaths to make motherhood safer: 2006-2008. *BJOG*, 118(s1):1-203.

African women who may have been newly arrived refugees or asylum seekers. Furthermore, many migrant groups experience higher diabetes mortality. The research on migrant mortality from diabetes mellitus in several European countries, conducted by the University of Amsterdam as part of the MEHO project, found that rates were particularly high in migrants from North Africa, the Caribbean, the Indian subcontinent and countries with a low gross domestic product (GDP).¹³⁷

2.3.1.2. Self-perceived health

This variable is included in the standard data-set for the European Union Statistics on Income and Living Conditions (SILC).¹³⁸ A fair amount of research is available on the self-perceived general health of migrants, and as SILC data become better implemented in EU countries, more can be expected. Most studies have found that migrants' judgements of their own health tend to be less favourable than those of the host population. A large part of this difference disappears when socioeconomic differences are controlled for, but in many studies the effect is not entirely removed.¹³⁹ A similar conclusion was drawn by the MEHO sub-study on self-reported health status of migrants and ethnic minorities, based on a literature review of European studies.¹⁴⁰ A striking exception is provided by a study in Belgium, which found that when migrants' living conditions were also controlled for, self-reported health actually seemed to be better.¹⁴¹

2.3.2. Non-communicable diseases

Several overviews on non-communicable diseases among migrants in Europe are available.¹⁴² The incidence of many of these diseases increases with age, and the growing volume of research on this topic is connected to the increasing numbers of older migrants in Europe.

2.3.2.1. Cardiovascular diseases

Cardiovascular diseases (CVD) are one of the major health threats which have been found to be elevated in many (but not all) migrant and ethnic minority groups. The risk of CVD mortality among migrants varies across Europe and according to the migrants' country of origin. Thus,

¹³⁷ Vandenheede, H. *et al.* (2012). Migrant mortality from diabetes mellitus across Europe: the importance of socio-economic change. *European Journal of Epidemiology* 27, 109–117.

¹³⁸ Website: http://epp.eurostat.ec.europa.eu/portal/page/portal/microdata/eu_silc

¹³⁹ See e.g. Devillé, W. *et al.* (2006). Perceived health and consultation of GPs among ethnic minorities compared to the general population in the Netherlands. In: Westert, G.P., Jabaaij, L., François, G., eds. *Morbidity, performance and quality in primary care*. Oxford, Radcliffe Publishing Ltd:85–96.

¹⁴⁰ Nielsen, S.S., Krasnik, A. (2010). Poorer self-perceived health among migrants and ethnic minorities versus the majority population in Europe: a systematic review. *International Journal of Public Health*, 55 (5): 357–371.

¹⁴¹ Lorant, V., Van Oyen, H., Thomas, I. (2008). Contextual factors and immigrants' health status: double jeopardy. *Health & Place*, 14:4:678–692.

¹⁴² See e.g. Kunst, A., Stronks, K. and Agyemang, C. (2011) Non-communicable diseases. In: Rechel *et al.* (2011), *op. cit.*, 101–120; Carballo, M. (2009a). Non-communicable diseases. In: Fernandes, A., Pereira Miguel, J., eds. (2009). *Health and migration in the European Union: better health for all in an inclusive society*. Lisbon, Instituto Nacional de Saúde Doutor Ricardo Jorge:71–81

Surinamese and Antilleans have a higher risk of CVD mortality compared to the native population in the host country, while Moroccans have a lower risk¹⁴³. However, differences found depend not only on the country of birth, but also on the destination country; similar findings were reported both in the original MEHO study on CVD¹⁴⁴, and in a later extension of the study¹⁴⁵.

Much research currently focuses on the complex interaction of factors which may underlie the higher risks of CVD among certain migrant and ethnic minority groups.¹⁴⁶ For example, research points to an elevated risk for developing diabetes and CVD amongst children of non-Western migrants residing in Europe. Recently, the Child Health and Heart Study (CHASE) in England sought to identify the association between low birthweight and risk markers for diabetes and CVD, as a way to explain the ethnic differences that exist. The study found that lower birthweight was in fact strongly associated with higher risk for developing diabetes and cardiovascular diseases, and that lower birthweights were more prevalent amongst children with South Asian (Indian, Pakistani and Bangladeshi) and Black African Caribbean children, compared to White European children residing in the UK. However, the study provided no conclusive evidence that these findings explain the higher prevalence of these diseases amongst South Asians and Black African Caribbeans compared to White Europeans residing in the UK. Other possible explanations suggested were life style factors such as energy consumption, physical exercise and diet.

2.3.2.2. Diabetes

As we saw in relation to mortality rates (Section 2.3.1.1), diabetes is particularly common among migrants. Age-standardised diabetes prevalence is higher in migrant populations in all the reviews studied, regardless of the country of origin of migrants^{147,148}. The European Union is supporting research in this field (**Project RODAM** and **GIFTS**) to identify the determinants of such differences.

2.3.2.3. Cancer

Cancer risk is often found to be lower in migrant populations¹⁴⁹, reflecting the fact that most types of cancer tend to be less common in many of the developing countries from which migrants often originate. However, a review conducted for the MEHO project showed that “migrants from non-western countries were more prone to cancers that are related to infections experienced in

¹⁴³ Ujcic-Voortman, J.K., Baan, C.A., Seidell, J.C., Verhoeff, A.P. (2012). Obesity and cardiovascular disease risk among Turkish and Moroccan migrant groups in Europe: a systematic review. *Obesity Reviews* 13, 2–16.

¹⁴⁴ Bhopal RS, Rafnsson SB, Agyemang C, et al. (2011). Mortality from circulatory diseases by specific country of birth across six European countries: test of concept. *Eur J Public Health* 22:353-9.

¹⁴⁵ Rafnsson, S.B., Bhopal, R.S., Agyemang, C., Fagot-Campagna, A., Harding, S., Hammar, N., Kunst, A.E. et al. (2013). Sizable variations in circulatory disease mortality by region and country of birth in six European countries. *Eur J Public Health*, 23 (4) 594 - 605.

¹⁴⁶ Bhopal, R. (2014, *op. cit.*),

¹⁴⁷ Vandenheede, H. et al. (2012). Migrant mortality from diabetes mellitus across Europe: the importance of socio-economic change. *European Journal of Epidemiology* 27, 109–117.

¹⁴⁸ Rechel et al (*op. cit.*), 2011

¹⁴⁹ *ibid*, p. 258.

early life, such as liver, cervical and stomach cancer. In contrast, migrants of non-western origin were less likely to suffer from cancers related to a western lifestyle, e.g. colorectal, breast and prostate cancer".¹⁵⁰ Likewise, a UK study on cancer rates among people born in different countries found variations in rates for different groups of migrants and types of cancer. While findings indicated an overall lower mortality for all cancers combined among people born in Bangladesh (except for lung cancer in men), India, Pakistan or China/Hong Kong, and lower lung cancer mortality among people born in West Africa or the West Indies, women born in West Africa and men born in West Africa or the West Indies experienced higher breast cancer mortality and higher prostate cancer mortality respectively.¹⁵¹

The latter study is based on country of birth, since death certificates in the UK report only country of birth and not ethnicity. Therefore, the figures for those born in England and Wales will also include descendents of migrants. For many types of cancer, incidence rates differ between non-industrialised and industrialised countries: incidence rates among migrants tend to change in the direction of the rate in the country to which they migrate (providing further evidence for the role of environmental factors in certain forms of cancer). For example, rates of breast cancer even increase among women migrating from the low-risk south of Italy to the higher-risk north.¹⁵²

Screening programmes can play an important role in the detection and early treatment of many types of cancer and it is often reported that migrants' participation in these programmes is lower than that of the majority population.¹⁵³ As with all screening programmes, there is often debate about the effectiveness of programmes which aim to detect cancer. Depending on the incidence in the group being screened and the aggressiveness of the type of cancer involved, it is possible that the risks of unnecessary treatment as a result of false-positives (as well as the anxiety and disruption this causes) may outweigh the advantages of early detection. Since these advantages and disadvantages involve a subjective element, it is increasingly regarded as good practice to allow individuals themselves to participate in the decision as to whether they should be screened. "Women cannot be expected to make an informed choice about participation in a screening programme unless they are given sufficient and adequate information." ¹⁵⁴

With migrants and ethnic minorities there is a real possibility that the incidence of cancer in their group may differ from that among the general population. The aggressiveness of the predominant type of cancer may also differ: for example, controversy has arisen in England over the minimum age for screening of Black women, among whom there is said to be a raised

¹⁵⁰ Arnold, M., Razum, O., Coebergh, J.W. (2010). Cancer risk diversity in non-western migrants to Europe: an overview of the literature. *Eur J Cancer* 46:2647–59

¹⁵¹ Wild, S.H. *et al* (2006). Mortality from all cancers and lung, colorectal, breast and prostate cancer by country of birth in England and Wales, 2001–2003 *British Journal of Cancer* 94, 1079 – 1085

¹⁵² Kolonel, L.N. and Wilkens, L.R. (2006), Migrant studies. In: Schottenfeld D, Fraumeni JF Jr (eds) *Cancer epidemiology and prevention*, 3rd edn. Oxford University Press, Inc., New York, pp 189--201

¹⁵³ Nørredam, M., Nielsen, S. and Krasnik, A. (2010). Migrants' utilization of somatic healthcare services in Europe – a systematic review. *European Journal of Public Health*, 20(5): 555–63.

¹⁵⁴ European Commission (2006) European guidelines for quality assurance in breast cancer screening and diagnosis (fourth edition). <http://www.euref.org/european-guidelines>

incidence (mainly among UK-born groups) of aggressive forms of breast cancer at an early age¹⁵⁵. How screening policies should best take account of these differences is not clear.

A recent article¹⁵⁶, based on many studies showing that breast cancer incidence is lower among Turkish migrants to Germany, argues that screening for this group may be less effective than for natives. However, rather than introducing different screening guidelines for these migrants (which could be experienced as stigmatising), the article recommends the provision of adapted information. Conversely, in response to the threefold elevation of the incidence of prostate cancer among Black African and Caribbean men in the UK, advocacy groups have called for programmes to increase awareness among the affected communities of the risks and the available screening methods¹⁵⁷.

As with all health problems, cancer rates for migrants or ethnic minorities vary by destination country as well as by country of origin, possibly reflecting differences in the accessibility and quality of health services (including screening programmes) for such groups. Another systematic review carried out in the framework of the MEHO project, comparing Turkish-born migrants in Belgium, Denmark, France and the Netherlands¹⁵⁸, showed that while all-cancer mortality rates were overall lower for Turkish migrants than for the local-born populations, for some types of cancer rates were higher. For example, rates for stomach cancer were higher for Turkish men in France and the Netherlands. Further research is urgently needed to explore the connections between cancer incidence, migrant status, ethnicity, country of origin, socioeconomic position and the length of stay in the host country.

2.3.5. Communicable diseases

On this topic, too, several overview articles are available.¹⁵⁹ Communicable diseases among migrants have always been a politically sensitive issue. The earliest initiatives on migrant health, such as the screening of US immigrants at Ellis Island from 1891-1930, were motivated by fears that 'import diseases' could infect the host population, while chronically ill or disabled individuals could become a burden on the community. Later in the century, such practices were

¹⁵⁵ D. Ingleby (2008) Early onset of breast cancer in Black British women: how reliable are the findings? *British Journal of Cancer* 99, 986-987.

¹⁵⁶ Berens, E-M, Spallek, J. and Razum, O. (2012). Breast cancer screening among immigrant women: do we need specific approaches in risk communication? In Ingleby, D., Krasnik, A., Lorant, V. & Razum, O. (Eds.) *Health inequalities and risk factors among migrants and ethnic minorities. COST Series on Health and Diversity, Volume I* (pp. 304-318). Antwerp/Apeldoorn: Garant.

¹⁵⁷ Prostate Cancer in BME Communities Parliamentary Stakeholder Group (2012). *Prostate Cancer in BME Communities: Raising Awareness and Improving Outcomes*. http://www.bmeprostatecancer.com/resource/downloads/Prostate_Cancer_in_BME_Communities_Report.pdf

¹⁵⁸ Spallek, J. et al (2012) Cancer mortality trends among Turkish immigrants in four European countries and in Turkey. *European Journal of Epidemiology* 27(12):915-21.

¹⁵⁹ See e.g. Wörman, A. & Krämer, A (2011). Communicable diseases, in Rechel et al (op. cit.), 2011: 121-138; Carballo, M. (2009b). Communicable diseases, in: Fernandes, A., Pereira Miguel, J., eds. *Health and migration in the European Union: better health for all in an inclusive society*. Lisbon, Instituto Nacional de Saúde Doutor Ricardo Jorge:53-69

frequently criticised because of their inaccuracy and lack of respect for human rights, as well as their often dubious scientific basis¹⁶⁰. At the same time, the success of campaigns to eradicate infectious diseases in the developing world further reduced concern about 'import diseases'. However, the resurgence of global epidemics (for example of TB, HIV/Aids or hepatitis) toward the end of the 20th century showed this relaxed attitude to be premature.

There is thus a renewed interest in the prevalence of infectious disease among migrants and the potential of screening, early detection and prevention. The European Centre for Disease Prevention and Control (ECDC) recently undertook an extensive overview of this area¹⁶¹. Serious and widespread data limitations were noted. Often it was possible to calculate the relative proportions of carriers of a disease who were migrants or non-migrants, but uncertainty about the denominators made it impossible to convert these figures into prevalence rates.

This issue is particularly worrying given the fact that many conditions are vaccine-preventable. As long as adequate information remains unavailable on prevalence rates and the take-up of vaccination programmes by migrants, it will be impossible to remedy important gaps in coverage. The ECDC has looked extensively into the obstacles to MMR vaccination coverage among hard to reach populations at the European level.¹⁶² They identified the following main barriers: discrimination; administrative and financial problems; language or literacy difficulties; lack of cultural knowledge; lack of information on health and vaccination; religious beliefs; a fatalistic approach to life or a distorted risk perception in relation to vaccines and vaccine-preventable diseases among some individuals and groups. The EC's **AURORA project**¹⁶³ promotes the use of evidence-based prevention for cervical cancer (in which transmission of the human papilloma virus or HPV plays an important role) through the exchange of information and expertise at European level. The project evaluated HPV vaccination programmes in five of the participating countries (Italy, Greece, Slovenia, Latvia and Romania) and found that the implementation of a public health education campaign to prepare the population for the vaccination programmes was key to their success or failure.¹⁶⁴ Other European level projects looking at the vaccination coverage and at the presence of specific programmes or regulations supporting the vaccination coverage of migrants and nomadic groups, include the **EpiSouth Project** and the **Promovax project**. **Episouth**¹⁶⁵ found that, of the 26 participating countries in the area of the Mediterranean and the Balkans, 20 had no specific regulations supporting vaccination programmes for migrant and nomadic groups, while 12 countries reported the presence of special programmes promoting vaccination coverage among those groups. Furthermore, findings indicated that even if regular migrants had equal entitlements to vaccines

¹⁶⁰ Bateman-House, A., Fairchild, A. (2008). Medical Examination of Immigrants at Ellis Island. *Virtual Mentor* 10(4), 235-241.

¹⁶¹ ECDC (2014a) Assessing the burden of key infectious diseases affecting migrant populations in the EU/EEA. European Centre for Disease Prevention and Control.

¹⁶² European Centre for Disease Prevention and Control (2013a). Review of outbreaks and barriers to MMR vaccination coverage among hard-to-reach populations in Europe. Stockholm: ECDC.

¹⁶³ www.aurora-project.eu (accessed 15/1/2015)

¹⁶⁴ *ibid*

¹⁶⁵ EpiSouth Network (2009). EpiSouth Project: Assessment of Countries Migration Status Profile and Vaccination Access of Mobile Population. http://www.episouth.org/outputs/wp7/WP7_9_Report_Assessment_Countries_Migration.pdf (Accessed 18 February, 2015).

as the general population in 18 of 22 countries that responded, access to vaccines and vaccine uptake was still patchy, especially among some groups, e.g. Roma, irregular migrants. The study's findings include the identification of a number of barriers to vaccination. **Promovax's** aims include the improvement of the knowledge base regarding barriers to vaccination coverage, and the development of recommendations for policy makers regarding the vaccination of hard to reach groups, including migrants.¹⁶⁶ A toolkit for health professionals developed as part of the project aims contribute to the wide dissemination of information regarding vaccinations to hard to reach groups, by assisting health professionals to assess the immunisation needs of these groups and thus increase vaccination rates.¹⁶⁷ At the national level, although vaccination coverage was found to be largely adequate in the Netherlands¹⁶⁸, other studies have shown that programmes sometimes do not reach migrants and ethnic minorities effectively¹⁶⁹. For example, the adult immigrant population from Latin America has been found to be especially susceptible to rubella, as most countries in Latin America only adopted Rubella vaccine since 2002. Subsequently, in 2003, an increase in rubella notifications was detected in Madrid among women born in Latin America. None of the women had been vaccinated against Rubella.¹⁷⁰ Similarly, in the UK, ethnic minorities are at an increased risk of rubella susceptibility, possibly because they migrated from countries with no rubella vaccination in their immunization programme, or when they were above the age of routine MMR in the UK.¹⁷¹

2.3.5.1. HIV

Despite the methodological problems just noted, many studies have found that certain groups of migrants have a higher risk of HIV infection. HIV is mainly concentrated in key populations at higher risk of HIV infection such as men who have sex with men, people originating from generalized epidemic countries (mainly sub-Saharan Africa) and other migrants, and PWID and their sexual partners.¹⁷² This is often connected with a raised prevalence of HIV in the countries from which migrants originate, but infections may also be contracted in the host country.¹⁷³ In fact, the main ways for transmission of HIV in Europe are unsafe sex among men who have sex with men and unsafe injecting drug use. Migrants tend to not be highly represented in either risk group.¹⁷⁴ However, migration remains an influential factor when considering heterosexual

¹⁶⁶ <http://www.promovax.eu/index.php/promovax/main> (Accessed 18 February, 2015).

¹⁶⁷ http://www.promovax.eu/toolkits/HCW_english_web.pdf (Accessed 18 February, 2015).

¹⁶⁸ Verweij A, Singels LW (2009). Preventie gericht op alloctonen: Wat is het bereik? In: Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. Bilthoven: RIVM, <http://www.nationaalkompas.nl> Nationaal Kompas Volksgezondheid\Preventie\Gericht op doelgroepen\Alloctonen> (accessed 15/1/2015)

¹⁶⁹ Borrás, E., *et al.* (2007). Vaccination coverage in indigenous and immigrant children under 3 years of age in Catalonia (Spain). *Vaccine*, 25(16): 3240-3.

¹⁷⁰ Lemos, C. *et al.* (2004). New Features of Rubella in Spain: Evidence of an outbreak. *Eurosurveillance*, Vol. 9, Issue 4.

¹⁷¹ Byrne, L. *et al.* (2012). Seroprevalence of low rubella IgG antibody levels among antenatal women in England tested by NHS Blood and Transplant: 2004-2009. Is rubella susceptibility increasing? *Vaccine* 30; 161-167.

¹⁷² European Centre for Disease Prevention and Control/WHO Regional Office for Europe (2014b). HIV/AIDS surveillance in Europe 2013. Stockholm: ECDC.

¹⁷³ ECDC (2014a), *op.cit.*

¹⁷⁴ Wörmann, T., Krämer, A. (2011). Communicable diseases. In: Rechel, B. *et al.* (eds.). Migration and health in the European Union. European observatory on health systems and policies. Open University Press.

transmission: migrants from high HIV prevalence countries accounted for 40% of all cases of transmitted HIV in Western Europe between 2007 and 2011.¹⁷⁵ In those countries with the highest prevalence of migrants among the HIV statistics (Belgium, Cyprus, France, Ireland, Luxembourg, Malta, Sweden and the UK), migrants from Africa (sub-Saharan) seemed to be the group most at risk, and of having acquired the infection in their country of origin.¹⁷⁶ A large study in Spain, found that among migrants with HIV, female sex-workers originating from Latin America were most at risk.¹⁷⁷ In terms of the disease's progression to AIDS, and subsequently potential AIDS mortality, migrants are over-represented, with especially high rates of deaths from AIDS among sub-Saharan Africans. However these rates varied according to EU country: e.g. sub-Saharan Africans in the UK come primarily from Nigeria and Ghana (lower prevalence of HIV), whereas in Portugal they originate mostly from Cape Verde, Mozambique and Angola (higher prevalence of HIV).¹⁷⁸

2.3.5.2. Tuberculosis

Tuberculosis notifications rates are higher in foreign born population than in native born population in Europe, with, on average, twice as many males as females among all TB cases reported.¹⁷⁹ Infected patients are mainly from countries where TB is less well controlled, in Asia, Africa and Europe (outside the EU)¹⁸⁰. In 2008, the total number of new cases of TB in the WHO European region was 461,645, (52.2 per 100,000 population) with the highest rates observed in countries of the former Soviet Union.¹⁸¹ Within the WHO European Region, an estimated 353 000 new TB cases were recorded in 2012, equivalent to an average of 39.4 cases per 100 000 population.¹⁸² These figures mark a significant increase from 2008, when the incidence rate averaged 16.7 per 100,000, with the highest rates in Romania (115.1), Lithuania, Latvia, Bulgaria and Estonia (33.1).¹⁸³ In the WHO European countries where TB surveillance data includes information on migrant status of persons with TB, the average percentage of all cases that were found in people of foreign origin in 2008 was over 20%.¹⁸⁴ In some countries this was much higher. For example, in Germany, approximately 46% of all new reported cases of TB in 2004 were born outside of Germany (many in countries of the former Soviet Union and the Russian Federation) and 35% had foreign citizenship. Children with foreign citizenship in Germany also face a high risk of TB infection.

¹⁷⁵ ECDC (2014a), *op.cit.*

¹⁷⁶ *ibid*

¹⁷⁷ *ibid*

¹⁷⁸ *ibid*

¹⁷⁹ European Centre for Disease Prevention and Control/WHO Regional Office for Europe (2014c). Tuberculosis surveillance and monitoring in Europe 2014. Stockholm: ECDC.

