



European  
Commission

# Roma Health Report

Health status of the Roma population

Data collection in the Member States

of the European Union

Written by

**matrix**  
share our insight

Health and  
Consumers

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# **Part 1**

## **Health Status of the Roma Population**

## Introduction

Roma experience extensive discrimination, violence and social exclusion. This has intertwined consequences across a range of sectors and these consequences have a negative impact on health. This is why it is often necessary for international agencies (intergovernmental, governmental and nongovernmental) to take action to protect the health and well-being of these groups.

This study has been carried out by Matrix Knowledge in collaboration with the Centre for the Study of Democracy, the European Public Health Alliance and individual national researchers on behalf of the Consumers, Health and Food Executive Agency (Chafea) and DG SANCO. The aim of this study was to provide the most up-to-date picture about Roma health status. The specific objectives were to prepare a report assessing the health status and health-related lifestyle attributes of the Roma population. The research team has also been supported by the European Union Agency for Fundamental Rights, which has shared data and provided feedback on the research process throughout the study.

The purpose of this report is to provide an evidence-based review of literature on Roma health, covering 2008-2013 and the following indicators:

1. Mortality and life expectancy
2. Prevalence of major infectious diseases
3. Healthy life styles and related behaviours
4. Access and use of health services and prevention programmes
5. Prevalence of major chronic diseases
6. Health factors related to the role of women in the Roma community
7. Environmental and other socio-economic factors.

To the extent possible from the available data, the report attempts to identify major past and expected future trends and developments in the health status of the Roma population. This report is dovetailed by a report which covers current and planned future measures to produce information on Roma health.

The report covers scientific literature as well as grey literature including reports published by the EU Member States, EEA/EFTA, national and international organisations such as the International Organization for Migration, OECD, the Council of Europe, the World Health Organization, the World Bank, the European Union Fundamental Rights Agency and UNDP. The report also takes into account outputs from the EU Health Programme Reports and other initiatives funded by the European Commission services. It furthermore draws on data collected by NGOs in Europe on the health status of Roma.

The study covers 31 countries – the EU-28 and EEA Member States – with in-depth country reports produced for Member States with large (migrant) Roma populations – Bulgaria, Croatia, the Czech Republic, France, Greece, Hungary, Italy, Romania, Slovak Republic, Spain and the United Kingdom.

## Policy context

This section sets out significant European and International bodies currently involved in Roma health matters in Europe alongside a consideration of the main pan-European policies and programmes relating to Roma health. The chapter examines the role of major institutions and the interplay between general health policy, Roma integration strategies and specific policies and programmes targeted at addressing the health needs of the Roma population. The chapter begins with a short examination of health inequalities and the Roma population.

### Health inequalities in the Roma population

Health inequalities can be defined as differences in health status or in the distribution of health determinants between different population groups<sup>1</sup>. For example, differences in morbidity between elderly people and the younger population or differences in mortality rates between people from different social classes. There has long been a consensus that compared with the non-Roma population in Europe, Roma have poorer health. Roma populations in Europe are also frequently socially excluded, suffer discrimination and consequently face barriers accessing good quality housing, health care and education. UNDP survey data from 2004 and 2011<sup>2</sup> on Roma show that:

- *"One third of Roma respondents aged 35 to 54 reported health problems limiting their daily activities. (2011)*
- *Approximately 20 per cent of Roma respondents were not covered by medical insurance or did not know if they were covered. (2011)*
- *66 per cent of Roma said they could not afford prescription drugs compared to 29 per cent of the majority population. (2004)*
- *15 per cent of Roma children under the age of 14 are not vaccinated compared to four per cent of children from non-Roma households. (2004)"<sup>3</sup>*

The poor health of Roma is closely linked to social determinants of health. Fully understanding the effects of social determinants on population health and on health inequalities requires working through long causal chains of mediating factors. Many of these factors tend to cluster among individuals living in underprivileged conditions and often interact with each other.<sup>4</sup> This is most effectively illustrated in the enriched version (see Figure 1) of the original Dahlgren and Whitehead model. The WHO Commission on Social Determinants of Health (CSDH) regards processes of social exclusion as the major cause of health inequalities among migrants and ethnic minorities. It must also be observed that in this context health is a holistic concept. It is not considered only as health care, but it also includes disease prevention, health promotion and efforts to address concerns in the wide range of health areas – i.e. nutrition, physical activities, alcohol, and tobacco – as well as in other policy sectors – i.e. employment, housing and environment<sup>5</sup>.