¹⁸⁰ ECDC (2014a), *op.cit.*

¹⁸¹ Wörmann & Krämer (2011), *op.cit.*

¹⁸² ECDC (2014c), *op.cit.*

¹⁸³ ECDC (2014a), *op.cit.*

¹⁸⁴ *ibid*

2.3.5.3. Other infectious diseases

The ECDC report mentioned above¹⁸⁵ also concluded that a higher risk of hepatitis B, malaria and Chagas disease may affect certain migrant groups. No increased risks of gonorrhoea and syphilis were found, however, and no reliable evidence was available on measles, rubella and hepatitis C. For an up-to-date and comprehensive overview of the epidemiological situation in the European Union relating to communicable diseases of public health importance, the ECDC's 2012 Annual Epidemiological Report presents an analysis of surveillance data from 2010 and of communicable disease threats detected in 2011.¹⁸⁶ For vaccine preventable diseases it reports an overall declining or stable trend in reported incidence of confirmed cases. More specifically, tetanus and diphtheria cases were rare, except for Italy where 57 cases of tetanus were reported in 2010. Rubella and mumps also showed a decline in rate of new infections, though the report stresses that the burden of disease is hard to assess due to variations in surveillance systems and reporting, and particularly low rates of laboratory confirmation. The report is intended primarily for policymakers, health service leaders, epidemiologists and researchers, and identifies opportunities where continued or increased public health responses may be needed to decrease the burden of these diseases.

2.3.6. Maternal and child health

A recent study by Médecins du Monde explored in detail the challenges and vulnerabilities faced by the thousands of individuals and families accessing their clinics all over Europe. Most of those accessing health services in Médecins du Monde clinics are migrants, but not all. Findings indicated that women and children were especially vulnerable as access to antenatal care for pregnant women and to essential childhood vaccinations are currently not universally guaranteed in the EU.¹⁸⁷

Migrant women in general are exposed to a higher risk of maternal mortality¹⁸⁸, while in many migrant groups worse outcomes are also found in relation to low birth weight, premature birth, perinatal mortality and morbidity and congenital malformations^{189,190}. However, as we saw in Section 1.6.2, rates of stillbirth and neonatal mortality among groups of migrant origin also vary between different countries of destination, which may reflect differences between European countries in the accessibility and quality of health care for pregnant women in those groups.¹⁹¹

¹⁸⁵ *ibid*

¹⁸⁶ European Centre for Disease Prevention and Control (2013b). Annual Epidemiological Report 2012. Reporting on 2010 surveillance data and 2011 epidemic intelligence data. Stockholm: ECDC.

¹⁸⁷ Chauvin P, Simonnot N, Douay C, Vanbiervliet F. (2014). *Access to healthcare for people facing multiple vulnerability factors in 27 cities across 10 countries. Report on the social and medical data gathered in 2013 in eight European countries, Turkey and Canada*. Paris: International network of Médecins du monde.

¹⁸⁸ Pedersen, G.S., Grøntved, A., Mortensen, L.H., Andersen, A.-M.N., Rich-Edwards, J., (2013). Maternal Mortality Among Migrants in Western Europe: A Meta-Analysis. *Matern Child Health J* 1–11.

¹⁸⁹ Bollini, P., Pampallona, S., Wanner, P., Kupelnick, B., (2009). Pregnancy outcome of migrant women and integration policy: A systematic review of the international literature. *Social Science & Medicine* 68, 452–4

¹⁹⁰ Reeske, A., Razum, O. (2011). Maternal and child health – from conception to first birthday. In Rechel et al. (2011), op. cit., 139-144

¹⁹¹ Villadsen SF, et al (2010). Cross-country variation in stillbirth and neonatal mortality in offspring of Turkish migrants in northern Europe. *European Journal of Public Health*, 20(5):530–535.

With regard to screening for different types of cancer such as cervical and breast cancer, one study conducted in the UK found that ethnicity was the only statistically significant predictor when researchers compared women who had had some screening with those who had had none. In other words, white women were significantly more likely to have had a cervical smear than other groups of women.¹⁹² Nevertheless, as another UK study illustrates, screening rates among different ethnic minority groups vary significantly. While South Asian women were in the focus for low screening rates, a closer look at how they compared to women from other ethnic groups in areas of high ethnic density, revealed that the rate of women who had never attended either breast or cervical cancer screening was significantly higher among women from other ethnic groups.¹⁹³ As a result, subsequent studies have explored screening rates for women from other ethnic groups in the UK.

The obstetric complications associated with female genital mutilation or cutting (FGM) also present challenges to health service providers. They require specialist knowledge about the potential health risks to mother and child, the legal and ethical frameworks surrounding this issue, and the most effective ways of meeting the health needs of the women subjected to or at risk of this procedure. This is in order to ensure qualified and effective preventive measures against FGM, and coping with the effects of the mutilation. (See Section 2.5.2.2.)

2.3.7. Mental health

2.3.7.1. General issues

A fundamental issue affecting research on the mental health problems of migrants and ethnic minorities is that cultures and countries vary in the way they conceptualise such problems, the types that they recognise and the way distress and disability is expressed¹⁹⁴. Whereas the presence or absence of physical diseases can be decided on the basis of objective biological indicators, psychiatric diagnosis has to rely on interpretation and judgement¹⁹⁵. This involves taking into account relevant cross-cultural variations: the evidence base in this area is not well developed. For this reason, research on mental health among migrants and ethnic minorities is less well developed than on other topics. (The **MEHO project**, for example, did not include mental health among the conditions it studied). **Project PROMO** (Best Practice in Promoting Mental Health in Socially Marginalized People in Europe) has chosen to focus on social marginalization as a starting point for approaching determinants of mental ill health, and asylum seekers, irregular migrants, and refugees are explicitly included, as are long-term unemployed, homeless, street sex workers, and travelling communities.¹⁹⁶ Its objectives, in short, are the delivery of health and social care for people with mental health problems who experience

¹⁹² Moser, K., Patnick, J., Beral, V. (2009). Inequalities in reported use of breast and cervical screening in Great Britain: analysis of cross sectional survey data. *British Medical Journal* 338:b2025

¹⁹³ Webb, R., Richardson, J., Esmail, A. and Pickles, A. (2004) Uptake for cervical screening by ethnicity and place-of-birth: a population-based cross-sectional study. *Journal of Public Health (Oxford)*, 26(3): 293–6.

¹⁹⁴ Bhugra, D., Gupta, S. (eds.) (2006). *Migration and Mental Health*. London and New York: Cambridge University Press

¹⁹⁵ Horwitz, A.V., Wakefield, J.C. (2006). The epidemic in mental illness: clinical fact or survey artifact? *Contexts*, 5(1): 19-23.

¹⁹⁶ <http://www.promostudy.org/project/> (Accessed 23 February, 2015).

exclusion and marginalization in society. For more information on the project outcomes and access to the project deliverables, please see <http://www.promostudy.org/outcomes/index.html>

2.3.7.2. Depression and anxiety disorders

These so-called ‘common mental illnesses’ are often hard to distinguish from “normal reactions to abnormal situations”. Appendix II lists a number of studies showing higher prevalences of depression and anxiety among migrants. It is known that social disadvantage and lower SES are associated with depression, but it is not clear how many of the problems among migrants can be accounted for in such terms. Some studies¹⁹⁷ have shown that perceived discrimination or racism can increase rates of common mental disorders.

2.3.7.3. Schizophrenia and related psychotic disorders

Although the overall prevalence of these disorders is low (around 1%), raised levels are found in some migrant groups. Many studies in the UK, the Netherlands, Sweden and Denmark have shown that young males from non-Western countries are particularly at risk¹⁹⁸.

2.3.7.4. Post-traumatic stress disorder (PTSD) and refugee mental health problems

It is often assumed that the main mental health problems of refugees and asylum seekers are post-traumatic disorders resulting from harrowing experiences in their country of origin. Although a meta-analysis¹⁹⁹ showed a prevalence of 9% among refugees, which is around ten times higher than in the general population, another meta-analysis²⁰⁰ concluded that rates of depression were twice as high among refugees as among labour migrants (44% versus 20%). The same was true for anxiety disorders (40% versus 21%). Mental health problems among refugees are thus not simply a matter of post-traumatic stress reactions. Moreover, the origin of these problems may lie not in the country of origin, but in experiences endured during the flight and the asylum application procedure²⁰¹.

2.3.8. Occupational health and safety

¹⁹⁷ E.g. Karlsen, S. *et al.* (2005). Racism, psychosis and common mental disorder among ethnic minority groups in England. *Psychological Medicine*, 35:12:1795–1803

¹⁹⁸ Ingleby, D. (2008). *New perspectives on migration, ethnicity and schizophrenia*. Willy Brandt Series of Working Papers in International Migration and Ethnic Relations 1/08, IMER/MIM, Malmö University, Sweden.

¹⁹⁹ Fazel, M., Wheeler, J., Danesh, J. (2005). Prevalence of serious mental disorder in 7000 refugees resettled in western countries: a systematic review. *The Lancet*, 365:9467:1309–1314.

²⁰⁰ Lindert, J. *et al.* (2009). Depression and anxiety in labor migrants and refugees – a systematic review and meta-analysis. *Social Science & Medicine*, 69:2:246–257.

²⁰¹ Ingleby, D. (ed.) (2005) *Forced migration and mental health: rethinking the care of refugees and displaced persons*. New York: Springer.

This is another area in which migrants are exposed to increased health risks. Many migrants work in so-called “3D jobs” – “dirty, demanding and dangerous”²⁰². According to a recent overview of the topic²⁰³, migrant workers experience higher rates of industrial accidents, injuries and work-related diseases. Because of their precarious employment conditions and poorer access to health services, many work-related illnesses may go unreported and treated. The **European Agency for Safety and Health at Work (OSHA)** explores the challenges faced by migrants, regular and irregular, their employers and co-workers, in the health care sector, and lists the following areas as requiring special health and safety attention: cultural (e.g. language-related) barriers to communication and training in OSH; the high prevalence of overtime work and related risks for accidents and ill health among migrant workers; and cooperation and leadership in multicultural teams and guidance on cultural diversity issues at work.²⁰⁴

²⁰² McCauley, L.A. (2005) Immigrant workers in the United States: recent trends, vulnerable populations, and challenges for occupational health. *Journal of the American Association of Occupational Health Nurses*, 53(7), 313–19.

²⁰³ Agudelo-Suárez, A.A., Ronda-Pérez, E. & Benavides, F.G. (2011). Occupational health. In: Rechel et al., *op cit.*, 155-168.

²⁰⁴ De Jong, *et al* (2014). Current and emerging issues in the healthcare sector, including home and community care. European Agency for Safety and Health at Work. <https://osha.europa.eu/en/publications/reports/current-and-emerging-occupational-safety-and-health-osh-issues-in-the-healthcare-sector-including-home-and-community-care> (Accessed 15 February 2015).

2.4. Health inequalities affecting the descendants of migrants

In this section we focus on the ‘second generation’, i.e. the European-born children of migrants (many of whom have of course now reached adulthood). As we saw in Chapter 1, this group tends to be invisible in statistics on health: they are by definition excluded from studies of migrants, while studies that disaggregate people on the basis of self-ascribed ethnicity tend to lump together migrants and their offspring born in the host country. In the Netherlands separate analysis is possible using registry data, while in several countries studies have been set up using specially recruited samples.

2.4.1. Findings from the UK

We begin with a recent summary²⁰⁵ of the main findings of UK research on ethnic differences in general, in which no distinction is made between migrants and their UK-born descendants.

- Generally poorer health among non-White minorities, with Bangladeshi people having the poorest health, followed by Pakistani, Black Caribbean, Indian and Chinese people;
- High, but variable, rates of diabetes across all non-White groups;
- High rates of heart disease among ‘South Asian’ people, but particularly among Bangladeshi and Pakistani people;
- High rates of hypertension and stroke among Caribbean and African people, but low rates of overall mortality, and mortality from coronary heart disease, for men born in the Caribbean;
- Low rates of respiratory illnesses across all non-White groups;
- High rates of admission to psychiatric hospitals with a diagnosis of psychotic illness for young Black Caribbean men;
- High rates of suicide among young women born in South Asia, or, more particularly, born in India;
- High rates of sexually transmitted illnesses among Black Caribbean people; and
- High rates of congenital abnormality and childhood disability among Muslim children.

The author of this summary goes on to say that “in contrast to research focussing on possible genetic or cultural underpinnings of ethnic differences in health, there is now considerable evidence that the social and economic inequalities faced by ethnic minority groups make a substantial contribution to ethnic inequalities in health”.²⁰⁶ It is not clear, however, what differences there are (if any) between migrants and their descendants.

²⁰⁵ Taken from James Y. Nazroo (2014). *Ethnic Inequalities in Health: Addressing a Significant Gap in Current Evidence and Policy* In *If you could do one thing...” Nine local actions to reduce health inequalities*. London: British Academy, p. 94. http://www.britac.ac.uk/policy/Health_Inequalities.cfm

²⁰⁶ *Ibid*, p. 96.

Some light on this question may be shed by a specially set up longitudinal study called DASH (Determinants of young Adult Social well-being and Health)²⁰⁷. DASH examines how social, environmental and biological factors affect the health and well-being of young people from different social and ethnic backgrounds in London. The highly multicultural environment of London may not be representative of other parts of the UK, let alone of Europe, but this study of over 6000 children born around 1990 has nevertheless produced extremely interesting findings.

- In adolescence, Black African and Black Caribbean girls were more likely to be overweight than participants from other ethnic groups. Contributory factors included skipping breakfast, drinking too many carbonated soft drinks and not eating enough fruit and vegetables. Girls from all ethnic backgrounds were far less likely to do any physical activity than boys.
- Although still within normal ranges, blood pressure rose faster over time for ethnic minority than White British children (cf the findings reported above on cardiovascular diseases).
- Contrary to many findings of poorer mental health among ethnic minorities, adolescent boys from ethnic minorities (particularly Black African boys) tended to report better mental health than White British children despite coming from poorer families and neighbourhoods. Positive factors identified were caring parents, doing things together as a family and having friends from different ethnic groups. Experiences of racism had a negative effect on mental health in all ethnicities.
- By their early 20s just as many or even more ethnic minorities completed a university degree compared with the White British, despite more deprivation in childhood.

The last finding not only runs contrary to the average results from the TIES and PISA projects (see section 1.7), but suggests – together with the preceding finding on mental health – that some groups of migrant origin obtain *better* outcomes after allowance is made for their socioeconomic conditions. In a Belgian study²⁰⁸, it was found that the self-reported health of migrants was actually better than that of natives when differences in their living conditions were controlled for.

2.4.2. Findings from the Netherlands

In the Netherlands data are available on the health of the four main groups of migrant origin: those originating in Turkey, Morocco, Suriname, and the Dutch Antilles and Aruba. Data on children born in the Netherlands with a mother and/or father who was born in the above countries are also collected, enabling the characteristics of the second generation to be studied. Some of the main findings are as follows.

²⁰⁷ <http://dash.sphsu.mrc.ac.uk>

²⁰⁸ Lorant V, Van Oyen H, Thomas I.(2008). Contextual factors and immigrants' health status: double jeopardy. *Health & Place*, 14:4:678–692.

- In terms of education and employment, the second generation does less well than people of Dutch origin, although those of Surinamese origin do better than the other three groups²⁰⁹.
- We have already noted that a higher proportion of non-Western migrants are diagnosed as 'psychotic' than the majority population. Dutch research shows the raised incidence to be even higher in the second generation^{210, 211}.
- Regarding behavioural risk factors, the usual expectation is that rates of risky behaviour in the second generation will converge towards the rates found in the majority population. A study in 2007 found this to be true in relation to smoking in Turkish men, overweight in Turkish and Moroccan women and physical inactivity in Turkish women. Alcohol consumption, however, remained low in all subgroups and did not converge towards the higher rates in the host population. In addition, there was a reversed trend among Turkish women regarding smoking: the second generation smoked significantly more, while the first generation did not differ from ethnic Dutch.²¹²
- In 2004-2005, the infant mortality rate for first-generation mothers with a non-western background was 4.7 times higher than the rate for native Dutch mothers; for second-generation mothers it was still 2.9 times higher²¹³. These findings are compatible with those reported for 1995-2000: in this earlier period, a comparison of first- and second generation mothers from the four main (non-western) ethnic minority groups²¹⁴ showed that only among Surinamese mothers was there a significant decline in infant mortality rates between the first and second generation. These persistent rates of increased infant mortality in groups with a migrant background may be contributing to the poor perinatal mortality ranking of the Netherlands compared to other European countries (rather than the popularity of home birth in the Netherlands²¹⁵). In section 4.1.1. we discuss the relevance to this of shortcomings in preventive services and health education for migrants.

2.4.3. Findings from other countries

²⁰⁹ Nederlands Jeugdinstituut (2009). Culturele diversiteit in opgroeien en opvoeden: feiten en cijfers. Nederlands Jeugdinstituut, 2009.

²¹⁰ Veling, W., Selten, J. P., Veen, N., Laan, W., Blom, J. D. & Hoek, H. W. (2006). Incidence of schizophrenia among ethnic minorities in the Netherlands: a four-year first-contact study. *Schizophr. Res*, 86, 189-193.

²¹¹ Selten, J. P., Laan, W., Kupka, R., Smeets, H. & van Os, J. (2011). Meer kans op depressie en psychose bij allochtonen. *Ned Tijdschr Geneesk*, 155.

²¹² Hoesper K, Nierkens V, Nicolaou M, Stronks K. (2007). Behavioural risk factors in two generations of non-Western migrants: do trends converge towards the host population? *Eur J Epidemiol*, 22(3), p. 163-72

²¹³ Statistics Netherlands Webmagazine, 17 November 2009. <http://www.cbs.nl/en-GB/menu/themas/dossiers/allochtonen/publicaties/artikelen/archief/2009/2009-2964-wm.htm>

²¹⁴ Troe, J.W.M., *et al* (2004). Ethnic differences in infant mortality in relation to degree of acculturation. *Ethnicity & Health*, 9, Supplement 1, p. S13.

²¹⁵ de Jonge, A., *et al* (2013). Perinatal mortality rate in the Netherlands compared to other European countries: a secondary analysis of Euro-PERISTAT data. *Midwifery* 29(8):1011-8.

A large study conducted in Denmark from 2004-2008 sought to portray the health status of first and second generation migrants compared to that of the majority Danish population.²¹⁶ The findings of this study reflect clearly the complexity of the issue of migrant and ethnic minority health, as the country of origin, gender, age and generation of migrant are just some of the factors influencing the state of health of migrants and ethnic minorities.

The study relied on data collected from a nation-wide survey of nearly 5,000 individuals. Descendants of migrants from Turkey and Pakistan were included in the study, as they make up the largest group of migrants' descendants in Denmark. The main findings included no significant difference in self-perceived health between descendants of Turkish and Pakistani migrants and ethnic Danes aged 18-39. However, across all groups, the older the migrants and their descendants, the greater the differences in perceived health when compared to ethnic Danes, i.e. the older the migrants, the more likely they were to rate their health as poor.

The data on diseases, chronic conditions and life style revealed a more complex picture of the health issues affecting descendants of migrants and their life-style practices. While many patterns were similar for migrants and their descendants, some notable differences did emerge. While the disease burden of three or more chronic illnesses was between 24-45% higher for all migrant groups compared to Danes, it was slightly lower among 18-39 year-old descendants of Pakistani and Turkish migrants.

In terms of life-style habits, the percentage of Turkish and Pakistani male descendants who reported to be daily smokers was slightly higher than migrants in general, and significantly higher compared to Danish men, while the percentage of descendants who never consumed alcohol was more than four times higher than the percentage of Danes who do not drink alcohol, for both women and men. Rates of physical activity were also higher among all migrants compared to Danes, and among descendants aged 18-39, rates of physical activity were significantly higher than that of Danes.

2.5. Health determinants

2.5.1. Location of determinants

The origin of health problems may lie in the country of origin, the journey, or in the host country.²¹⁷ The 'life-course' perspective²¹⁸ considers that there may be highly complex

²¹⁶ Singhammer, J. *et al* (2008). Etniske minoriteters sundhed. Partnerskabet for undersøgelse av etniske minoriteters sundhed, Center for Folkesundhed

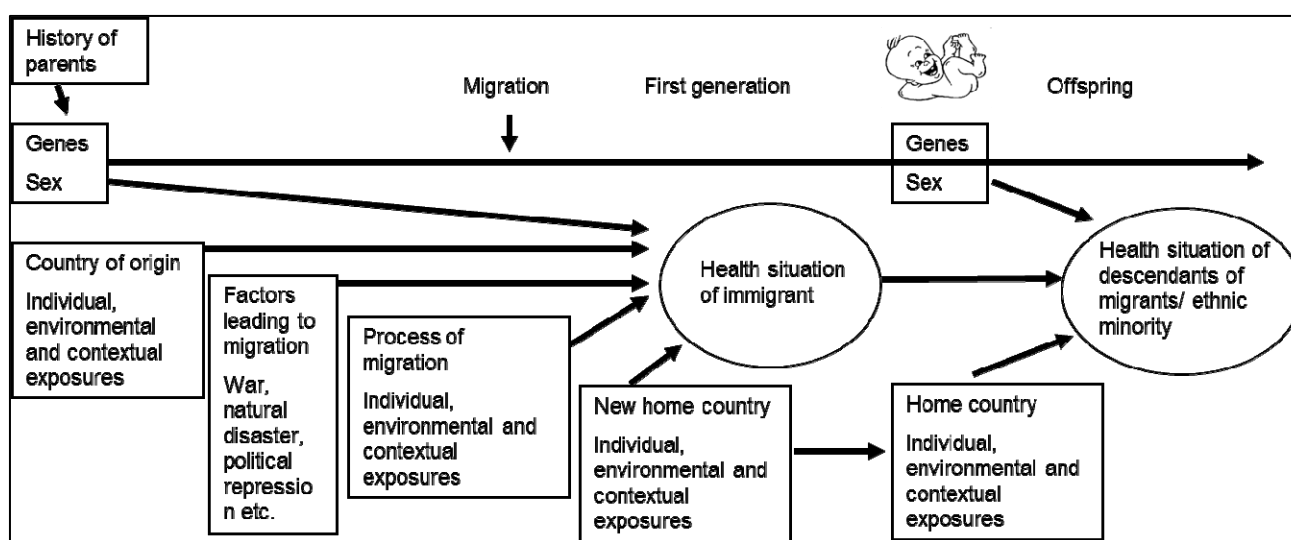
²¹⁷ Gushulak, B., Pace, P., Weekers, J. (2010). Migration and health of migrants. In: *Poverty and social exclusion in the WHO European Region: health systems respond*. Copenhagen, WHO Regional Office for Europe.

²¹⁸ Reeske, A. and Spallek, J. (2012) Obesity among migrant children and adolescents: a life-course perspective on obesity development. In: Ingleby, D., Krasnik, A., Lorant, V. & Razum, O. (Eds.) *Health*

interactions between all three factors. The diagram below illustrates the complexity of these determinants of migrant health. It must also be borne in mind that these factors do not affect health directly, but through various intervening variables and pathways: this complicates the analysis still further.

Figure 11 Different exposures during the life course on the health of migrants

(Adapted from Reeske & Spallek, 2012²⁹)



2.5.2. Nature of determinants

Many different kinds of factors may underlie the prevalence of disease among migrant groups.

2.5.2.1. Genetic factors

The traditional concept of 'race' - a putative biological factor determining the characteristics of large population groups - has been widely discredited on scientific grounds²¹⁹. If the concept still has any use at all, it is to refer to social constructions which, though unwarranted in biological terms, are nevertheless real in their social effects. However, particular genetic differences may well be the key to understanding differences between population groups in their vulnerability to certain diseases. It has long been known that sickle-cell anaemia occurs predominately in African

inequalities and risk factors among migrants and ethnic minorities. COST Series on Health and Diversity, Volume I (pp. 237-256). Antwerp/Apeldoorn: Garant

²¹⁹ Bhopal, R. (2002). Revisiting race/ethnicity as a variable in health research. *Am J Public Health*. 92(2):156-157.

Americans, while Tay-Sachs disease is mainly found in Ashkenazi Jews. Developments in genetic profiling will undoubtedly discover more such links, though intermarriage and complex interactions with other factors weaken the impact of any such effects.

2.5.2.2. Cultural factors

Differences in lifestyle linked to 'culture' have been a popular type of explanation in the study of migrants' health. Again, some quite strong connections can be found: for example, the difference in smoking habits between men and women in traditional Bangladeshi and Pakistani communities is reflected in marked sex differences in lung cancer incidence.²²⁰ As Bhopal points out²²¹, many cultural traditions (such as prohibitions on alcohol and sexual promiscuity) can have a positive influence on health.

Female genital mutilation or cutting (FGM) is perhaps the most well-known example of a practice that negatively affects health and is linked to traditional cultures. FGM procedures include the partial or total removal of the external genital organs for cultural or other non-therapeutic reasons. The practice has severe short- and long-term physical and psychological consequences for the victims.²²² Over 140 million women are affected by this practice, both in the countries where these practices originate (countries in Africa and the Middle East), and also in migration destinations. Due to under-reporting and the lack of reliable comparable data, no exact figures exist on the prevalence of FGM in Europe. However, it is safe to say that thousands of women and girls in Europe live with the effects of FGM or face the risk of undergoing the procedure in a European country or in Africa or the Middle East.²²³ The largest groups of women and girls originating from countries in which the practice of FGM is widespread live in the following EU countries: Austria, Belgium, Denmark, Germany, Spain, Finland, France, Ireland, Italy, the Netherlands, Portugal, Sweden and the United Kingdom.²²⁴ The health impacts of FGM are well documented. Research has linked FGM with an increased risk in complications during childbirth, e.g. prolonged labour, obstetric lacerations, obstetric haemorrhage, and difficult delivery.²²⁵ Midwives especially should be trained in how to prepare for potential delivery complications associated with FGM.

While FGM is a clear example of a culture-bound practice linked to a health problem, there are two main problems with explanations of ill-health in terms of 'culture'. Firstly, the notion that each ethnic group or country of origin is associated with a stable and homogeneous culture has come under fire in recent decades, as we will see in relation to the concept of 'cultural competence'. Secondly, lifestyles are not practised in a vacuum: healthy eating, for example, is not just a personal choice but also depends on the availability and affordability of the right

²²⁰ Jack, R.H., Davies, E.A. & 1 Møller, H. (2011) Lung cancer incidence and survival in different ethnic groups in South East England. *British Journal of Cancer* 105, 1049–1053.

²²¹ Bhopal, R. (2014) *op cit*.

²²² As defined by the World Health Organisation, 1998.

²²³ Leye, E. (2006). Health care in Europe for women with genital mutilation. *Health Care for Women International*, 27:4. Pg. 362-378.

²²⁴ http://ec.europa.eu/justice/gender-equality/gender-violence/eliminating-female-genital-mutilation/index_en.htm (accessed 18 February, 2015).

²²⁵ Berg, R.C. *et al* (2014). An Updated Systematic Review and Meta-Analysis of the Obstetric Consequences of Female Genital Mutilation/Cutting. *Obstetrics and Gynecology International*, Volume 2014

foodstuffs, as well as having the time and facilities to prepare them. Advertising and social pressures are also powerful determinants of behaviour.

Religious beliefs may also exert an impact on health and health seeking behaviours, both in positive and negative ways. For example, a study on the non-biomedical procreation beliefs of infertile Middle Eastern migrants in Western European societies, and the possible effects of these beliefs on the experience of seeking and engaging in fertility treatment, found that some Islamic beliefs on procreation might have an impact on the use of artificial reproductive technologies such as sperm donations.²²⁶ The opposition of the Catholic Church to artificial methods of birth control has had consequences throughout the world for the prevention of infection by condom use and the avoidance of unwanted pregnancies.

Some cultural beliefs may be misunderstood as resistance to care.²²⁷ For example, Sudanese women in Canada were found to perceive pregnancy and delivery as natural processes that do not necessarily call for intensified contact with health services.

Another study explored the impact of cultural factors on the interactions between health professionals and Somali women in Finland.²²⁸ Physicians, nurses and midwives described situations where cultural norms on both sides hampered, delayed or prevented the delivery of adequate care in a timely manner. Most Somali women were reported to request female gynaecologists, for example. Other examples included different communication styles, the taboo of hand-shaking and other forms of physical contact with male physicians, as well as religious beliefs related to childbirth).

However, as the composition of migrant and ethnic minority populations varies from country to country, as does the degree of integration among groups and individuals, as well as their adherence to traditional or cultural practices, health professionals should avoid relying on cultural stereotypes and instead approach those they come into contact with in a patient-centered way, remaining alert to different forms of diversity. On a health services level, identifying specific needs of a community or a group, such as for example, communities known to practice FGM, targeted and well-informed strategies should be devised in collaboration with civil society actors. For more detailed information on the role of culture in health service delivery see **Section 5.2.1**.

²²⁶ Van Rooij, F.B., van Balen, F., Hermanns, J.M.A. (2004). A review of Islamic Middle Eastern migrants: traditional and religious cultural beliefs about procreation in the context of infertility treatment. *Journal of Reproductive and Infant Psychology*. Vol. 22:4.

²²⁷ Higginbottom, G.M. *et al* (2013). "I have to do what I believe": Sudanese women's beliefs and resistance to hegemonic practices at home and during experiences of maternity care in Canada. *BMC Pregnancy Childbirth*. 13:51.

²²⁸ Degni, F. *et al* (2012). Communication and Cultural Issues in Providing Reproductive Health Care to Immigrant Women: Health Care Providers' Experiences in Meeting Somali Women Living in Finland. *Journal of Immigrant and Minority Health*. Volume 14, Issue 2. Pg. 330-343.

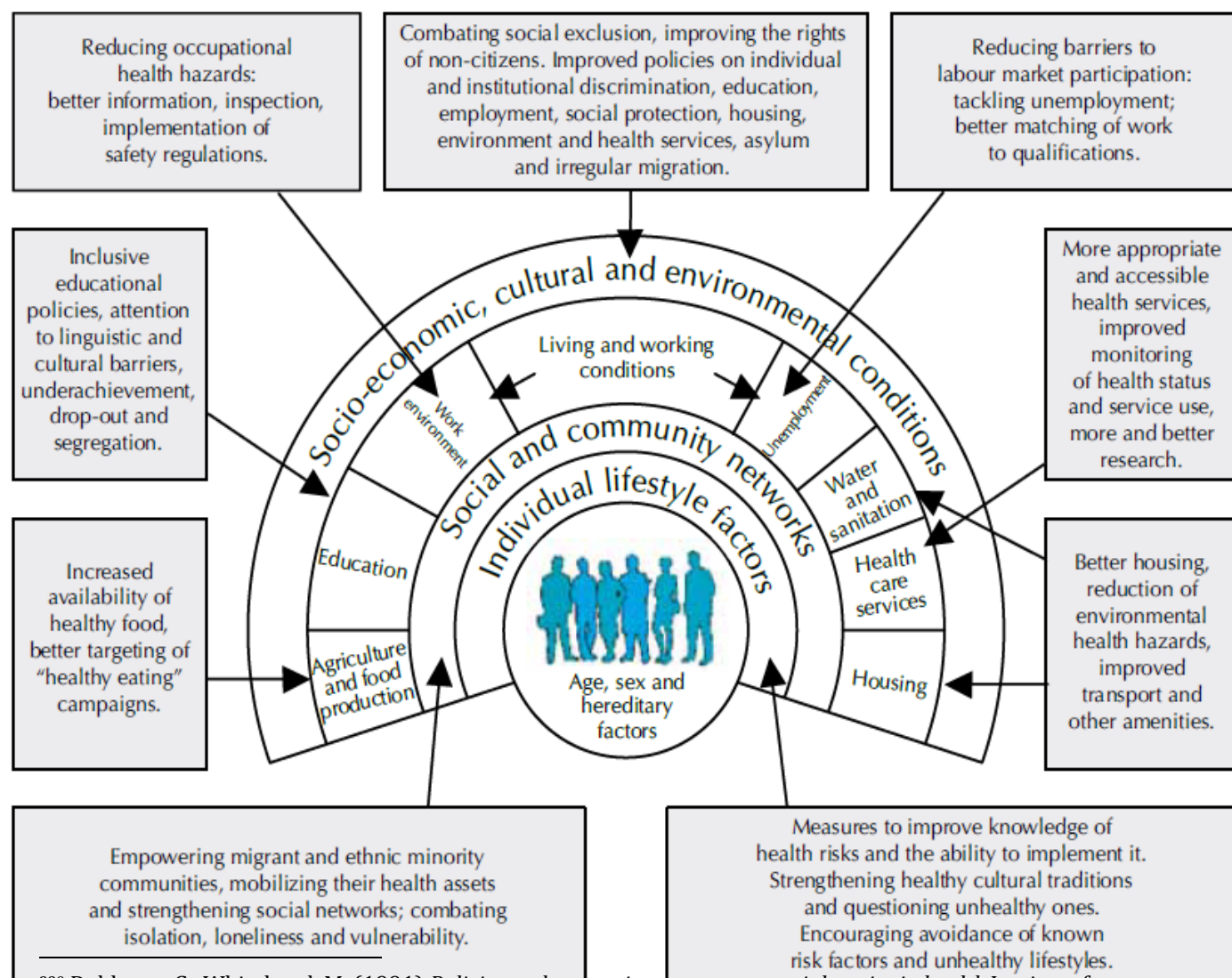
2.5.2.3. Health system factors

Health may be impaired by shortcomings of the health system in providing adequate prevention programmes, health education and promotion, or health services that are accessible and of high quality.

2.5.2.4. Social determinants

The 'rainbow diagram' of Dahlgren and Whitehead²²⁹ is a way of representing the social determinants of health that has gained widespread influence since it was first presented in 1991. In the WHO's 2010 Policy Briefing on migrant and ethnic minority health²³⁰ this diagram was adapted to show the social determinants of migrant health. This is reproduced below.

Figure 12 'Rainbow' diagram showing social determinants of migrant health, WHO 2010¹



²²⁹ Dahlgren, G., Whitehead, M. (1991) *Policies and strategies to promote social equity in health*. Institute for Future Studies, Stockholm.

²³⁰ WHO (2010), *op. cit.*

The information in the Rainbow diagram can also be represented in the form of a table (below). Here, a distinction has been made between determinants which have a 'direct' effect (i.e. those which specifically affect migrants) and those with an 'indirect effect' (i.e. those which affect people in occupying disadvantaged socioeconomic positions, and affect migrants disproportionately because many migrants are likely to be in such positions).

Table 1 Risk factors for migrants' health

	Direct determinants	Indirect determinants
Nutrition	Lack of targeted health promotion, unawareness of dangers of Western food, too little variation in diet.	Healthy food unavailable, unaffordable, or too time-consuming; necessity of relying on processed and ready-made food
Education	Non-recognition of qualifications, inequities in education system (e.g. unfair assessments, lack of opportunity for newcomers to catch up)	Barriers to good education (schooling and training) for the less well-off.
Work environment	Lack of targeted safety measures at work (e.g. bilingual instructions and warnings). Discrimination on the work floor.	Low-paid jobs often dangerous as well as poorly regulated and inspected
Living and working conditions	Diverse forms of social exclusion based on ethnicity or migrant status. Some connected with immigration policy, e.g. detention (which is a health threat in itself) or difficult family reunion.	Diverse forms of social exclusion based on low socioeconomic status
Employment	Discrimination in hiring and promotion, non-recognition of qualifications	Precarious work, long hours, strenuous and stressful work, poor working conditions
Water, sanitation, housing	Discrimination in allocation of housing, fewer rights for non-citizens	Poorer neighbourhoods are unhealthy ones
Health services	Fewer entitlements, poorer accessibility of services, lower quality (lack of 'difference sensitivity'). Inadequate screening and vaccination programmes.	Health services insufficiently adapted to those with low language ability, 'health literacy' and social capital
Social and community networks	Networks may be weakened by uprooting. Segregation helps social contact but makes upward social mobility harder	Lack of leisure time, low participation in community activities, less social capital
Individual lifestyle factors	Lack of effectively targeted health promotion. Cultural habits may undermine but also support health	Lack of effectively targeted health promotion. 'Unhealthy lifestyles' have determinants further upstream.

As we saw in Section 2.1.3, there is an increasing tendency in studies of migrant and ethnic minority health to focus on more ‘upstream’ risk factors underlying health problems, as well as strategies for combating them – which almost always involve intersectoral interventions going beyond the health sector itself.

[2.6. Health inequalities affecting Roma and national ethnic minorities, and their determinants](#)

2.6.1. General issues

Surveys and national level research have identified general trends in the state of health and health determinants characteristic of Roma communities in Europe.²³¹ Even though most of the research on Roma is not comparable at a European level, some generalisations are well documented.²³² Roma in Europe suffer significant health inequalities when compared to the majority non-Roma population. Roma women are generally worse off in terms of health compared to Roma men and the general population, especially considering the higher rates of maternal health risks and outcomes, as well as higher rates of domestic violence.²³³ While genetic or cultural determinants of health and ethnicity may explain some of the inequalities in health compared to non-Roma populations, social and environmental determinants also play a significant role, such as lower income, poor living conditions, discrimination and racism, and barriers to accessing health services.^{234,235} These factors may help to explain the lower life expectancy, the incidence of certain infectious diseases (such as tuberculosis and hepatitis) generally associated with poor living conditions, as well as the prevalence and earlier appearance of some chronic conditions less frequent in non-Roma populations, as well as maternal and child morbidity and mortality.²³⁶

In terms of data collection on Roma communities in Europe, a number of obstacles stand in the way. As discussed in Section 2.1.1., population data collection in many countries in Europe does not disaggregate data by ethnicity, and where it does, Roma may try to hide their ethnicity in order to avoid stigmatisation. Furthermore, census data tend to undercount Roma. Historical misuse of data on certain populations, for purposes of persecution or worse, has inspired some

²³¹ Open Society Institute. (no date) *Left Out: Roma and Access to health care in Eastern and South Eastern Europe*. Public Health Program.

²³² Fésüs, G. *et al.* (2012) Policies to improve the health and well-being of Roma people: The European experience. *Health Policy* 105: 25-32.

²³³ Matrix Consulting (2014). Roma Health Report. European Commission: Consumer, Health and Food Executive Agency.

²³⁴ Voko, Z. *et al.* (2009) Does socioeconomic status fully mediate the effect of ethnicity on the health of Roma people in Hungary? *J Epidemiol Community Health*; 63: 455-460.

²³⁵ Masseria, C., Mladovsky, P., Hernández-Quevedo, C. (2009) The socio-economic determinants of the health status of Roma in comparison with non-Roma in Bulgaria, Hungary and Romania. *European Journal of Public Health*, Vol. 20, No. 5: 549-554.

²³⁶ Schaaf, M. (2007) *Confronting a Hidden Disease: TB in Roma Communities*. Open Society Institute: Roma Health Project.

countries to prohibit the recording of ethnic or race-related data. In addition, there is a lack of agreement regarding the terminology and definitions used when referring to Roma minorities.²³⁷

EU projects such as "**Health and the Roma Community, Analysis of the Situation in Europe**" (see Appendix VI) worked to overcome the challenges of collecting empirical and comparable data on the health of Roma communities, by systematically collecting and comparing qualitative and quantitative data obtained in the seven participating countries. Some of the findings of this project are discussed below in *Section 2.4. Differences found* and for the literature on the state of health of Roma populations in Europe, see Appendix II.

As mentioned in Chapter 1, research on national ethnic minorities is quite limited, in part due to the fact that many of these minority groups are not recognised and not all groups experience inequalities. The Sami, an indigenous minority group in the north of Norway, Finland and Sweden however, has been the subject of numerous studies. The University of Tromsø's Centre for Sami Health Research has conducted extensive research on the Sami's health status and the barriers they experience in accessing health services. The **project SAMINOR**, a population-based study of health and living conditions in areas with both Sami and Norwegian inhabitants in Norway, collected data from 2002-2004. Findings on self-reported health indicated that Sami respondents reported to be in worse health than Norwegian respondents, and Sami women more so than men. Additional findings included experiences of discrimination in encounters with health services (especially reported by Sami women), and language barriers.²³⁸

2.6.2. Differences found

2.6.2.1. General measures of health

In general, as has been stated above, Roma have a significantly worse health profile when compared to non-Roma. On average, Roma are estimated to live approximately 10 years less than non-Roma.²³⁹ However, mortality rates and life expectancy estimates vary across and within countries, as well as in different groups within the Roma populations. For example, estimates in Austria suggested mortality rates 14% higher for Roma at the regional level than for the rest of the country. Poorly integrated Roma living in settlements with poor living conditions in Slovakia were found to have a mortality rate twice to three times as high as that of well-integrated Roma, and higher infant mortality rates were found in Bulgaria, Slovakia, Hungary and the Czech Republic.²⁴⁰

²³⁷ Kallayova, D., Bosak, L. (2012) Improvement of health services for Roma communities in Slovakia. In: Ingleby, D. et al (eds.) *Inequalities in Health Care for Migrants and Ethnic Minorities. COST Series on Health and Diversity*. Antwerpen: Garant Publishers.

²³⁸ Hansen, K., Melhus, M., Lund, E. (2010) Ethnicity, self-reported health, discrimination and socioeconomic status: a study of Sami and non-Sami Norwegian populations. *International Journal of Circumpolar Health*, North America, 69.

²³⁹ Masseria et al (2010).

²⁴⁰ Matrix Consulting (2014). Roma Health Report. European Commission: Consumer, Health and Food Executive Agency.

Research, over time, has gone from covering communicable diseases, child health and genetic disorders, to non-communicable diseases, chronic illnesses and related risk factors. The role of ethnicity and socioeconomic determinants in Roma health has been explored extensively, though given the limitations of reliable data collection, most of the findings are inconclusive. Nevertheless, they clearly point towards the need for intersectoral interventions to tackle the social determinants of Roma health.^{241, 242} Little attention has been paid to protective factors with regard to Roma health, such as the role of family and women.²⁴³ The dual discrimination suffered by Roma women (because of their ethnicity and gender) is, however, documented.^{244, 245}

Below is presented an overview of the main health issues affecting Roma populations in Europe, as identified through literature and EU reports. A more detailed overview of these is included in the literature review in Appendix II, and in the reports published based on the results of the EU funded projects **Roma Health Report: Health status of the Roma population and data collection in the Member States of the European Union**, and **Health and the Roma Community: analysis of the situation in Europe** (See Appendix VI for a full description of the projects and outcomes).

2.6.2.2. Non-communicable diseases

Research into non-communicable diseases affecting the Roma is still quite limited, despite repeated calls over the last decade for more studies in this field.^{246,247} However, studies suggest that the prevalence of chronic diseases such as cardiovascular disease, diabetes, obesity, hypertension and asthma is higher in the Roma populations than in the non-Roma.^{248,249} Gender and age play an important part, with Roma women experiencing a higher prevalence of some of these health problems than Roma men. UNDP findings reported Roma over the age of 65 suffered a steeper increase in chronic diseases and related problems than non-Roma (70% vs. 56% respectively).²⁵⁰ In terms of social determinants of health, factors associated with poverty such as poor living conditions, poor diet and malnutrition are listed by the **Roma Health Report** as potentially leading to chronic conditions such as obesity, hypertension, diabetes and CVD. Factors associated with poor living conditions, such as damp, cold and poor quality housing may contribute to respiratory disease or musculoskeletal diseases, according to the same report. In addition the above listed effects of poverty and poor living conditions, lifestyle related factors

²⁴¹ Földes *et al* (2012).

²⁴² Masseria *et al* (2010).

²⁴³ Dobranici, M., Buzea, A., Popescu, R. (2012). The cardiovascular risk factors of the Roma (Gypsies) people in Central-Eastern Europe: A review of the published literature. *Journal of Medicine and Life* Vol. 5, Issue 4: 382-389.

²⁴⁴ Surdu, L., Surdu, M. (2006) Broadening the agenda: the status of Romani women in Romania. Budapest: Open Society Institute.

²⁴⁵ European Roma Rights Centre (2006). "Ambulance not on the way. The disgrace of health care for Roma" in Europe. Budapest: European Roma Rights Centre.

^{246,246} Parekh *et al* (2011).

²⁴⁷ Hajioff, S., McKee, M. (2000) The health of the Roma people: a review of the published literature. *J Epidemiol Community Health*; 54: 864-869.

²⁴⁸ Zeljko, H.M. *et al* (2013) Age trends in prevalence of cardiovascular risk factors in Roma minority population of Croatia. *Economics and Human Biology* 11: 326-336.

²⁴⁹ Dobranici *et al* (2012).

²⁵⁰ Matrix Consulting (2014).

such as smoking, drug and alcohol use, and limited physical activity were found to be influential in the development of the health conditions listed above.

2.6.2.3. Mental illnesses: general considerations

As with non-communicable diseases, there is a dearth of research into the mental health of Roma in Europe. Links have been suggested between low socioeconomic status (SES) of Roma and its negative impact on mental health, as well as the impact of discrimination and racism on mental health.²⁵¹ Furthermore, in terms of prevention and care, Roma populations' social representation of mental health and well-being, e.g. the importance of family and social network, are found to be of significance in the development and implementation of interventions.^{252,253}

2.6.2.4. Communicable diseases

The early emphasis of research on Roma health was more suggestive of the threat posed to the general population by the higher prevalence of communicable diseases in Roma populations, than of their health needs.²⁵⁴ Nevertheless, research reports higher rates of infectious diseases such as measles and hepatitis A, as well as a higher risk of outbreaks of infectious diseases, especially amongst Roma living in segregated conditions. Available evidence on vaccination shows that, with the exception of Croatia, Hungary and the Czech Republic, overall rates of childhood vaccination uptake in Europe is lower or much lower in the Roma populations. The limited evidence existing related to rates of HIV/AIDS points to faster disease progression.²⁵⁵

More recent research in the area of communicable diseases has explored the health determinants that lead to higher rates of certain communicable diseases in Roma populations. These studies point to factors related to low SES and the living conditions associated with poverty, and other socioeconomic determinants such as access to health services, as possible explanations.²⁵⁶ Research results strongly recommend the need for targeted preventive and care interventions to decrease the marginalisation that is found to lead to drug use and crime, and to improve the lives and survival rates of those living with infectious diseases.^{257,258}

2.6.3. Health determinants

²⁵¹ Skodova, Z. *et al* (2010). Psychosocial factors of coronary heart disease and quality of life among Roma coronary patients: a study matched by socioeconomic position. *International Journal of Public Health*; 55(5): 373-80

²⁵² Monteiro, A.P. *et al* (2013). Promotion of mental health in Roma people: social representations of mental health and wellbeing in a Roma community. *European Psychiatry: Abstracts of the 21th European Congress of Psychiatry*.

²⁵³ Smith, D., Ruston, A. (2013). 'If you feel that nobody wants you you'll withdraw into your own': Gypsies/Travellers, networks and healthcare utilisation. *Sociology of Health and Illness*, Vol. 35; 8:1196-1210.

²⁵⁴ Hajioff *et al* (2000).

²⁵⁵ Matrix Consulting (2014). The Roma Health Report. Consumers, health and food executive agency.

²⁵⁶ Casals, M. *et al* (2011). Incidence of infectious diseases and survival among Roma population: a longitudinal cohort study. *The European Journal of Public Health*, 1-6.

²⁵⁷ *Ibid.*

²⁵⁸ *Ibid.*

Given the well documented and persistent inequalities in health between Roma and non-Roma in Europe, the focus of research (and of policy interventions such as the Decade of Roma Inclusion) has lately shifted towards social determinants of health. Findings, however, are inconclusive, and researchers have not yet been able to answer the question concerning the extent to which Roma health disadvantages are linked to their ethnicity or to more general issues such as SES and other factors affecting disadvantaged groups in general.²⁵⁹

What research *can* prove is that Roma have low levels of education and skills, often leading to long-term unemployment and increasing levels of poverty.²⁶⁰ Roma generally lack adequate living conditions, with the most severely overcrowded accommodation reported in Slovakia and Hungary.²⁶¹ Many Roma are found to live in marginalised communities with limited access to basic services.²⁶² Roma children especially, face many barriers when trying to access health care.²⁶³ The discrimination, racism and exclusion faced by this community is also a strong determinant of health. Based on these known factors, recommendations have been made for more integrated, multi-sectoral solutions.^{264,265}

For the Sami, research has shown, that while their health differs little from that of the majority population, one significant risk factor is their livelihood, namely reindeer herding. This activity can be hazardous and leads to the observed higher rates of injuries from herding accidents.²⁶⁶

Work towards addressing the social and economic exclusion lived by many ethnic minorities and especially the Roma, has focused on combating discrimination based on gender, racial or ethnic origin, religion or belief, disability, age or sexual orientation (see Appendix III for more details on the **Decade of Roma Inclusion**). Strategies to increase labour market participation and participation in social, cultural and political life are at the centre of European initiatives for social protection and social inclusion. For example, the Treaty of Lisbon, which came into force in 2009, reaffirmed the importance of combating social exclusion and discrimination. Progress, however, continues to be slow and inconsistent.²⁶⁷

Policy measures put forth by the EU include educating the public and effectively enforcing legislation on discrimination against migrants and ethnic minorities, the implementation of educational policies that will facilitate the integration of migrant and ethnic minority children in

²⁵⁹ Masseria *et al* (2010).

²⁶⁰ Matrix Consulting (2014).

²⁶¹ *ibid*

²⁶² Kallayova, D., Bosak, L. (2012). Improvements of health services for Roma communities in Slovakia. In: Ingleby, D. et al (eds.) *Inequalities in Health Care for Migrants and Ethnic Minorities*. COST Series on Health and Diversity. Antwerpen: Garant Publishers.

²⁶³ Rechel, B. *et al* (2009). Access to health care for Roma children in Central and Eastern Europe: findings from a qualitative study in Bulgaria. *International Journal for Equity in Health*, 8: 24.

²⁶⁴ *Ibid*.

²⁶⁵ Masseria *et al* (2010).

²⁶⁶ Sjölander, P. (2009). What is known about the health and living conditions of the indigenous people of northern Scandinavia, the Sami? *Global health Action* 4.

²⁶⁷ WHO (2010). *How health systems can address health inequities linked to migration and ethnicity*. Copenhagen: WHO Regional Office for Europe. <http://bit.ly/hKAe3T>

mainstream schools, employment policies that will removed the barriers to employment affecting them, social protection policies, housing and equitable health policies, that ensure access and quality of health services for all groups.²⁶⁸ The EU **Directorate-General of Home Affairs** has published guidelines for monitoring the integration of immigrants and evaluating the effectiveness and outcomes of integration policies. The report presents a tool that countries can use, the 'Zaragoza' European Integration Indicators, that aims to help policy makers and other stakeholders assess the societal integration outcomes of national integration policies, as reflected in for example education, employment and democratic participation outcomes.²⁶⁹

Chapter 3: Legal and policy framework relating to migrant and ethnic minority health in the EU

3.1. Importance of the international dimension

Legal instruments and policy initiatives aimed at protecting the health of migrants and ethnic minorities often originate at the international or regional, rather than national, level. Even after years of residence, it may be difficult or impossible for them to obtain citizenship and the rights that go with it: in important ways, they are *disenfranchised* and have no voice. This disenfranchisement is most pronounced among irregular migrants who, for all intents and purposes, represent an invisible and silent group, excluded from political and social life. Irregular migrants have very few rights, and those which they have they are generally afraid to claim because of the risk of detection and deportation. Most 'national minorities' do have citizenship, but they are by definition numerically weak and may face additional obstacles to getting their voice heard in law-making institutions. As a result, the interests of both migrants and ethnic minorities tend to be poorly represented in national legislation. Therefore, action by international organisations and agencies is often necessary to ensure that the rights and interests of these groups are respected.

3.1.1. Inherent weaknesses of international laws and initiatives

There is a large body of human rights conventions and legal instruments applying to migrant and ethnic minority health, but in spite of their existence there are still serious inequalities in the state of health of these groups and their access to adequate and appropriate health care. Despite good intentions, the effectiveness of these instruments remains disappointingly limited. There are two main reasons for this 'implementation gap'.

²⁶⁸ *Ibid.*

²⁶⁹ Huddleston, T., Niessen, J., Tjaden, J.D. (2013). "Using EU Indicators of Immigrant Integration." Report for DG Home Affairs. http://ec.europa.eu/dgs/home-affairs/e-library/documents/policies/immigration/general/docs/final_report_on_using_eu_indicators_of_immigrant_integration_june_2013_en.pdf (Accessed 19 February, 2015).

Firstly, in order to be enforceable – to have ‘clout’ – an international or regional legal instrument has to be ‘justiciable’. It must be possible to bring a case to court under it. For several reasons, however, it is often difficult, if not impossible, to claim the rights granted by such instruments in court. Several hurdles have to be overcome:

- The country in which one resides must have ratified the instrument in question. In the EU, the majority of such instruments have been accepted by all member states, but there are some exceptions. For example, the *Charter of Fundamental Rights of the European Union* (2000) was implemented by the Lisbon Treaty of 2009, but the UK and Poland succeeded in obtaining a protocol which in theory prevented any of their national legislation from being deemed illegal under the Charter. On a global level, the *International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families* was adopted by the UN in 1990. In 2014, 64 countries had ratified it or announced their intention to do so, but all were primarily ‘sender’ countries. Not a single migrant-receiving state in Western Europe, North America, or the Persian Gulf has ratified the Convention²⁷⁰. This instrument to protect the rights of migrants is therefore recognised only by the countries they come from, not the countries they go to, and is effectively impotent. In general, countries often insist on ‘reservations’ which limit their compliance with the provisions of a legal instrument.
- Transposing international law into domestic law can be a very slow and imperfect process - and even then, bringing a case before a domestic court will require a substantial investment of time and resources. Bringing a case before an international court requires an even greater investment, which few migrants or members of ethnic minorities can mobilise. Also, years may go by before a verdict is delivered – and when it is, it may be simply ignored.
- Many legal instruments, conventions and declarations are much less binding than they appear to be at first sight. Often it has only been possible to obtain widespread acceptance of them by judicious watering-down, using qualifying phrases such as “to an extent consistent with national legislation”.
- The powers of the EU in matters relating to health systems are in any case limited by the principle of ‘subsidiarity’, which gives member states freedom to regulate their health systems in virtually any way they like. “Measures intended to harmonize healthcare policies across the EU are actually forbidden in the EU Treaty²⁷¹.”

A second kind of ‘implementation gap’ concerns the actual carrying-out of a legal decision. For example, a country may introduce legislation to extend health coverage to irregular migrants, but many factors may still prevent these migrants from benefiting from it. Health workers may not know or understand the details of the legislation; there may be no monitoring of compliance, or

²⁷⁰ <http://bit.ly/1m6qOXO>

²⁷¹ Global Health Europe (2010). Does subsidiarity trump solidarity? (News article). Available at <http://bit.ly/1xLVZ03>

sanctions for non-compliance; migrants themselves may simply not know about the law; or they may be too afraid of being reported to the authorities to make use of it. For all migrants and ethnic minorities, procedural issues such as out-of-pocket payments or complicated bureaucratic procedures may form obstacles to equitable access to health care services.²⁷² We will examine these obstacles more closely in Chapter 4.

3.1.2. Constructive versus coercive power of legal instruments

It would be a mistake, however, to regard the function of international legal instruments as purely coercive, i.e. compelling people to do certain things and refrain from doing others. Such instruments are also intended to inspire and guide – to set out a vision and a framework which will encourage governments and others to bring about the desired state of affairs. Taking the argument a step further, it is possible for initiatives or measures that have no binding force whatsoever to have as much (or more) impact on shaping policies as legal instruments. To do this they must carry authority, and increasingly they must back up this authority by providing evidence for their recommendations. The many declarations and resolutions of the World Health Organization, for example – a body with very limited coercive powers but a great deal of authority – fall into this category.

That is why in this chapter we consider not only legal frameworks affecting health systems, but also the much more numerous category of 'policy initiatives' – actions which have set out to advocate for change, propose standards, disseminate guidelines and facilitate action, in order to guide and inspire the many actors that influence health policy.

3.1.3. The complex nature of governance in health systems

This second type of initiatives, which we call policy-making rather than law-making, may be even more important than legal instruments, for the following reason: health systems are seldom hierarchically structured, top-down organisations which can be altered by simply changing national legislation. When it comes to the rules governing entitlement to health care coverage, such measures may indeed be appropriate – but when we are concerned with removing practical obstacles to access and improving the quality of care, laws may not have much traction. This is because the governance of health systems is often complex, involving many actors and stakeholders. As well as national government, policies may be shaped by professional organisations, insurance providers, local health authorities, service providers, and organisations responsible for teaching and accreditation. Depending on the country, the principle of 'subsidiarity' may be found to a large extent *within* the health system itself.

3.2. International, regional and national legal frameworks

3.2.1. International level

²⁷² Rechel, B. *et al* (2013). Migration and Health in an increasingly diverse Europe. *The Lancet*, Vol. 381; 1235-1245.

The right to health is a fundamental human right, incorporated in many international legal instruments (for more details see Appendix III). We describe here the main instruments.

The **International Covenant on Economic, Social and Cultural Rights** (ICESCR, 1966) states that everyone has the right to “the enjoyment of the highest attainable standard of physical and mental health”. The capacity to enjoy good health is also related to other inalienable rights such as the right to food, housing, safe working conditions or education, and the health status of individuals depends on the fulfilment of these interconnected rights. The failure to provide one of these rights may impact negatively on the health of individuals, which implies that an intersectoral approach must be taken to the fulfilment of the right to health. Finally, the scope of the ICESCR regarding the right to health also covers the *availability*, *accessibility* (including *affordability*), *acceptability* and *quality* of healthcare services²⁷³. Attention for the issue of ‘affordability’ was a very important (and surprisingly late) afterthought. Without it, the right to access services could be interpreted simply as giving people the right to use them: the problem of the crippling bills that may face users, especially in countries such as the USA where many people had no insurance coverage, was simply swept under the carpet.

The **International Convention on the Elimination of All Forms of Racial Discrimination** (CERD, 1963) commits signatories to eliminating all forms of racial discrimination, including of course those affecting health or health care. Moreover, states parties have to ensure that all legislative guarantees against racial discrimination apply to everyone, regardless of their migration status or nationality²⁷⁴. The instrument also applies to national minorities.

The international legal framework also includes specific instruments dedicated to targeted populations experiencing vulnerabilities and in need of extra protection, such as children, women or minorities. Thus, the **Convention on the Rights of the Child** (CRC, 1989) requires that accessible, high-quality health care should be provided for all children. The **Convention on the Elimination of All Forms of Discrimination Against Women** (CEDAW, 1979) specifies that access to healthcare should be provided “on the basis of equality of men and women”. These conventions also stipulate that care must be provided to meet the special needs of these populations according to their increased vulnerability, in order to promote equality among human beings.

UN instruments (apart from the CERD) which protect the rights of minorities include the following:

In the **International Covenant on Civil and Political Rights** (ICCPR, 1966), article 27 provided that “In those States in which ethnic, religious or linguistic minorities exist, persons belonging to such minorities shall not be denied the right, in community with the other members of their

²⁷³ OHCHR (2000) *CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)*. Adopted at the Twenty-second Session of the Committee on Economic, Social and Cultural Rights, on 11 August 2000. New York: United Nations, Office of the High Commissioner for Human Rights.

²⁷⁴ ICERD, 64th session, General Recommendation No. 30 on Discrimination against Non-Citizens, CERD/C/64/Misc.11/rev.3, 2004, para. 7

group, to enjoy their own culture, to profess and practise their own religion, or to use their own language". According to Kugelmann²⁷⁵, "most of the prominent cases in which article 27 ICCPR was applied are cases concerning indigenous issues."

The **United Nations Declaration on the rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities** (1992) refers to minorities based on national or ethnic, cultural, religious and linguistic identity and urges States to protect their existence.

The **Declaration on the Rights of Indigenous Peoples** was adopted by the UN General Assembly in 2007. Although not legally binding, the declaration sets a standard of treatment and protection of indigenous peoples around the world, based on the respect of fundamental human rights. The declaration is meant as a tool against discrimination, marginalisation and the violation of human rights, and refers to both individual and collective rights of indigenous peoples. Furthermore, it recognises their rights to culture, identity, language, employment, health, education and highlights "the rights of indigenous peoples to maintain and strengthen their own institutions, cultures and traditions, and to pursue their development in keeping with their own needs and aspirations".²⁷⁶

International legal instruments highlight protection of health, including universal access to healthcare, as a key measure of the degree to which countries uphold fundamental human rights. But the strength of this framework is limited by the high degree of discretion allowed to countries in their interpretation and implementation of the law, and the absence of strategies to combat multiple discrimination. Even though some of the texts are particularly oriented against discrimination (gender, race, age, sexual orientation, disability, religion, etc.), none of them combat multiple discriminations, leading to gaps in the framework. Moreover these instruments are not designed to be translated as operational policy strategies under national laws, thus further reducing their scope of influence.

3.2.2. Regional (European) level

Two separate bodies are concerned with regional legislation in Europe: the Council of Europe (CoE), covering 47 member states, and the European Union (EU), covering 28. However, accession to the EU implies acceptance of the main CoE instrument, the **European Convention for the Protection of Human Rights and Fundamental Freedoms** (ECHR). These two bodies have introduced several legal instruments intended to ensure the protection of health and minimum standards of access to health care for all.

- The **European Convention for the Protection of Human Rights and Fundamental Freedoms** (ECHR) (CoE, 1950).

²⁷⁵ Kugelmann, D. (2007). The protection of minorities and indigenous peoples respecting cultural diversity. In Bogdandy A.V. and Wolfrum, R. (Eds.). *Max Planck Yearbook of United Nations Law*, Vol. 11: 262.

²⁷⁶ "United Nations adopts Declaration on Rights of Indigenous Peoples". United Nations News Centre, 13 September 2007. <http://www.un.org/press/en/2007/ga10612.doc.htm> (accessed: 8 October, 2014)

- The **European Social Charter** (CoE, 1961, revised 1996) guarantees access to healthcare for everyone in article 11 and 13, and some provisions are expressly made for migrant workers and their family in article 19. However, nine EU members states have not accepted all provisions of the Charter (see Appendix), in particular article 13 referring to the provision of medical assistance regardless of the legal status of individuals.
- The **Framework Convention for the Protection of National Minorities** (CoE, 1998) is a key treaty with regard to national and indigenous minorities. While most CoE member countries have ratified the treaty, 8 countries (France, Turkey, Belgium, Iceland, Luxembourg, Andorra and Monaco have not).^{277, 278}
- The **Charter of Fundamental Rights of the European Union** (EU, 2000), implemented by the Treaty on the Functioning of the European Union (2009), refers to the right to health and right of access to health services, including emergency care, preventive care and medical treatment. However it only applies, “under the conditions established by national laws and practices”.
- The **Treaty on European Union – Maastricht Treaty** (EU, 1992) recognizes and commits members to the promotion of the human rights of all those living in the EU, including the rights of persons belonging to minorities (Article 2). The treaty also commits members to respecting the EU's cultural and linguistic diversity, and promoting cultural heritage. The Treaty also refers to the Union's recognition of the rights (including health and right of access to health services), freedoms and principles set out in the **Charter of Fundamental Rights** of the European Union (see above), including the prohibition of discrimination on the basis of membership in a national minority.²⁷⁹

In addition, the following European Commission Directives (which are binding on all member states) relate to the health of migrants and ethnic minorities (see Appendix III for details):

- **Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin** (the ‘race directive’).
- **Council Directive 2003/9/EC of 27 January 2003 laying down minimum standards for the reception of asylum seekers.**
- **The “Returns Directive” of 2008 (Directive 2008/115/EC of 16 December 2008 on common standards and procedures in Member States for returning illegally staying third-country nationals).**
- **Proposed Council Directive of July 2008 on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation** (the ‘equality directive’). The directive is still under negotiation in Council.^{280, 281}

²⁷⁷ <http://www.refworld.org/publisher/COESFCPNM.html> (accessed on January 15, 2015)

²⁷⁸ <http://www.coe.int/en/web/minorities/home>

²⁷⁹ http://europa.eu/about-eu/basic-information/decision-making/treaties/index_en.htm (Accessed: 6 October, 2014).

²⁸⁰ http://ec.europa.eu/justice/newsroom/discrimination/news/150216_en.htm (Accessed: 20 February, 2015).

3.2.3. National level

Entitlement

Legal measures relating to the provision of health services to migrants and ethnic minorities are mostly concerned with the issue of *entitlement*, that is to say the possibilities for migrants in different categories – legal migrants, asylum seekers and irregular migrants – to participate in the national system of coverage for health service costs. The **European Migration Network's** 2014 report *Migrant access to social security and healthcare: policies and practice*, provides a very detailed map of the policies and administrative practices that shape third-country nationals' access to social security, including healthcare.²⁸²

Two main systems of coverage are currently in force in EU member states: tax-based 'Beveridge' systems and social insurance-based 'Bismarck' systems. The main difference between these lies in the extent to which the State finances, owns and runs health services. However, it is not the case that one of these systems has clear-cut advantages over the other when it comes to the entitlements of migrants. This issue is further discussed in Appendix III.

'Out-of-pocket' (OOP) payments in the sense of co-payments at point of supply – may be levied within both types of system. Usually these are open and above board, but they may take the form of informal ('under-the-table') payments. In some countries these would be called bribes, but in others they are regarded as normal expressions of gratitude. Unless generous exemptions and ceilings are available, OOP payments can have highly inequitable effects: effectively, they undo the very principle of collective coverage for health costs. Migrants and ethnic minorities, whether regular or irregular, to the extent that they may be less well off than the majority population (as shown in Section 1.5.3), may be particularly hard-hit by OOP payments. Another very important issue is that formal entitlement to care does not always guarantee effective access: this is the topic of Chapter 4.

We will briefly discuss the entitlements of different categories of migrants separately. A comprehensive survey on this topic has not been carried out until recently: the 'Big Picture' project, which is a collaboration between the COST Action ADAPT, the IOM's **EQUI-HEALTH** project, and the Migration Policy Group (MPG), is currently collecting data which will be published in a new 'Health strand' in the forthcoming edition of the MIPEX index, as well as in Country Reports to be published by the EQUI-HEALTH project (Appendices III and VI provide more details about these projects). The following information is therefore provisional.

Legal migrants

This category refers to those granted a regular visa or residence permit for work, study, family reunion or other purposes. In EU/EEA countries there is an important difference between legal migrants who are nationals of another EU/EEA country and others ('third country nationals' or

²⁸¹ http://fra.europa.eu/sites/default/files/fra-2013-opinion-eu-equality-directives_en.pdf (Accessed: 20 February, 2015).

²⁸² European Migration Network (2014). *Migrant access to social security and healthcare: policies and practice*. DG Home, European Commission.

TCN's). Health care entitlements which EU/EEA migrants have in their home country are transferable to the host country, in line with the EU's *Directive 2011/24/EU on patients' rights in cross-border healthcare*. Under the provisions of this Directive, patients from another EU country should enjoy equal treatment with the citizens of the country in which they are treated. However, they are only entitled to the treatments to which they are entitled at home, and can only be reimbursed (by their home country) up to the level of the costs of the same treatment at home. TCN's must either be admitted to the host country's coverage system or take out private health insurance (which is almost always more expensive). For TCN's, the difficulty and expense of obtaining adequate coverage varies considerably between countries.

Asylum seekers

Up to a point, free health care is provided to asylum seekers (who, as long as their application is being processed, are in care of the State). The 2003 EC Minimum Standards Directive (see previous section and Appendix III) requires member states to provide at least free emergency care to this group, and to pay special attention to the needs of 'vulnerable' asylum seekers. However, there are considerable variations in the extent of the care provided and the conditions attached to it – for example, whether it is available outside asylum-seeker centres. An earlier overview of coverage for asylum seekers was published in 2006.²⁸³

Irregular migrants

The greatest variations in entitlement are found in this category. Several major surveys and reports, mostly carried out by NGO's²⁸⁴, have dealt with issue in the past decade: the project **NOWHERELAND**, co-financed by the EC (EAHC), summarised all the available information in 2009 (see Appendix VI). While a small group of countries allow irregular migrants access to the same range of services as nationals, most countries restrict provisions to emergency care, while some require that irregular migrants pay even for that. To a large extent, it is left to NGO's to provide rudimentary services for such migrants. However, many countries apply special provisions for particularly vulnerable groups, such as women and children, people with TB or HIV, and victims of torture or trafficking.

Although the entitlements for migrants and ethnic minorities are a matter of national legislation, it is important that health workers of all kinds and at all levels should be well informed about them. For two reasons, they need to know what rights to care an individual has: firstly, to make sure those rights are being respected; and secondly, to fully understand the situation the person is in and be able to respond appropriately to it. For this reason it will be important to facilitate the transfer of findings from the 'Big Picture' project to the MEM-TP project, and to ensure that this material is available to trainees.

Other aspects regulated by national legislations

Besides entitlement, other aspects of health systems affecting migrants and ethnic minorities may be embodied in national legislation, although many national-level policies may be

²⁸³ Norredam, M., Mygind, A & Krasnik, A. (2006) [Access to health care for asylum seekers in the European Union — a comparative study of country policies](#). *Eur J Public Health* 16(3): 285-289.

²⁸⁴ A list of these projects was compiled by the project **MIGHEALTHNET**: see <http://bit.ly/1o4VW0m>

introduced by other bodies than governments and their agencies (for example professional bodies, insurers or service provider organisations).

- Many countries have laws on ‘informed consent’ which require that patients should understand and agree to their treatment. This can be regarded as requiring the provision of interpreters, but whether the law is actually interpreted in this way is a different question. At most, laws on ‘informed consent’ can be cited as an argument in favour of providing free or subsidised interpreters.
- Some countries have laws stipulating the health care must be given in a way that respects religious or cultural differences, which in effect mandates ‘sensitivity to diversity’.
- Collection of data on migrant status or ethnicity may be regulated by law.
- Laws may also require health workers to report irregular migrants, or even forbid aid to them, thus impeding access for this group.

However, the fact that such legal measures exist in the statute book does not always mean that they are enforced or taken very seriously in day-to-day health service practice.

Discrimination in health care

Anti-discrimination legislation, to the extent that it covers ‘institutional’ or ‘indirect’ discrimination rather than only the ‘individual’ or ‘direct’ kinds, may have some leverage when it comes to inequities in service provision. The EC ‘Race Directive’ of 2000 implicitly required all countries to tackle such inequities, but so far this has had little effect on national legislation in the field of health. An exception is the UK Equalities Act, which requires providers of all public services not only to forbid discrimination of all kinds, but to take active measures to monitor and combat it.

The EU Fundamental Rights Agency (FRA) has undertaken several studies of discrimination in health care, focusing both on *indirect or institutional discrimination* (unfairness in the way the health system is organised) and *individual or direct discrimination* (hostile or unfriendly behaviour by health staff, rooted in prejudice).

- The first round of the **EU-Midis Survey**²⁸⁵, based on data from 2008, reported that 17% of Roma had experienced discrimination by health care staff in the last 12 months. Generally speaking Roma report the highest levels of discrimination, but 24% of North Africans living in Italy answered positively to the same question.
- The FRA report on **Inequalities and multiple discrimination in access to and quality of health care**²⁸⁶ (2013) tackled for the first time the question of *multiple* discrimination. European anti-discrimination legislation focuses on sex, age, disability, religion or belief, race or ethnic origin, and sexual orientation: however, it does not consider discrimination based on multiple grounds (e.g. being an elderly female migrant). Not only may the strength of the resulting discrimination be more than the sum of the separate effects: it may also have a qualitatively different character (cf the notion of ‘intersectionality’ is

²⁸⁵ FRA(2009). *EU MIDIS: European Union Minorities and Discrimination Survey (Main Results Report)*. Vienna: EU Fundamental Rights Agency.

²⁸⁶ FRA (2013). *Inequalities and multiple discrimination in access to and quality of health care*. Vienna: EU Fundamental Rights Agency.

discussed in section 5.2.1.). This pioneering study was carried out in five countries and considered sex, ethnicity or migrant status, disabilities and age, as well as combinations of these characteristics. It provided qualitative information on the types of barriers created by multiple discrimination and recommended stronger measures to deal with it.

3.3. International and regional policy initiatives

We list here the main policy initiatives and their contribution to the framework regulating migrant and ethnic minority health. (Those relating specifically to Roma are listed in the following section.) Appendix III contains a more complete inventory of initiatives.

3.3.1. International level

World Health Organization (WHO)

The World Health Organization has published valuable general recommendations and instruments such as the WHO Constitution 1946, the Declaration of Alma Ata 1978, the Tallinn Charter 2008 and the Rio Political Declaration on Social Determinants of Health 2011. These documents stress the need for universal health care coverage, the importance of primary care and prevention, and the priority that should be given to tackling the underlying social causes of inequalities.

The first specific initiative of WHO in relation to migrant health was the 1983 conference organised by WHO Euro and the Dutch Government in The Hague²⁸⁷. In 2003 WHO also published the document *International Migration, Health and Human Rights*²⁸⁸, which provided an overview of some of the key challenges for policy-makers in addressing the linkages between migration, health and human rights.

In 2008 Resolution 61.17 of the World Health Assembly on Migrant Health was passed²⁸⁹. This resolution listed 9 recommendations for member states and 11 for the WHO, covering a broad spectrum of policy measures needed to tackle problems of migrant health. These recommendations placed the onus for improving migrant health not only on health professionals, but also on service provider organisations, national governments and international agencies, collaborating centres, academic institutions, civil society and other key partners. Intersectoral cooperation between the health sector and other sectors was advocated.

The resolution was revisited three years later in a Global Consultation organised by WHO and IOM in Madrid (April 2010). This meeting resulted in a 112-page report²⁹⁰ analysing in detail the 'state of the art' in relation to the issues named in Resolution 61.17. There was no follow-up to

²⁸⁷ Colledge, M., Van Geuns, H.A., Svensson, P.G., eds. (1986). *Migration and health: towards an understanding of the health care needs of ethnic minorities. Proceedings of a consultative group on ethnic minorities (The Hague, Netherlands, November 28–30, 1983)*. Copenhagen, WHO Regional Office for Europe

²⁸⁸ <http://www.who.int/hhr/activities/en/FINAL-Migrants-English-June04.pdf>

²⁸⁹ http://apps.who.int/gb/ebwha/pdf_files/A61/A61_R17-en.pdf

²⁹⁰ http://www.who.int/hac/events/consultation_report_health_migrants_colour_web.pdf

this report on a global level (reportedly because of a lack of support from member states), but WHO Euro has since started several initiatives on migrant health (see Appendix). A 35-page policy briefing entitled *How health systems can address health inequities linked to migration and ethnicity*²⁹¹ was published in 2010.

International Organization for Migration (IOM)

The IOM has a long history of work in the area of migrant health and the Appendix describes many of its initiatives, most of which are at the level of projects. Two projects spanning the whole of Europe and resulting in wide-ranging policy recommendations were **AMAC** (Assisting Migrants and Communities: Analysis of Social Determinants of Health and Health Inequalities, 2008-2009), which culminated in an EU-level Consultation in Lisbon²⁹², and **Equi-Health** (Fostering health provision for Migrants, the provision for Migrants, the Roma and other vulnerable groups, 2013-2015)²⁹³. As part of Equi-Health, an additional strand on Health is being added to the MIPEX instrument (Migrant Integration Policy Index). Both these projects received financial support from the European Commission (EC).

3.3.2. Regional (European) level

3.3.2.1. Council of Europe

Above we have listed several legal instruments of the Council of Europe which are relevant to the protection of migrant and ethnic minority health. The Council has also issued three sets of recommendations which do not have legal force, but are intended as guidelines and standards for member states:

Recommendation 1503 (2001)[1] of the Parliamentary Assembly regarding Health conditions of migrants and refugees in Europe

This recommendation²⁹⁴ noted that “migrants are particularly vulnerable to health problems” and expressed concern about the lack of comprehensive health policies concerning migrants and refugees. Many migrants (particular ‘clandestine’ ones) fall outside the scope of existing health and social services. Health services must be socially and culturally adjusted to the needs of migrants and refugees. Governments were urged to take a wide range of measures to tackle this situation.

Recommendation Rec2006(18) of the Committee of Ministers to Member States on health services in a multicultural society

²⁹¹ http://www.euro.who.int/_data/assets/pdf_file/0005/127526/e94497.pdf

²⁹² <http://www.migrant-health-europe.org/>

²⁹³ <http://equi-health.eea.iom.int/>

²⁹⁴ <http://assembly.coe.int/Main.asp?link=/Documents/AdoptedText/ta01/EREC1503.htm>

This recommendation²⁹⁵ advocated for a shift from a narrow emphasis on ‘cultural competence’ in health care (“an approach that is limited to dealing with minority-linked cultural diversity”) to “a general diversity-based approach – that is, one that takes into account all sources of diversity that may be relevant to health and health care issues”. In keeping with this, it adopted “a broad definition of culture that recognises cultural subcategories based on shared attributes (such as gender) or shared life experiences (such as education, occupation, socioeconomic status, trauma, homelessness, being without ID papers)”. It expressed concern that “a narrow focus on cultural issues denies the importance of class or socioeconomic status, age, sexual orientation, gender, religion, geographic location, physical and mental ability that may all distinctly affect any group’s health needs, interests and concerns”. Emphasis was placed on “diversity issues that are relevant for the organisation of health care services”. This document was remarkable in its adoption of a system-focused, intersectional and intersectoral view of migrant health policy, before such thinking was widely accepted in other circles.

Recommendation CM/Rec(2011)13 of the Committee of Ministers to member states on mobility, migration and access to health care²⁹⁶

This recommendation built on the previous two and on many other recent initiatives by international and regional bodies. It made 14 recommendations, explained in 23 guidelines and an Explanatory Memorandum with 57 action points. The content was divided into 6 categories:

1. Improving knowledge about migrants and their situation
2. Migrants’ state of health
3. Entitlement to health service provision
4. Accessibility of the health system
5. Quality of health services
6. General measures to promote change

This document provided the basis for the MIPEX Health Strand which is being developed as a joint venture²⁹⁷ by the IOM’s Equi-Health project, COST Action IS1103 ADAPT (“Adapting European health systems to diversity”), and the Migration Policy Group (MPG) which publishes MIPEX. These recommendations were characterised by a strong emphasis on an integrated approach. Migrant health must be mainstreamed within all parts of the health system; ‘joined-up’ health and social services are required; within service providers a ‘whole organisation’ approach should be adopted; and participation by users in the design and delivery of health services is essential.

Prior to publishing these recommendations, the Council of Europe was also responsible for the **Bratislava Declaration on Health, Human Rights and Migration²⁹⁸** (2007), which encouraged countries to take measures to address migrants’ health needs regardless of their legal status, and to promote equity in healthcare access by tackling the practical obstacles preventing migrants from receiving the appropriate care that EU and international frameworks entitle them to. A year earlier in 2006, the Parliamentary Assembly had published **Resolution 1509 on Human Rights**

²⁹⁵ <https://wcd.coe.int/ViewDoc.jsp?id=1062769&BackC>

²⁹⁶ <https://wcd.coe.int/ViewDoc.jsp?id=1872157>

²⁹⁷ <http://ec.europa.eu/eahc/news/news292.html>

²⁹⁸ http://www.coe.int/T/DG3/Health%5CSource%5Cdeclaration_en.pdf

of irregular migrants²⁹⁹, which argued that “emergency health care should be available to irregular migrants and states should seek to provide more holistic health care, taking into account, in particular, the specific needs of vulnerable groups such as children, disabled persons, pregnant women and the elderly”.

3.3.2.2. European Union

Apart from the legal instruments described above, many policy initiatives have been launched by the European Commission and its agencies.

From 2003-2013 the **Directorate-General for Health and Consumers (DG SANCO)** supported projects on health inequalities in its Health Programme. These are described in Appendix V and provide much of the information contained in this Report. A brochure describing them has been published by the EAHC³⁰⁰.

Several EC reports have tackled health inequalities and their social determinants in recent years.^{301, 302} In 2009 the **EC Communication Solidarity in health: reducing health inequalities in the EU** was published. This Communication incorporated both of the approaches to health inequalities current at the time – one in terms of ‘vulnerable groups’ (including migrants and minorities), focusing mainly on inequalities in health care and the need for better access, treatment and prevention; the other in terms of ‘the socioeconomic gradient’, focusing on the effect of class differences and the need for intersectoral action on the social determinants of health. These two approaches were described in the EAHC brochure mentioned above.

Many other policy initiatives by the EC and its agencies are described in the Appendix.

As well as the European Commission, the **European Parliament** passed the **Resolution of 8 March 2011 on reducing health inequalities in the EU (2010/2089(INI))**³⁰³. This resolution contained 78 recommendations addressing a very wide range of issues, including support for access to healthcare for undocumented migrants.

EU Presidency Conferences

The presidency of the European Union is held by member states on a half-yearly rotating basis. During their presidencies, member states may launch policy initiatives which are at the same time national actions *and* EU actions. A number of presidencies have chosen to focus on health inequalities, in particular those affecting migrants and ethnic minorities.

UK Presidency 2005: a conference on Mental Health Inequalities in Europe was held at Stansted Airport on 7-8 November 2005. The programme reflected the dualism of current approaches to

²⁹⁹ <http://assembly.coe.int/main.asp?Link=/documents/adoptedtext/ta06/eres1509.htm>

³⁰⁰ http://ec.europa.eu/eahc/documents/health/health-inequality-brochure_en.pdf

³⁰¹ http://ec.europa.eu/health/social_determinants/docs/report_healthinequalities_swd_2013_328_en.pdf

³⁰² <http://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1396946539740&uri=CELEX:52009DC0567>

³⁰³ *Ibid.*

health inequalities: the first day was devoted to ‘Migrant Mental Health’³⁰⁴ and the second to “Government Action to Tackle Mental Health Inequalities”³⁰⁵, which discussed social disadvantage and social exclusion but did not mention migration and ethnicity.

Finnish Presidency 2006: promotion of the “Health in All Policies” (HiAP) approach. Taking an intersectoral approach to the social determinants of health has become a central feature of contemporary approaches to health inequalities, and the EU Treaty obliges all EU policies to adhere to the HiAP approach³⁰⁶.

Portuguese Presidency 2007: organisation of the conference “Health and migration in European Union: better health for all in an inclusive society”³⁰⁷. This event was attended by 300 people and resulted in major publications and a closing declaration. There was direct input to the Bratislava Declaration and WHA Resolution 61.17 (see above), as well as the conclusions on “Health and migration in the EU”³⁰⁸ published by the Council of the European Union (not to be confused with the Council of Europe). The conference stressed the importance of going beyond isolated ‘good practices’ in order to mainstream migrant health in policies across the health system. It also called for cross-sectoral action – a “Health in All Policies” approach – and stressed the importance of data collection and research. However, nothing was said about migrants’ participation in policy-making and service delivery

Spanish Presidency 2010: publication of the report “Equity in Health: Monitoring social determinants of health and the reduction of health inequalities”³⁰⁹. This report combined an approach to health inequalities in terms of socioeconomic differences with attention for vulnerable groups. This demonstrates the tendency of work on migrants and ethnic minorities in the past decade to shift ‘upstream’, i.e. to consider more fundamental and long-term approaches to the health problems of these groups.

.A report was published in 2012 describing the Portuguese and Spanish Presidency Conferences, the IOM’s EU-level Consultation (AMAC, 2010), the WHO/IOM Global Consultation (2010) and several other recent policy initiatives³¹⁰.

The **Greek Presidency** and **Italian Presidency** during 2014 also organised activities around the theme of migrant health, though on a smaller scale than those organised earlier by Portugal and Spain. Both countries stressed the urgent need to cope with the health needs of the increasing ‘mixed migration’ streams (irregular migrants and asylum seekers) arriving at Europe’s Southern borders.

To conclude this section we will attempt to summarise the main tendencies that can be discerned in the policy initiatives undertaken since 2000.

³⁰⁴ http://www.triestesalutementale.it/english/doc/2005_eur-mentalhealthinequalities_1.pdf

³⁰⁵ http://www.triestesalutementale.it/english/doc/2005_eur-mentalhealthinequalities_2.pdf

³⁰⁶ http://www.health-inequalities.eu/healthequity/en/policies/health_in_all_policies/

³⁰⁷ <http://www.insa.pt/sites/INSA/Portugues/Publicacoes/Outros/Paginas/HealthMigrationEU2.aspx>

³⁰⁸ <http://bit.ly/1pwUIbB>

³⁰⁹ <http://bit.ly/1o0ZqQI>

³¹⁰ Peiro, M-J. and Benedict, R. (2010). Migrant health policy: The Portuguese and Spanish EU Presidencies. *Eurohealth* 16(1), 1-4. http://www.gla.ac.uk/media/media_177502_en.pdf

- All these initiatives have tried to draw the attention of politicians, policy-makers and the public to the needs of migrants and ethnic minorities. This ‘agenda-setting’ function continues to be important – in fact, its importance is probably increasing, given the increase in negative attitudes to migration as a result of the crisis and the cuts in health service funding, resulting in a drift towards inequity rather than equity.
- Also noticeable is an increasing focus on ‘mainstreaming’ measures to protect the health of migrants and ethnic minorities, rather than relying on short-term, localised, ‘one-off’ interventions or categorical (separate) provisions for these groups. This reflects growing awareness that migration is here to stay, and that ethnic minorities must be regarded as an integral part of society.
- A logical consequence of ‘mainstreaming’ is the ‘whole organisation approach’, which stresses that adaptation to diversity is a task involving all components of a service provider organisation or health authority. In addition, an integrated, ‘joined-up’ approach to migrants’ problems is emphasised, involving collaboration between different agencies concerned with social protection and policy-making.
- The involvement of health service users and migrant groups is stressed in some initiatives, though many fail to mention this topic at all.
- Thinking about health has been transformed in this century by the rise of attention for the social determinants of health. ‘Upstream’ causes of illness have been increasingly stressed by epidemiologists, while policy-makers have sought remedies at the macro-social level using the ‘health-in-all-policies’ (HiaP) principle. However, those who think along these lines tend to focus more on socioeconomic inequities than on the effects of migrant status or ethnicity. The HiaP principle is less well worked out in relation to migrants and ethnic minorities than it is in relation to SES, though there are signs of more cross-fertilisation between these fields (for example, the introduction of the concepts ‘intersectoral’ and ‘intersectional’ in the discourse on migrants and ethnic minorities).

3.3.3. National level

This section examines the extent to which the policies regulating health services for migrants and ethnic minorities (and other policies affecting their state of health) reflect the standards and guidelines which have been developed in the policy initiatives described above. Like section 3.2.3 on legal frameworks, this is the topic with which the ongoing ‘Big Picture’ project is concerned. There does exist a literature on the strengths and shortcomings of policies in various European countries, but only a small number of countries have up to now been investigated from this point of view and the dimensions examined vary from study to study. The ‘Big Picture’ project, on the other hand, sets out to cover all the issues covered by the 2011 Council of Europe Recommendations and to do so in a standardised way in all EU/EEA countries.

We are concerned here with the readiness of policy-makers in each country to tackle inequities in their health system affecting migrants and ethnic minorities. What is the level of adaptation to diversity? A ‘road map’ has been outlined by the series of policy initiatives described above, but are any countries following it? Is ‘adaption to diversity’ increasing? Because the results of the Big

Picture project are not yet available, we will not risk any generalisations here. Some findings, however, are already beginning to emerge:

- There are enormous differences in the ‘diversity sensitivity’ of health systems: in many country, the principle seems to be totally unknown.. Very often, these are countries with little experience of migration – but this is by no means always the case. In some countries the principle that “all patients must be treated identically” appears to dominate.
- Provision of good entitlements for migrants is not always accompanied by efforts to adapt services to their needs, although this is usually the case.
- An extremely important variable influencing the overall ‘migrant-friendliness’ of health systems is the GDP per capita. Poor countries give migrants fewer entitlements (even compared with the level for their own citizens) and make less effort to adapt services to the needs of migrants. It should be borne in mind that the variations in GDP in the EU are enormous, ranging from rich countries like Luxembourg and Norway (264 and 191 respectively, compared to the EU average of 100), and Bulgaria and Romania on the other extreme (47 and 54 compare to the EU average of 100). (Based on EUROSTAT data for GDP per capita, purchasing power adjusted, in 2013).

To sum up, the degree to which action is needed in EU countries, and the issues such actions should focus on, appear to vary greatly. A ‘one-size-fits-all’ approach is as unlikely to be productive here as it is in health care itself.

3.4. Legal instruments and policy initiatives specifically addressing health inequalities of ethnic minorities, including the Roma

Many, if not most, of the legal instruments and policy initiatives discussed above also apply to ethnic minorities such as the Roma. Obviously, instruments dealing exclusively with migration apply only to ethnic minority members who migrate, but the fact is that a growing number of Roma do indeed migrate, now that accession of their countries of residence to the EU makes it much easier to do so.

A number of international and European instruments exist to protect the rights of indigenous, traditional and national minorities, but because most members of ethnic minorities have national citizenship there are few specific measures at national level. However, some countries have laws regulating the collection and use of ethnic data. As far as policy initiatives are concerned, most of these (especially since 2000) relate to the Roma, as a result of their large numbers, extreme poverty and their presence in most European countries. In this section we will discuss the main policy initiatives targeting the Roma. Since policies have developed in a number of phases, this will be done in chronological order.

It was not until the 1970's that a 'Romani Movement' arose to bring together Roma communities and advocate for their interests. The 1990's saw the first attempts to form political parties to obtain a voice in government³¹¹. In the same period, international organisations became increasingly involved in the situation of Roma in Europe, for example:

- The Council of Europe has concerned itself with Roma issues since 1969 and has launched numerous initiatives to promote their rights, such as for example the **Recommendation 1203 (1993) on Gypsies in Europe**³¹².
- The Organisation for Security and Co-operation in Europe (OSCE) has been involved with Roma since the 1990's. In 2000 it published a major **Report on the situation of Roma and Sinti in the OSCE Area**³¹³.
- The United Nations Development Programme (UNDP) has focused on collecting and analysing data to underpin policies on Roma. The document **Avoiding the Dependency Trap: The Roma Human Development Report**³¹⁴ provided robust statistical evidence of the challenges faced by Roma in respect of illiteracy, infant mortality and malnutrition.

During the 1990's NGO's also started to become involved on a large scale with the problems of Roma. A key actor was (and still is) the **Open Society Institute (OSI)** (now the Open Society Foundations), set up in 1993 and financed by the philanthropist George Soros.

The World Bank, OSI and the European Commission joined forces to organise the 2003 conference "Roma in an Expanding Europe: Challenges for the Future" in Budapest. This conference was attended by 500 people (125 of them Roma), representing a wide range of NGO's, international organisations and governments. The involvement of the EC was connected with the fact that there were plans for several countries with large Roma populations to join the EU during the first decade of the 21st century.

The momentum generated by the Budapest conference led to a policy initiative, the **Decade of Roma Inclusion**, which runs from 2005-2015. The 8 founder countries were Bulgaria, Croatia, the Czech Republic, Hungary, FYR Macedonia, Romania, Serbia and Montenegro, and Slovakia (since joined by Albania, Bosnia & Herzegovina and Spain). All signed a commitment to closing the gap in welfare and living conditions between the Roma and non-Roma populations and putting an end to the cycle of poverty and exclusion. Each country formulated a national Decade Action Plan for the priority areas of education, employment, health and housing.

From 2009 onwards the European Commission became more involved with Roma inclusion. In that year the EU's **European Roma Platform** was set up, with strong civil society representation. In the same year the **Fundamental Rights Agency (FRA)** issued a report³¹⁵ proving that Roma

³¹¹ The information in this section draws on the Council of Europe Roma fact sheets (undated), available at http://www.coe.int/t/dg4/education/roma/histoculture_EN.asp

³¹² <http://assembly.coe.int/main.asp?Link=/documents/adoptedtext/ta93/erec1203.htm>

³¹³ <http://www.osce.org/hcnm/42063?download=true>

³¹⁴ <http://hdr.undp.org/en/content/avoiding-dependency-trap>

³¹⁵ <http://fra.europa.eu/en/publication/2009/eu-midis-data-focus-report-1-roma>

experience the highest levels of discrimination in Europe. This report was based on the findings of the agency's *European Union Minorities and Discrimination Survey* (EU-MIDIS).

The European Commission set up the **EC Roma Internal Task Force** following its 7 April 2010 **Communication on the Roma**³¹⁶, which was adopted just before the Second Roma Summit in Cordoba in Spain. The Task Force was charged with investigating the use of EU funds for Roma integration and identifying ways to improve the funds' effectiveness. Its first reports on the situation were highly critical.

In 2011 the EU published the **EU Framework for National Roma Integration Strategies (NRIS)**³¹⁷ up to 2020. Member States were requested to present by the end of 2011 national Roma integration strategies that would include "EU Roma integration goals, with targeted actions and sufficient funding" and a "robust monitoring mechanism to ensure concrete results for Roma". A year later, the FRA, UNDP and World Bank published a joint report on the social position and human rights of Roma (*The situation of Roma in 11 EU Member States: Survey results at a glance*)³¹⁸, showing that although slight improvements had taken place in some countries, the overall situation of Roma remained grim.

We may note that the entry of the EC into the policy-making process is generating two parallel but overlapping sets of 'road maps': countries are now required to produce not only 'Decade of Roma Inclusion National Action Plans', but also 'National Roma Integration Strategies'. These plans, however, tend to be closely related to each other.

The following year, in 2012, the EC published a Communication reviewing the national integration strategies³¹⁹. This showed that programmes on health were mainly focused on improving access to health care. However, as we noted above (Section 2.1.3.2), the recent emphasis on 'social determinants of health' and 'health in all policies' has called in question the distinction between 'health interventions' and other efforts to tackle social disadvantage. Health is thus an aspect of the other priority areas (education, employment, housing).

The emphasis on critical evaluation of what had been achieved so far was also seen in the work of the Decade Secretariat, which in 2012 introduced what it called 'shadow reporting'³²⁰ – civil society monitoring reports on the implementation of Decade of Roma Inclusion National Action Plans and National Roma Integration Strategies (NRIS). The 2014 EC **Roma Health Report** included a part dedicated to data collection, which includes an overview of what actions countries and supranational bodies are taking to improve data collection on the health of Roma, followed by a series of recommendations for how to improve data collection and coordination.³²¹

³¹⁶ http://europa.eu/rapid/press-release_MEMO-10-121_en.htm

³¹⁷ http://ec.europa.eu/justice/policies/discrimination/docs/com_2011_173_en.pdf

³¹⁸ http://fra.europa.eu/sites/default/files/fra_uploads/2099-FRA-2012-Roma-at-a-glance_EN.pdf

³¹⁹ http://ec.europa.eu/justice/discrimination/files/roma_nat_integration_strat_en.pdf

³²⁰ <http://www.romadecade.org/civilsocietymonitoring>

³²¹ European Commission (2014). Roma Health Report.

http://ec.europa.eu/health/social_determinants/docs/2014_roma_health_report_en.pdf (Accessed: 22 February, 2015).

Two other ongoing initiatives will be mentioned in this overview. WHO Euro is carrying out an **Interagency coordination initiative**, which is developing training for health professionals seeking to deliver more equitable health services to all. The four principles of the initiative (see Appendix II, section 2.1.1) reflect the latest 'state of the art' in thinking about how to tackle health inequalities:

1. The initiative adopts an **intersectional approach**: besides focusing on Roma, it also considers other groups experiencing poverty and social exclusion;
2. It recognises the need for a **whole organisation approach**, because as well as involving 'hands-on' health-professionals it trains administrators, managers, researchers and policy-makers;
3. It encourages **user participation** by engaging Roma and other civil-society organizations as active partners; and
4. It adopts an **integrated, intersectoral, multilateral** approach by also involving partner agencies.

Secondly, the IOM's project **Equi-Health**³²² combines critical evaluation of NRIS with a training component (see Appendix). Again, a **whole organization approach** is adopted in these evaluations, as the progress of national health plans is assessed at all implementation levels. Additionally, user participation and an **integrated, intersectoral, multilateral** approach feature prominently in the project's aims and methodology, as key stakeholders (governmental and non-governmental) are involved. Future funding priorities in the area of Roma health under EU structural and social cohesion funds will be identified based on the project's results.

³²² <http://equi-health.eea.iom.int/>

Chapter 4: Barriers to accessing health services and good practices addressing them

4.1. Dimensions of access

An often-used definition of access to health services is as follows³²³: “Facilitating access is concerned with helping people to command appropriate health care resources in order to preserve or improve their health”. Although the right to receive health care was laid down in the *International Covenant on Economic, Social and Cultural Rights* in 1966, the Covenant did not specify in detail how this right should be implemented. However, as we saw in the previous chapter, a General Comment was adopted in 2000³²⁴ setting out that care must be *available, accessible, acceptability* and of adequate *quality* (often abbreviated to ‘AAAQ’). In this chapter we are concerned with the second requirement, accessibility, which the General Comment divides into four overlapping dimensions: *non-discrimination, physical accessibility, economical accessibility (affordability)* and *information accessibility*.

The most fundamental of these dimensions is economical accessibility or affordability. Because health care costs can be extremely high, whether care is affordable mainly depends on a person’s entitlement to health care ‘coverage’, i.e. their inclusion in a collective system of risk-sharing that protects them from catastrophic costs. In many parts of the world such systems do not exist: health care which is not provided free has to be paid for at the point of supply. In EU member states, however, coverage for health care is available to almost everybody (although types of migrants such as asylum seekers and irregular migrants may not be allowed to participate in the same schemes as nationals).

Coverage embodies two kinds of solidarity, ‘horizontal’ and ‘vertical’³²⁵. The ‘horizontal’ kind is the solidarity of healthy people with those who become ill, which is the essence of the very idea of coverage. Indeed, healthy people may not opt out of such a system, because their contributions are necessary to pay for the care of the sick. Moreover, in most state-regulated (as opposed to commercial) risk-sharing schemes, those who are ill or disabled must be allowed to join the system on the same terms as the healthy. Exclusion or extra charges for those with pre-existing conditions undermine the principle of ‘horizontal solidarity’. Most state-regulated systems, whether tax-based or insurance-based, also build in a degree of ‘vertical’ solidarity, by which the rich subsidise the poor. Premiums or taxes are made ‘progressive’, so that the burden they represent for poor people is not greater than for rich people. Introducing payments at the point

³²³ Gulliford, M. *et al* (2002). What does “access to health care” mean? *Journal of Health Services Research & Policy*, 7(3), 186–188.

³²⁴ OHCHR (2000) *CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)*. Adopted at the Twenty-second Session of the Committee on Economic, Social and Cultural Rights, on 11 August 2000. New York: United Nations, Office of the High Commissioner for Human Rights.

³²⁵ Ter Meulen, R., Arts, W. A. & Muffels, R. J. A. (eds.) (2001). *Solidarity in Health and Social Care in Europe*. Dordrecht/Boston/London: Kluwer.

of supply ('out-of-pocket' payments) undermines both kinds of solidarity, though these effects may be mitigated by exemptions for chronically ill or poor people.

Affordability is such a basic dimension of access to health services that it is often discussed separately under the heading of 'entitlement' or 'coverage'. It is usually regulated at national level, although in some countries regional governments may have a say in laying down the rules. Legal entitlements to health care coverage in European countries were dealt with in Chapter 3 in the section on national legal or policy frameworks: they will not be discussed again here. That does not mean, however, that the question of entitlement is unrelated to all the other dimensions of access. The General Comment referred to the four dimensions as 'overlapping'³²⁶, because they may interact with each other. For example, a migrant or member of an ethnic minority who is entitled to care may be prevented from using it if he or she is discriminated against, unable to reach the service provider, or kept in the dark about their rights and how to exercise them. In the rest of this chapter we will focus on barriers to access *other than* entitlement.

4.1.1. General issues concerning access

Access to preventive services and health education

It is important to stress that access concerns health 'services' and not simply health 'care'. Prevention, screening, health education and health promotion are services for the entire population, not just for those in need of care. In these cases, however, 'access' takes on a different meaning. Whereas it is the individual who seeks the health care provider, preventive and educational programmes go in search of the individual. If they succeed in finding him or her, the individual has 'access' to them. Usually, because these services are in the public interest, they are provided free of charge (up to a certain basic level): the issue of coverage in the sense of financial support is therefore not relevant. However, it is important whether these services have universal coverage in the sense that all members of the population are legally entitled to receive them. In general, nationals (including ethnic minorities) do have such entitlement, but some groups of migrants (especially asylum seekers and irregular migrants) may not be permitted to use preventive and educational services or may remain out of reach of these services. As we will describe further down in this section, developing culturally adapted services in prevention, health promotion and education can help expand the accessibility of these services and increase the likelihood of participation of hard to reach groups.

Who creates the barriers – the user or the system?

Sometimes barriers to accessing services will result from a person's own attitudes or beliefs (their preferred 'help-seeking behaviour').³²⁷ Such barriers are often referred to as 'demand-side', in order to distinguish them from the 'supply-side' barriers which are created by the health system. For example, a person may not realise they need care, they may wrongly think they are not entitled to it, or they may not regard the available health services as appropriate sources of help.

³²⁶ OHCHR (2000), paragraph 12b.

³²⁷ Nørredam, (2011)

However, to a certain extent these barriers can be reduced by efforts on the part of the health system to provide information, increase health literacy, and overcome unjustified reluctance to seek care. For this reason the distinction between ‘demand-side’ and ‘supply-side’ barriers is not as clear as it looks at first sight. In the end, it becomes a question of who is regarded as *responsible* for solving problems of access. Health systems with what Bollini³²⁸ referred to as a ‘passive’ response to diversity leave the responsibility with the user; this usually goes along with the attitude that migrants and ethnic minorities should *assimilate*. Systems adopting an ‘active’ response take on much of the responsibility for removing barriers to access themselves: this approach is often inspired by a ‘multicultural’ approach, using a two-way concept of *integration*.

Measuring barriers to access

The existence of barriers to access can be established in two ways – directly or indirectly. The *direct* method involves asking migrants whether they were able to access services when they needed them. Appendix IV gives examples of EU-funded projects that collected qualitative data from migrants and ethnic minorities regarding access to health services, such as **Healthy Inclusion** or **Promovax**. Sometimes NGO’s may be able to provide such data on the basis of what they are told by migrants and ethnic minorities (see information in Appendix VI on the projects **NowHereLand** and **Averroes**). Research using ‘direct’ methods has revealed a great deal about the barriers that exist, although it may not always show whether the barriers identified are greater for migrants and ethnic minorities than for the majority population. For example, migrants may say they are put off by long waiting lists, inconvenient opening times, hard-to-reach services or the reluctance of health professionals to give treatment without first carrying out lengthy tests. However, many other health service users may experience the same barriers.

The *indirect* method of identifying barriers involves comparing the rate of utilisation of services by migrants or ethnic minorities with that of the majority population. However, to use this method it is necessary to allow for the fact that differences in utilisation may simply be the result of differences in need. For example, in a country where geriatric services are hardly ever used by migrants, this could arise simply because few migrants are elderly – not because there are access problems. Service utilisation is determined by both need and access, and it is impossible to estimate one of these parameters without knowing the other.

Data on service utilisation often show that the population of service users does not reflect the composition of the population for which the service is supposed to cater: in particular, migrants and ethnic minorities may be under-represented. In Table 1 of Appendix 4 data are presented from a wide range of European studies on health service utilisation by migrants and ethnic minorities. These studies are classified by country and type of service. However, in many cases it is not possible to determine whether differences in service use reflect differences in need or in access. For example, several studies report increased use of GP services by migrant and ethnic minority patients. Is this because such patients have more health problems, or because they have a lower threshold for seeking help? Or is the increased use due to ‘revolving-door patients’, who

³²⁸ Bollini, P. (1992). Health Policies for Immigrant Populations in the 1990s. A Comparative Study in Seven Receiving Countries. *International Migration*, Vol. 30 (Special Issue: Migration and Health in the 1990s), 103-119.

keep coming back to the GP because their health problem has not been resolved? Screening participation among ethnic minority women is known to be lower than for non-ethnic minority women, however, cervical and breast cancer rates vary depending on ethnic minority group, but are clearly lower among some ethnic minorities as shown in Chapter 2.

Another phenomenon visible in Table 1 is the increased tendency in some countries for migrants and/or ethnic minorities to use accident and emergency departments. This too is difficult to interpret. It could be due to the fact that these groups experience more barriers to accessing primary care, so that the A&E department becomes in effect their substitute for the general practitioner or community health centre. Or it could be because their health needs really are more acute – perhaps as a result of the same barriers to access, leading to help only being sought when the need for it becomes overwhelming³²⁹. More serious symptoms at first contact can sometimes be found elsewhere in other services, however, which gives a clearer indication that something is deterring people from seeking help when problems have not yet become acute³³⁰.

In the next chapter we will discuss good practices for improving the *quality* of health services for migrants and ethnic minorities. These issues arise once a person has got inside the door, as it were, of the service provider, i.e. when any barriers to access have been overcome. However, the issues of ‘access’ and ‘quality’ are not entirely distinct. Firstly, if the quality of a service is poor – or is *perceived* as being poor – this will create a barrier to accessing it. Secondly, there are some factors which affect both access and quality. The most obvious ones are language barriers: these may prevent a migrant from obtaining crucial information about health problems, entitlements, health services and ways to get help. Once inside the door, as we will see in the next chapter, language barriers may prevent mutual understanding between patients and health professionals.

4.1.1. Barriers to access for the descendants of migrants

Learning how and when to use health services is an important aspect of integration in the host society³³¹. Since the ‘second generation’ is born in the host country and has the opportunity from birth to become familiar with its language, culture and health services, it is to be expected that their patterns of health service utilisation will be closer to those of the majority than those of their parents. Moreover, as natives of their country of residence they are more likely to have entitlement to coverage for health care. However, although few studies are available of differences between these patterns in the first and second generations, it is clear that some differences from the majority population persist.

For example, one area in which differences have been found in the Netherlands concerns perinatal care. Regular check-ups during pregnancy are important in reducing childbirth complications and effectively managing complications when they do arise. We saw in section

³²⁹ Nørredam, M., Nielsen, S.S., Krasnik, A. (2009). Migrants' utilisation of somatic health care services – a systematic review. *European Journal for Public Health*, Vol. 20 (5): 555-563.

³³⁰ Nørredam, M. *et al* (2010a). Excess use of coercive measures in psychiatry among migrants compared with native Danes. *Acta Psychiatrica Scandinavica*, 121 (2): 143-151

³³¹ Ingleby, D. (2012). Acquiring health literacy as a moral task. *International Journal of Migration, Health and Social Care*, 8(1), 22-32.

2.4.2. that among mothers of non-Western origin, rates of infant death were only slightly lower in the second generation than in the first. This is related to findings that these mothers make less use of preventive services during pregnancy as well as maternity care³³². The age at which mothers have children, and the number of children that they have, are more similar to native Dutch mothers in the second generation than the first: compared to their own mothers, second-generation women have fewer children and at a later age. Nevertheless, they still make too little use of preventive services and receive less health education. Mothers were inadequately informed over the importance of prenatal checkups and the services available. Less use was also made of maternity care after the birth. Despite the fact that they were born in the Netherlands, it is clear that these mothers are not being effectively reached and influenced by preventive services and health education. This is particularly worrying given the recent policy in the Netherlands of cutting back targeted interventions for migrants³³³.

4.2. Examples of barriers to access and good practices to address them

In Table 2 of Appendix 4 the results of a review of the European literature on barriers to access for migrants and ethnic minorities are presented. Table 3 gives examples of projects that have put forward solutions to these access problems. We describe here the main barriers that have been found and some of the solutions proposed for them, drawing on these and other sources.

It should be noted at the outset that measures to improve access may need to be taken at different levels in the health system. Some problems may have to be tackled by national governments (especially when they concern legislation or nation-wide programmes). Others may be primarily a task for service provider organisations (in particular the leadership, policy-makers and managers). Relatively few problems of access can be tackled by individual health workers themselves, for the basic reason that those who do not succeed in overcoming access problems never come in contact with a health worker.

4.2.1. Lack of information, poor 'health literacy'

First, a note on the term 'health literacy'. This is defined as "the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions and [access] services needed to prevent or treat illness"³³⁴. Poor health literacy implies a lack of knowledge about health, illness and the health care system. It leads to the following difficulties in accessing healthcare: not knowing the connection between risky behaviours and health, not being able to locate providers and services, not knowing the

³³² A.J.M. Waelput, P.W. Achterberg (2007). *Etniciteit en zorg rondom zwangerschap en geboorte: een verkenning van Nederlands onderzoek*. RIVM: Centrum Volksgezondheid Toekomst Verkenningen.

³³³ D. Ingleby (2009), Migranten en etnische minderheden in de Nederlandse gezondheidszorg: een internationaal perspectief. In: A. Sbiti & I. Boedjarath (red.), *Gekleurde Gekte. 25 jaar werken aan interculturele GGZ*, 100-117. Rotterdam: MIKADO.

³³⁴ U.S. Department of Health and Human Services (2013, December). *About Health Literacy*. Health Resources and Services Administration. Retrieved from <http://www.hrsa.gov/publichealth/healthliteracy/healthlitabout.html>

meaning of application forms, notices, and brochures, not being able to fill out complex health forms, or to share medical history with providers³³⁵. Sometimes, low language proficiency can be an important factor preventing migrants from improving their health literacy.

Often, however, migrant and ethnic minority users are regarded as having 'low health literacy' when the root of the problem may be simply that they have not been provided with adequate information. Such information needs to address the following issues:

- a) Entitlements and the procedures necessary to claim them.
- b) How to use the health system (e.g. whether specialist care can be accessed directly or only through a 'gatekeeper').
- c) Health maintenance in specific conditions (living with diabetes, cancer etc.).
- d) Health education and health promotion: how to recognise problems, when to seek help, how to look after one's own health.

A great deal of research, much of it supported by the EU, has been carried out in the last decade on shortcomings in the information available to migrants as well as 'good practices' to overcome them. The European Health Literacy Project has been conducting research on the conceptualisation of health literacy and sharing knowledge on the subject. They also conducted a European health literacy survey, which resulted in comprehensive report, and featured the following findings:³³⁶

"The first time data on health literacy in eight countries generated interesting and relevant results. Almost one in two, on average 47%, has risk of limited health literacy across the eight countries and the levels vary between the countries. In certain subgroups of the populations there are higher risks, such as among elderly, among people with low levels of education, among people with low socio-economic status and among people considering having a bad health."³³⁷

An important finding is that such information often needs to be *targeted*: the language used, the means of dissemination, and the content may all have to be adapted in order to reach migrants effectively.^{338,339,340} Some of these interventions also call for intersectoral and intersectional approaches, requiring the engagement of policy makers and key stakeholders outside the health sector and at all levels of health organisations, and looking at health inequalities through a wider

³³⁵ Institute of Medicine, (2004). *Health Literacy: A Prescription to End Confusion*. Washington DC: Institute of Medicine.

³³⁶ European Health Literacy Survey (2012).

<http://www.maastrichtuniversity.nl/web/Institutes/FHML/CAPHRI/DepartmentsCAPHRI/InternationalHealth/ResearchINTHEALTH/Projects/HealthLiteracyHLSEU/HealthLiteracyHLSEU.htm> (Accessed: February 23, 2015).

³³⁷ *Ibid.*

³³⁸ Priebe, S. *et al* (2011). Good practice in health care for migrants: views and experiences of care professionals in 16 European countries. *BMC Public Health*, 11:187.

³³⁹ Mladovsky, P. *et al* (2012a). Good practices in migrant health: the European experience. *Clinical Medicine*, Vol 12, No. 3: 248-52.

³⁴⁰ Netto, G., *et al* (2010). How can health promotion interventions be adapted for minority ethnic communities? Five principles for guiding the development of behavioural interventions. *Health Promotion International*, 25: 248-57

'diversity' lens. Other interventions involve front-line health professionals who come into contact with the target group in their daily work, and representatives of the communities they serve.

The case study below illustrates how one regional government in Spain developed and implemented a migrant health policy programmes to improve the knowledge and information available on migrant health, in order to promote equal access to and better quality of health services.

Case Study: Catalonia and the Master Plan for Immigration and Health³⁴¹

Catalonia, in the face of a rapidly growing migrant population, was one of the first regional governments to implement migrant health policy. In 2005 it adopted a regional policy, the Master Plan for Immigration and Health (MPIH) to adapt its health care system to the increasing numbers of migrants, and promoted organisational change with the help of clear political commitment.

The Catalan health system is characterised by a high degree of autonomy from the central government, and its guiding vision is that of universal access to all residents of Catalonia, free of cost. Everyone residing in Catalonia is thus eligible to receive a personal health care card, which guarantees access to free health care. Pregnant women and children under 18 do not have to prove residence in the region in order to get a personal health care card. However, recognising that a series of factors characteristic of migrants, such as their culture, religion, language, different ways of interpreting health and illness, may create barriers to accessing health services, the Catalan government developed a plan for improving access to and quality of health services provided to migrants: the Master Plan for Immigration and Health. The plan aimed to create a strong knowledge base about the health situation of migrants in Catalonia and subsequently be able to develop strategies for adapting the health system to their needs. A vigorous programme of research over a number of years, including the analysis of health records and other data such as perceptions and needs of healthcare professionals, produced a series of reports and publications. Based on these outcomes, a list of recommendations was produced and subsequently three areas of intervention were defined and implemented as part of an action plan for 2007-2010: 1) reception, 2) mediation and 3) professional training.

- 1) Reception: The aim here was to break down the barriers to access to health services for migrants, through the improvement, coordination and adaptation of information regarding health, health services and entitlement.
- 2) The mediation plan: The role of intercultural mediator was incorporated as a key element for facilitating intercultural relations, especially in the case of new arrivals where great linguistic and cultural barriers may impede access and quality of care. Evaluation results for the initial phase (2008-2011) emphasised the relevance and responsiveness of the mediator programme, both in terms of the needs of migrants and of health professionals. Recommendations included the increase in number of mediators, and the extension of the programme throughout the entire region.
- 3) Training for professionals in health care services: To improve the knowledge and skills needed to achieve a level of cultural competence required to guarantee quality of care for all, a training course was developed and taught by the Institute of Health Studies. The course was delivered throughout the regions, in a coordinated way, through the regional health actors.

Funding for the programme was provided by a public-private partnership with La Caixa Foundation. At present, despite the lack of specific budget allocations for the implementation of the migrant health policies described above, and the austerity measures resulting from the economic crisis, the MPIH continues to be implemented. In this next phase, research will focus on the impact of austerity of vulnerable migrant groups, and on planning actions to address health problems arising as a result of austerity measures.

³⁴¹ Lizana, T. (2011). Developing a migrant health policy for Catalonia. In: Inequalities in health care for migrants and ethnic minorities. COST Series on Health and Diversity, Vol. 2. Antwerp: Garant Publishers

Recommendations for tackling lack of information and poor 'health literacy' include the following:

- Information on entitlements, the health system, and prevention/health promotion information should be provided in the appropriate languages and distributed strategically to reach the maximum number of target groups (identified as good practice by health practitioners in 16 European countries through the **EUGATE project**, see Appendix 3). Possible means of distributing information include brochures, websites and public announcements, as well as workshops on health and the health care system in introductory language courses for newly arrived migrants. (See Appendix 3 for information on EU funded project **AVERROES** which set up **the HUMA network** of NGOs charged with disseminating knowledge about access to health care)
- When implementing a prevention programme, such as HPV vaccination, the public should be well informed beforehand on why the programme is being implemented, what the benefits are of participating and the risks associated with not participating. The **Aurora** project identified the lack of appropriate education campaigns previous to the implementation of HPV vaccination programmes as a significant factor in the low HPV vaccination rates that resulted from the programmes.³⁴²
- Innovative health education models such as "**With Migrants for Migrants**" or the **MiMi Programme**, have been used to train transcultural mediators, who organise and conduct information and education sessions on HIV/AIDS for the targeted groups (see the project **AIDS and Mobility** in Appendix 3),
- **Cultural or health mediators** have been used successfully in a number of countries to link services and hard to reach communities, such as the Roma, and thus improve access to health services (see more information on **NGO-led Roma Health Mediator initiatives** in Appendix VI). They have been found to play a key role in helping communities to understand and navigate the health system, as well as clarifying issues of entitlement and assisting with national insurance enrolment procedures.³⁴³

4.2.2. Practical barriers

Typical practical barriers to accessing health services that have been identified in research include the following:

- Geographical barriers affect especially populations living in isolated areas with limited access to health services, or those who rely on public transport to reach services but

³⁴² www.aurora-project.eu (accessed on 15 January, 2015)

³⁴³ How health systems can address health inequities linked to migration and ethnicity. Copenhagen, WHO Regional Office for Europe, 2010.

cannot afford it.³⁴⁴ Mobile health units have been found to be an effective means of bringing services to especially vulnerable groups.³⁴⁵

- Opening hours of health care providers often do not reflect the working hours of migrants who might be in precarious employment and might face problems in getting time off work, e.g. loss of salary for hours gone from the job, conflict with management, or losing their job.
- Overly complicated registration procedures and lack of needed documentation have been cited as serious obstacles for Roma populations accessing health services^{346, 347}.
- Screening participation amongst ethnic minorities in some countries is found to be generally lower compared to the general population.³⁴⁸ Fear, lack of information, and misunderstanding of risk are cited as possible barriers to accessing timely screening. In the UK, an intervention targeting women living in one of the most deprived and ethnically diverse borough of London with very low breast cancer screening rates, used telephone reminders. Through culturally and language adapted telephone reminders, the intervention managed to significantly improve breast cancer screening attendance.
- In order to improve screening coverage, research encourages the routine collection within general practice of additional sociodemographic information to aid monitoring of inequalities in screening coverage and inform policies to correct them.³⁴⁹
- For irregular migrants, going to a health care provider may carry with it the risk of being reported to authorities. In some countries, health professionals are required to report such migrants. Even where this is not the case, in the absence of reassurances to the contrary irregular migrants are liable to assume that such a risk is present.
- Even when irregular migrants have the right to (certain forms of) care, health professionals may not be aware of these rights or feel obliged to respect them. Work done by **PICUM**, **NowHereLand** and the **HUMA network** (amongst others) explores in detail the entitlements and health of irregular migrants in Europe (see Appendix 3). The project **EUGATE** recommended educating health professionals at *all* levels about entitlements for different groups of migrants (see Appendix 5),
- Migrants in detention may face obstacles to accessing the health services they need because of limited provision and availability of health providers³⁵⁰.
- Health services providers may be unfamiliar with certain medical procedures which may be needed by a small group, such as for example defibulation for women who have undergone female genital mutilation (FGM) or cutting. Defibulation is a routine

³⁴⁴ Schaaf, M. (2007). *Confronting a hidden disease: TB in Roma Communities*. Research report: Roma Health Project, Open Society Institute.

³⁴⁵ For more details, see NOWHERELAND project, Country Report: Portugal. Policies on health care for undocumented migrants.

³⁴⁶ Kingston, L., Cohen, E., Morley, C. (2010). **Limitations on universality: the "right to health" and the necessity of legal nationality**. *BMC International Health and Human Rights*, 10 (11).

³⁴⁷ Kühlbrandt, C., Footman, K., Rechel, B., McKee, M. (2014). An examination of Roma health insurance status in Central and Eastern Europe. *Eur J Public Health*;24(5):707-12.

³⁴⁸ Offman, J. *et al* (2014). A telephone reminder intervention to improve breast screening information and access. *Public Health*;128(11):1017-22.

³⁴⁹ Moser, K., Patnick, J. and Beral, V. (2009) Inequalities in reported use of breast and cervical screening in Great Britain: analysis of cross sectional survey data. *British Medical Journal*, 338: b2025.

³⁵⁰ Jesuit Refugee Service Europe, (2010). *Becoming Vulnerable in Detention*. Report of the DEVAS project (co-financed by the EC, European Refugee Fund). Available at <http://bit.ly/100Jo31>

procedure in countries where FGM is widespread: women are often defibulated (or ‘opened up’) when they get married and/or are pregnant. After migrating to countries where FGM is not practiced, women with FGM may not have access to this procedure for a variety of reasons, and consequently, may encounter problems during childbirth.³⁵¹

A further problem of access stems from the increasing fragmentation of disciplines and specialties within the health system.³⁵² Migrants and ethnic minorities may experience difficulties in trying to navigate the system of referrals and appointments with several providers in different locations. In some countries, “one stop” services for migrants are provided to reduce the risk that patients will “fall through the cracks” (e.g. the Migrant Helpline in London, Migrant Health Clinic in Copenhagen). However, separate provision for migrant and ethnic minority patients could also lead to mainstream services over-relying on migrant clinics rather than addressing issues of diversity in their organisations. A related issue is the poor integration of health and social care services in many countries. Many migrants have a need for several different kinds of help, but may be daunted by the task of negotiating two or more separate access procedures.³⁵³

4.2.3. Language barriers

We will discuss use of interpreters in the next chapter (on service quality). However, interpretation or translated materials may be necessary in order to get into care, e.g. to communicate with staff at reception, negotiate registration procedures, and read information about getting access to care.

4.2.4. Discrimination and mistrust

Many migrants and ethnic minorities experience discrimination in trying to access health services, according to research.^{354, 355} Reports of denial of services, or making available a limited and sometimes inferior range of services for certain groups, are common in a number of countries with high percentages of Roma.³⁵⁶ Mistrust of healthcare services and professionals may develop as a result of expectations of discrimination, and thus also act as a deterrent to seeking treatment for vulnerable groups. Trust is widely recognised to be essential for good care, but there may be a *structural, general* lack of trust between migrant and ethnic minority

³⁵¹ ³⁵¹ Leye, E. (2006). Health care in Europe for women with genital mutilation. *Health Care for Women International*, 27:4. Pg. 362-378.

³⁵² Mladovsky, P. *et al*, (2012b). Responding to diversity: an exploratory study of migrant health policies in Europe. *Health Policy*, 105: 1-9.

³⁵³ Priebe *et al* (2011)

³⁵⁴ European Roma Rights Centre (2006). *Ambulance not on the way. The disgrace of health care for Roma in Europe*. Budapest: Roma Rights Centre.

³⁵⁵ Kosa, K., Adany, R. (2007). Studying vulnerable populations: lessons from the Roma minority. *Epidemiology* 18: 290-9

³⁵⁶ Public Health Fact Sheet. *Left Out: Roma and access to health care in Eastern and South Eastern Europe*. Open Society Institute, Public Health Program, Roma Health Project. (no date)

communities and public authorities, based on linguistic or cultural differences³⁵⁷ or more deeply-rooted and long-standing antagonisms.³⁵⁸

Both discrimination by health workers and mistrust on the part of users reflect a less-than-ideal relationship between those working in the health system and the communities they serve. A number of good practices have been recommended to improve this relationship.

- The involvement of migrant and ethnic minority groups in the design and/or delivery of services is often cited as a key tool for improving access and quality of health services. However, these groups are usually poorly represented in the 'participatory spaces' designed to further such involvement³⁵⁹. Some projects aim to reduce the gap between health services and migrants and ethnic minorities. Community-based approaches – which aim to mobilise the health resources that communities already possess, rather than simply teaching people to become consumers of resources developed by others – are particularly promising in this respect³⁶⁰.
- A number of EU projects have aimed to improve user involvement in the design, implementation and evaluation of health services, especially migrant and ethnic minority involvement (see Appendix IV). **EURO HIV EDAT**, for example, will engage service providers and clients alike in the evaluation and design of improved services, and tools for how to access the services. **Aurora**, **TAMPEP** and **TUBIDU** also involve local stakeholders such as civil society and community organisations in their research, planning and development of interventions addressing cervical cancer (Aurora) and communicable diseases (TAMPEP, TUBIDU) in vulnerable populations. (See the case study below for a more detailed plan for how to successfully involve stakeholders in intervention planning and development)

Training of health professionals as well as migrants and ethnic minorities can help to reduce direct discrimination and mistrust, by raising awareness of the prejudices people have that they are not aware of, and equipping them with the knowledge and skills needed for diversity-sensitive health care. For more information on good practices in cultural competence training for health professionals, see Appendix V.

Cultural mediators, discussed in more detail in the next chapter, can also play a role in facilitating participation and engagement of migrants and ethnic minorities in health care services, and thus reducing mistrust and discrimination.

³⁵⁷ Priebe et al (2011).

³⁵⁸ Ingleby, D. (2008). *New perspectives on migration, ethnicity and schizophrenia*. Willy Brandt Series of Working Papers in International Migration and Ethnic Relations 1/08, IMER/MIM, Malmö University, Sweden

³⁵⁹ De Freitas, C. (2011) *Participation in mental health care by ethnic minority users: Case studies from the Netherlands and Brazil*, Utrecht: Utrecht University (PhD Thesis),

³⁶⁰ Garcia Ramirez, M., Hatzidimitriadou, E. (2009). User involvement and Empowerment in Health Care Practices with Ethnic Minority Groups: A Community Approach. *International Journal of Migration, Health and Social Care*. 5; 2-5

Chapter 5. Factors undermining the quality of health service delivery and good practices addressing them

5.1. What is meant by 'quality'?

The quality of health services can be assessed in many different ways. The most commonly used approach (the 'Donabedian model'³⁶¹) distinguishes three aspects of quality: structure, process and outcome. 'Structure' refers to resources such as buildings, equipment and staff, 'process' to the actions carried out in service delivery, and 'outcome' to the effectiveness of these actions in improving health. In the present context we are mainly concerned with process and outcome, because the structures within which MEMs are treated are to a large extent the same as those used by everybody else.

Assessing outcomes – discovering whether a given practice improves the effectiveness of care for MEMs – is the hardest kind of assessment to carry out, because it requires a controlled comparison of methods and their outcomes, possibly with long-term follow-up. In practice, such studies are difficult to set up: many contaminating and confounding factors have to be controlled for, ethical problems arise, and studies tend to be very expensive. Attention therefore usually focuses on process, and in particular two aspects: (1) the extent to which the procedures for diagnosis and treatment are properly carried out, avoiding erroneous diagnosis, noncompliance and dropout; and (2) the satisfaction (of both users and health professionals) with the treatment.

A fundamental principle of health service provision in diverse societies is that **providing the same care to all does not guarantee quality**. It is certainly a step forward from the situation in which sub-standard care is regarded as acceptable for certain groups of patients. However, unless the care is matched to the different characteristics and situation of different patients, providing the same care to all will amount to providing inferior care to some. Good care must be 'matched' or 'appropriate'³⁶² in certain ways. The notion of 'patient-centeredness' has received increasing emphasis in recent years, particularly among agencies responsible for accreditation of service providers. In many countries, however, few attempts are made to apply this principle to the needs of MEMs (see Chapter 3). Even though these groups may be given legal access to health services, the help offered is not 'targeted' or 'tailored' in any way.

As was pointed out in the previous section, the same factors which create barriers to access may also undermine the quality of care. This concerns in particular language barriers, poor health literacy, discrimination and mistrust.

³⁶¹ Donabedian, A. (1988). The quality of care. How can it be assessed? *JAMA : The Journal of the American Medical Association* 260 (12): 1743–8.

³⁶² Institute of Medicine (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: The National Academies Press.

5.2. Factors undermining quality and good practices addressing them

5.2.1. Cultural barriers

Important changes have taken place over the last 30 or 40 years in the way ‘culture’ has been understood. During much of this period, ‘cultural differences’ (conceptualised in a certain way) have been considered to be the main barrier standing between MEM patients and health service providers.³⁶³ In this conceptualisation, ‘culture’ is a relatively fixed and homogeneous set of characteristics that migrants bring with them, like baggage, from their country of origin. Language, religious beliefs, diet, hygiene practices and gender roles are typical items in this ‘cultural baggage’. Unawareness of these cultural characteristics was seen as hampering the delivery of appropriate care. Knowledge of different cultures was proposed as the way to tackle this barrier, and textbooks on different cultures became the main training tools for health professionals.

This view of the role of culture in health services for MEM has increasingly come under fire since the 1990’s. Rather than labelling and stereotyping patients according to simplistic conceptualisations of culture, attention has been drawn to the diversity within cultures, the fluid and many-layered nature of culture, and migrants’ interactions with the host country culture – which gives rise to new, ‘hybrid’ cultures and identities.

At the same time, given the increase in the number and diversity of sending countries, becoming a culturally competent health provider has become increasingly difficult for those who try to follow the traditional text-book approach. A different approach has come to the fore, which proposes that little of use can be learned about a patient’s culture from books. Instead, the first task is seen as understanding one’s *own* culture: in this way one can become better able to accept and understand that of others. As in ‘patient-centered care’, the way to overcome cultural barriers is to take the time to get to know the patient better.³⁶⁴ The appropriate attitude for health professionals is therefore one of ‘cultural humility’ - “a commitment and active engagement in a lifelong process that individuals enter into on an ongoing basis with patients, communities, colleagues, and with themselves”³⁶⁵(p. 118).

It is important to note that abandoning a static, stereotypical view of MEM ‘cultures’ does not mean abandoning the concept of culture altogether in favour of a purely individual-centred approach. MEMs are likely to appreciate a health worker who knows and respects their traditions and shows an informed interest in their country of origin. In addition, although a huge

³⁶³ This section draws on Ingleby, D. (2012). Introduction by series editor. In: D. Ingleby, A. Chiarenza, W. Devillé & I. Kotsioni (Eds.) *Inequalities in Health Care for Migrants and Ethnic Minorities. COST Series on Health and Diversity, Volume II* (pp. 9-28). Antwerp/Apeldoorn: Garant.

³⁶⁴ Saha, S., Beach, M.C., Cooper, L.A. (2009). Patient centeredness, cultural competence, and healthcare quality. *Journal of the National Medical Association*, 100 (11): 1275-85

³⁶⁵ Tervalon, M., & Murray-García, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved*, 9(2), 117–125.

variety of cultural and ethnic groups can be found across Europe, large migrant communities often gravitate to specific locations, making it possible for service providers to focus on the needs of particular groups without necessarily pigeon-holing them according to rigid stereotypes.

An example is the case of migrant communities that originate from countries where FGM is practiced. Health providers catering to these communities need to have a thorough understanding of the practice itself, who is affected by it, the health implications of the procedure, and how to meet the needs of women who have undergone or are at risk of undergoing FGM. Literature has identified several factors that may inhibit the provision of adequate care for women with FGM³⁶⁶ :

1. Lack of knowledge about FGM among health care professionals
2. Health professionals' personal emotions and feelings regarding this cultural practice, e.g. anger, fear of dealing with culturally sensitive topic, powerlessness.
3. Lack of technical guidance for caring for women with FGM
4. Lack of knowledge of the health care expectations and needs of affected communities
5. Lack of coordination and coherence among health and social services, other agencies (e.g. schools, police, immigration), policymakers, and civil society, prevent an integrated approach to prevention and care.

Similarly, in order to optimize the healthcare given to infertile migrant couples, clinicians should be aware of the possible impact of non-biomedical beliefs concerning procreation, both on treatment issues and on the specific psycho-cultural stress associated with childlessness.³⁶⁷

Along with this radical change in the way 'culture' is conceptualised, the concept of cultural competence has evolved into a more comprehensive notion involving not only 'knowledge' but also skills and attitudes (often referred to by the acronym KAS)³⁶⁸. In addition, the concept has been broadened to encompass not only individual caregivers, but organizations too. Indeed, the 'National standards on culturally and linguistically appropriate services (CLAS)'³⁶⁹ – which have had a major influence on health care not only in the United States, but also in Europe – are primarily addressed to service provider organisations, as are the 'Equity Standards' developed by the HPH-WHO Task Force on Migrant-Friendly and Culturally Competent Health Care (TF MFCCH).³⁷⁰ The 'whole organisation approach'³⁷¹ stresses that health care is given by individuals who are part of a team. According to this approach, focussing exclusively on 'front-line' professionals ignores their need for back-up and support from all levels of the organisation. This

³⁶⁶ Leye, E. (2006). Health care in Europe for women with genital mutilation. *Health Care for Women International*, 27:4. Pg. 362-378.

³⁶⁷ Van Rooij, 2004.

³⁶⁸ Expert Panel on Cultural Competence Education for Students in Medicine and Public Health (2012). *Cultural competence education for students in medicine and public health: Report of an expert panel*.

Washington, D.C.: Association of American Medical Colleges and Association of Schools of Public Health.

³⁶⁹ OMH (2000). *National standards on culturally and linguistically appropriate services (CLAS) in health care*. Washington, United States Department of Health and Human Services.

³⁷⁰ Website: <http://bit.ly/1A6PdFq>

³⁷¹ Mladovsky, P. et al (2012a). Good practices in migrant health: the European experience. *Clinical Medicine*, Vol 12, No. 3: 248-52.

implies that systematic training and education, not only of health workers but also of policy-makers, managers and researchers, is required to bring about these changes.³⁷²

The most recent development in the concept of 'cultural competence' has called into doubt the very centrality of the concept of 'culture' itself, arguing instead for the adoption of an 'intersectional' approach.³⁷³ This approach calls for a more general improvement in the health system's 'sensitivity to diversity', encompassing gender, age, religion, disability, sexuality and socio-economic position.³⁷⁴ It arose as a logical development of the call for health systems to recognise the 'super-diversity' of modern migrant populations (referred to in Chapter 1). If the differences in educational level, legal status, gender, age (etc.) within migrant or ethnic minority groups need to be considered, why should these factors not be considered as important their own right? Such an approach extends the notion of 'sensitivity' beyond MEM alone to the whole society. (This view was also voiced in the Council of Europe's 2006 Recommendations on 'Health care in a multicultural society', discussed in Chapter 3, and in the 2013 revision of the CLAS Standards³⁷⁵). The notion of 'intersectionality'^{376,377} implies furthermore that different dimensions of diversity do not simply have an additive effect, but may also interact with each other: the effects of low educational level, for example, may differ between male and female migrants.

Addressing culture- and diversity-related barriers to quality in health services

Cultural competence or diversity sensitivity may have a positive impact on the following barriers to quality:

- It may facilitate communication about different frames of reference regarding health.
- It may help professionals to overcome deeply-rooted prejudices.
- It may help to bridge the gap between widely differing understandings of health and illness in general, as well as the nature, manifestations, causes, effects and social meanings of particular illnesses.
- It may help to reconcile conflicting expectations concerning appropriate behaviour for doctors and patients.

Promoting cultural competence or diversity sensitivity at the level of both organisations and individuals is seen as a central component of the changes which have to be made in order to adapt services to users with widely varying beliefs, expectations, needs and social positions. It is

³⁷² Cattacin, S., Chiarenza, A. and Domenig, D. (2013). "Equity Standards for Health Care Organisations: a Theoretical Framework." *Diversity and Equality in Health and Care* 10(4): 249-258.

³⁷³ Chiarenza, A. (2012). Developments in the concept of 'cultural competence'. In: D. Ingleby, A. Chiarenza, W. Devillé & I. Kotsioni (Eds.) *Inequalities in Health Care for Migrants and Ethnic Minorities. COST Series on Health and Diversity, Volume II* (pp. 66-81). Antwerp/Apeldoorn: Garant.

³⁷⁴ Renschler, I., Cattacin, S. (2007). Comprehensive 'difference sensitivity' in health systems. In: Bjorngren-Cuadra, C, Cattacin, S. (eds). *Migration and Health: difference sensitivity from an organizational perspective*. Malmö: IMER: 37-41 (<http://hdl.handle.net/2043/4289>, accessed 28/7/14).

³⁷⁵ <https://www.thinkculturalhealth.hhs.gov/>

³⁷⁶ Malmusi D, Borrell C, Benach J. (2010). Migration-related health inequalities: showing the complex interactions between gender, social class and place of origin. *Social Science and Medicine* 71, 1610-9.

³⁷⁷ Iyer, A., Sen, G., Ostlin, P. (2008). The intersections of gender and class in health status and health care. *Global Public Health*, 3(S1):13-24.

also important for targeting health promotion interventions for migrants, so as to take into account the different ways in which people perceive and experience health problems.³⁷⁸

5.2.2. Language barriers

Miscommunication due to language barriers is a common and costly problem affecting the accessibility and quality of health services for migrants and ethnic minorities. Research from the US has shown that billions of dollars are lost annually due to communication problems often arising from language differences, leading to faulty diagnoses, lack of compliance with therapies, lower patient safety and lower treatment satisfaction in patients and providers. According to the Institute for Healthcare Communication (IHC)³⁷⁹,

Research evidence indicates that there are strong positive relationships between a healthcare team member's communication skills and a patient's capacity to follow through with medical recommendations, self-manage a chronic medical condition, and adopt preventive health behaviors. Studies show that the clinician's ability to explain, listen and empathize can have a profound effect on biological and functional health outcomes as well as patient satisfaction and experience of care. Further, communication among healthcare team members influences the quality of working relationships, job satisfaction and has a profound impact on patient safety.

Understanding what is said in health service encounters is often a challenge even when the patient and health professional share the same language. For migrants, basic fluency in the language of the host country may not be enough to effectively communicate their health problem or understand what the health professional says. In addition, in some countries, language proficiency has become a politically sensitive topic and a symbol of integration. Although learning the language of their host country is essential for integration, and some migrants may need help or encouragement to do so, language proficiency should not be a precondition for accessing and receiving adequate care.

To overcome language barriers in health services and ensure quality of care is not compromised by communication problems, a number of interventions have been successful. For **written materials**, for example, the following methods can be used:

- Translation of written materials such as forms, information brochures, health promotion or educational materials.
- Introduction of pictures and diagrams, or informative videos to facilitate understanding, and provide alternatives to written materials in case of illiteracy.

However, it is unreasonable to expect that health care providers will provide translated materials in every language that is spoken in the area they serve. In areas with large MEM populations, the

³⁷⁸ Netto, G. *et al* (2010). How can health promotion interventions be adapted for minority ethnic communities? Five principles for guiding the development of behavioural interventions. *Health Promotion International*.

³⁷⁹ IHC (2011). *Impact of Communication in Healthcare*. Available at <http://bit.ly/1o6nHGj>

number of languages spoken is simply too high. Health care providers should then prioritise translation of written materials for the largest language groups, and find alternative means of meeting the communication needs of patients belonging to smaller language groups.

Concerning **interactions** in health care, a variety of methods have been proposed for overcoming language barriers.³⁸⁰

Professional face-to-face interpretation is considered most accurate, but requires setting aside resources, and planning in advance, which is not always possible in emergency situations, leading to possible delays. To ensure the effectiveness face-to-face interpretation, health professionals should receive training in how to use interpreters. It should be noted that in some instances, using an interpreter from the same community as the patient, may inhibit open communication for confidentiality reasons.

Professional interpretation by telephone can be the solution for situations where logistical planning is not possible, for example when ambulance personnel need interpretation. Despite the challenges of not being able to read non-verbal communication, costs can be reduced considerably by not having an interpreter physically present.

Informal face-to-face interpretation is perhaps the most widely-used method, but most controversial, as the reliance on family members is fraught with problems stemming from confidentiality issues, the appropriateness of using children as interpreters. Sometimes, a member of staff in the healthcare setting is called upon to act as an interpreter. Given the lack of training and skills of informal interpreters, relying on them can lead to serious misunderstandings with dire consequences.

Bilingual professionals with a command of the migrant or minority patient's language present many advantages over the above-mentioned methods. However, their proficiency in the migrant's language needs to be quite high, and the range of languages catered for can only be slightly increased by this method. Here again, if one is dealing with large minority groups such as Spanish-speakers in the United States or Russian-speakers in Latvia or Estonia, this may not be a serious drawback.

'**Cultural mediators**' are health workers who not only provide linguistic interpretation, but mediate actively between health professionals and service users. They are concerned with overcoming not only language barriers, but also cultural and social ones. The minorities concerned must be fairly large, but this method has many advantages and the role of "cultural mediators" may be varied and extensive, involving trying to help caregivers and users understand each other's point of view and offering advice on ways to solve problems. Some may even operate independently of medical professionals and function as a kind of "gatekeeper". European countries where cultural mediation seems to be a favoured approach include Belgium, France, Ireland, Italy, the Netherlands, Spain and the United Kingdom. Many Roma speak only

³⁸⁰ Ingleby, D. (2011). Good practice in health service provision for migrants. In: Rechel, B. et al (eds). *Migration and Health in the European Union*. European Observatory on Health Systems and Policies Series. Maidenhead: Open University Press.

Romani, and in countries with high numbers of Roma, cultural mediation initiatives have been quite successful in helping to bridge the language gap..

We should note that even if the health worker understands the need for an interpreter, it is necessary for the management of the organisation they work in to solve the logistic problems of arranging one and paying the bill. To be efficient, in fact, interpretation facilities may have to be organised at national level, so the issue becomes one that cannot be solved at the level of local managements. Moreover, health workers need training in order to be able to work effectively with interpreters, and this training has to be organised as well.

In spite of numerous demonstrations of the need for and usefulness of interpreters, not enough use is made of them³⁸¹. This reluctance may have a number of causes. People often have the illusion of understanding each other when in fact they do not; the importance of good communication may not be appreciated; the practical problems of organising an interpreter may be regarded as outweighing the advantages. A major problem is cost. Where no assistance is available from government or health insurers, service provider organisations may decide to save money by restricting the use of interpreters.

Legal measures and professional standards, where they exist, do not seem to be enough to overcome all the factors that discourage the use of interpreters. More effective arguments may be provided by the financial considerations mentioned earlier. A growing body of literature in the USA, matched by an increasing number of studies in Europe, have shown that a small investment in the costs of interpretation may pay itself back many times by making health care more cost-effective.

Ongoing projects, such as **Equi-Health** and its sub-project “*Cost analysis of health care provision to migrants and ethnic minorities*” conducted by the Centre for Health and Migration and the International Organisation for Migration (IOM), are in the process of conducting cost analysis studies to establish a consensus on “acceptable standards of health care provision.” Identifying the cost of not providing adequate interpreter services may provide the much needed economic stimulus to mainstreaming these kinds of services.

5.2.3. Barriers between the health system and migrant or ethnic minority communities

As we noted when discussing problems of access in Chapter 4, barriers may exist not simply at the individual level, but also at the level of health services and communities. In section 4.2.4 it was noted that the involvement of migrant and ethnic minority groups in the design and delivery of services seems to be a key tool for improving both access and quality.

³⁸¹ Meeuwesen, L., *et al* (2012). Interpreting in health and social care: policies and interventions in five European countries. In D. Ingleby, A. Chiarenza, W. Devillé, & I. Kotsioni (Eds.), *Inequalities in health care for migrants and ethnic minorities* (pp. 158–70). Antwerp-Apeldoorn, Belgium: Garant Publishers.

Increasingly, a high value is coming to be placed on 'user participation' in health services³⁸². There is a drive to make the relationship between health services and their users one of partnership. In order to improve policies and increase their acceptance and effectiveness, users must become more than passive consumers of care: they should take active responsibility for their own health, and when they become ill they should contribute actively to their treatment. In addition, they should come to think of themselves as 'owners' of the health system itself. To further this change, 'participatory spaces' (representative bodies, etc.) have been created to allow service users to contribute to designing and running services.

However, migrants and ethnic minorities are usually poorly represented in these 'participatory spaces'. They are often reluctant to join in, and when they do their voice tends to be ignored or ineffective.³⁸³ The lack of involvement from migrant and ethnic minority communities seems to be the Achilles heel of many efforts to improve health and health service delivery for these groups. In Chapter 4 we described several EU-supported projects which set out to tackle this problem. However, such efforts are few and far between: as a rule, research is carried out 'on' minority communities instead of 'with' them, and interventions are designed and implemented from above.

It is notable that in some major documents outlining a 'road map' for improving migrant health (see Chapter 3), the issue of user participation or community involvement has not even been mentioned. Resolution WHA61.17 (2008) seems to envisage a purely 'top-down' approach to the health of migrants, although the topic of participation did receive some attention at the WHO/IOM Global Consultation in 2010. In relation to interventions for Roma, however, attention is paid much more consistently to user involvement. A recent statement by the European Commission³⁸⁴ spoke of measures

to promote the empowerment, active involvement and necessary participation of Roma themselves, at all levels of policy development, decision-making and implementation of measures, including by raising awareness of their rights and duties, as well as to consolidate the capacity of Roma NGOs and encourage the better involvement of civil society and all other stakeholders.

Nevertheless, to judge from the assessments that are emerging of projects to further Roma inclusion, this commitment to community participation appears easier to make on paper than to realise in practice. This is not difficult to understand, given that one is dealing with a group with a long history of segregation and exclusion. However, it is essential that for projects to be successful, they should be 'owned' by the community they are meant to benefit. Health workers dealing with migrants and ethnic minorities need to learn about the approaches that

³⁸² WHO (2006). *Ninth futures forum on health systems governance and public participation*, Copenhagen: WHO Regional Office for Europe.

³⁸³ De Freitas, (2011).

³⁸⁴ European Commission, (2011). *Council conclusions on an EU Framework for National Roma Integration Strategies up to 2020*. Brussels: European Commission.

exist to empower communities and encourage participation, for example in the traditions of Community Psychology and Community-Based Participatory Research³⁸⁵.

Case Study: The Aurora project – Good practices for involving key stakeholders in the planning and development of a cervical cancer prevention and control programme.³⁸⁶

As part of its aim of promoting cervical cancer screening in the new EU Member States, the project identified and analysed good practices and strategies for developing and implementing cervical cancer prevention and control programmes. To summarise the good practices, a framework has been built for the development of a complete programme, including the following key areas of action: 1) policy, 2) planning the programme, 3) preparing to launch the programme, and 4) Implementation. The first three areas of action include very detailed guidelines for how to involve key stakeholders. A summary of these guidelines is provided below:

- 1) Policy: Engage high-level stakeholders
 - a. Involving public scientific committees and societies may bring credibility to the message
 - b. To increase public interest and media coverage, enlist the commitment of a celebrity
 - c. Invest time in acquiring the support for nation, regional and local authorities.
 - d. Involving another national government (e.g. US Agency for International Development) as a supporter might aid the implementation of the objectives of an intervention.
- 2) Planning the programme: Engage local stakeholders
 - a. Involving health care professionals and/or mediators from the start and regularly seeking their input throughout the project, will promote the participation of hard-to-reach (HTR) populations and thus may contribute to positive project outcomes.
 - b. Increase engagement through direct incentives, e.g. rewarding participants.
 - c. Non-profit organisations may play an especially important role helping to reach HTR populations.
 - d. Volunteers can play a key role in awareness raising through low budget, community events.
 - e. Involving previously inactive new stakeholders, such as GPs, nurses, teachers, etc., as they may remain engaged and committed to further interventions.
- 3) Preparing the launch of the programme: Provide orientation for community, stakeholders and staff, and ensure their training and availability.
 - a. Create a well-defined and recognisable identity for your programme, e.g. a logo that is featured at events and on information materials associated with the programme.

³⁸⁵ Faridi, Z. (2007) Community-based participatory research: necessary next steps. *Preventing Chronic Disease*, 4(3). Available at http://www.cdc.gov/pcd/issues/2007/jul/06_0182.htm

³⁸⁶ Ilardi, M., Kovacs, Z. (2009). A European Network on cervical cancer surveillance and control in the new Member States. D4 – Report about the good practices identified and analyzed. Consumers, Health, and Food Executive Agency. www.aurora-project.edu (accessed on 2 January, 2015).

Chapter 6. Developing a European framework for collaboration on migrant and ethnic minority health

The MEM-TP project will provide information and inspiration for shaping, running and evaluating training programmes for health professionals and other key actors in order to equip them with the necessary knowledge and skills to meet the health needs of migrants and ethnic minorities in Europe.

To promote the sustainability and continual development of the training packages, the actors involved in the training aspect of MEM-TP could initiate a European level collaboration, based on sound, interprofessional collaboration theories.

Research in the field of interprofessional collaboration suggests that theories applying to health care settings have in common several concepts underpinning the processes that characterize different forms of collaboration.³⁸⁷ These concepts are 'sharing', 'partnership', 'interdependency', and 'power'. Sharing refers to a range of processes, from information and decision-making sharing, to shared responsibilities and philosophy. Partnership as a central notion of collaboration implies the coming together of two or more partners in a 'collaborative undertaking' characterized by an authentic and constructive relationship, requiring honest and open communication, mutual trust and respect. Interdependency refers to the concept of actors depending on each other in their common goal of addressing health care users' needs. Power, as a concept in collaborative relationships, implies the empowerment of each partner, based on the experience and knowledge that is created and shared

The training programs will mainly take place in national, regional and local settings according to the national traditions and procedures for postgraduate training. In order to support these activities, it will be relevant to establish a sharing platform including information and up-dated learning material as indicated in figure 13. The sharing platform would also include and make extensive use of assessment and evaluation tools such as the C2ME assessment tool and the MIPEX indicators tool, as well as potential training materials from, for example, the 'Big Picture' project and Mighealth net.

A sustainable platform requires some kind of organizational set-up, characterised by partnership working, in a suitable European migrant health research institution (university, research centre) or a larger organization focusing on migrant health, in collaboration with a relevant EU-agency and possibly the WHO office for the European Region. Additionally, it would be relevant to offer regular European courses on specific aspects of migrant and ethnic minority health targeting national and local trainers and key nation experts. This could be offered by national institutions/universities and perhaps coordinated by an international public health organization

³⁸⁷ D'Amour, D. *et al* (2005) The conceptual basis for interprofessional collaboration: Core concepts and theoretical frameworks. *Journal for Interprofessional Care*, May, Supplement 1: 116-131.

like ASPHER (Association of Schools of Public Health in the European Region) or EUPHA (the European Public Health Association, Section of Migrant and Ethnic Minority Health) - in collaboration with other organisations such as EPHA and IOM. During the remaining MEM-TP project the possibilities for involving such institutions/organizations in a European framework will be further examined.

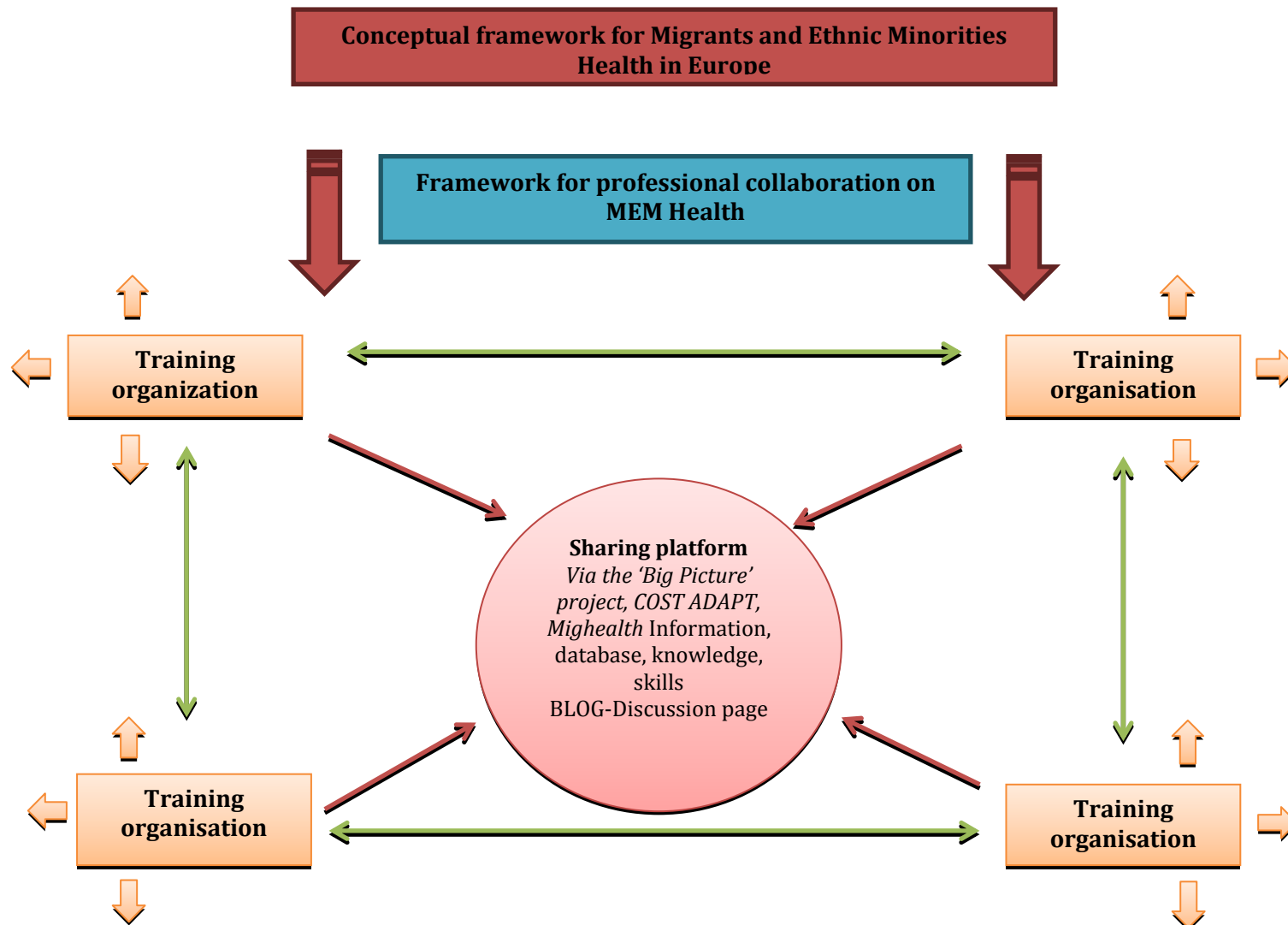


Figure 13 Conceptual framework for MEM health in Europe