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<sup>1</sup> WHO definition of health inequalities. Available at <http://www.who.int/hia/about/glos/>

<sup>2</sup> Covering the EU Member States Bulgaria, Croatia, the Czech Republic, Hungary, Romania and Slovakia

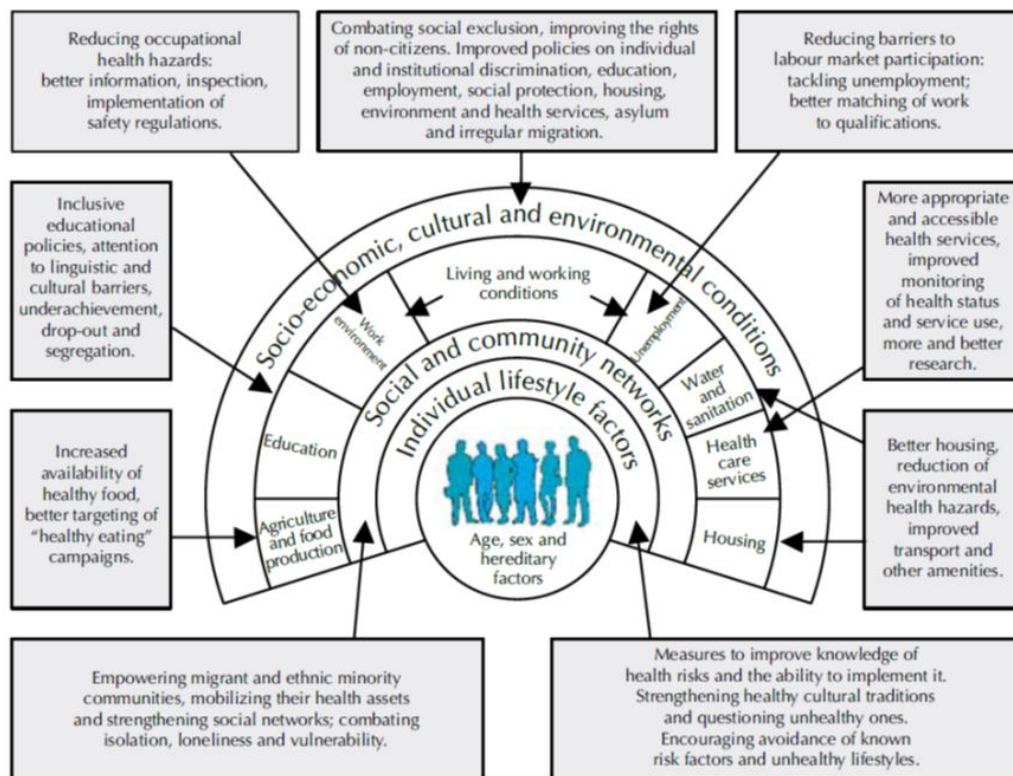
<sup>3</sup> UNDP Data on Roma. Available at <http://www.undp.org/content/rbec/en/home/ourwork/povertyreduction/roma-in-central-and-southeast-europe/roma-data/>

<sup>4</sup> Solar O, Irwin A. A conceptual framework for action on the social determinants of health. Social Determinants of Health Discussion Paper 2 (Policy and Practice) 2010.

<sup>5</sup> WHO Regional Office for Europe (2008). The Tallinn Charter "Health Systems for Health and Wealth". Copenhagen, WHO Regional Office for Europe. Available at



**Table 1 Social determinants of health and policy measures required to tackle them in the case of migrants and ethnic minorities**



Source: WHO Regional Office for Europe (2010). "How health system can address health inequities linked to migration and ethnicity". Copenhagen, WHO Regional Office for Europe. (p.14).

In the specific context of the health status of Roma, it is important to understand that health status of Roma populations, and variations of health status amongst Roma populations in different countries, may be due to factors that are unrelated to a person's status as a member of the Roma population, but may be a result of other socio-economic, cultural or environmental conditions. For example, in the specific context of Roma accessing regular health check-ups with primary care physicians, uptake of services or lack thereof could be due either to (i) barriers created by social exclusion, i.e. living far from service providers, (ii) discrimination; such as by primary care services preventing Roma without proof of domicile from registering, (iii) the result of a lack of health literacy due to barriers in accessing health education programmes and hence limited understanding of the benefits of preventive education, or (iv) cultural definitions of 'ill' health which decrease Roma engagement with health services unless symptoms arising from serious health problems impact on functioning.

Comparison of data specific to Roma with data specific to particular population groups (where other socioeconomic, cultural and environmental conditions are broadly similar) could be used to inform an analysis of how different socio-economic factors impact on the health status of different Roma populations, and identify specific areas of focus to address health inequalities and improve the health outcomes of Roma communities. However, in practice, data for these vulnerable populations – both Roma and non-Roma – are generally of too poor quality to allow for such comparison. In

particular there is a lack of data on migrant and undocumented Roma and gender disaggregated data. However, recent research from UNDP is beginning to build a knowledge base on Roma migration, in particular providing data on the conditions of Roma migrants in France and Italy<sup>6</sup>

Therefore to a degree there is still a lack of understanding as to the specific causes of health gaps between Roma and non-Roma. Research often relies on old data, proxy indicators (if more relevant ones are unavailable), anecdotal evidence and small scale studies which cannot be extrapolated to larger populations. With better data and more knowledge, more effective policies can be developed to support the Roma population with the needs that they have, and the impact of existing policies can be more robustly evaluated.

The quality of data on Roma health is affected by a number of factors including:

- Lack of 'ethnic' data tags to specifically identify Roma populations within national, regional or local datasets;
- The heterogeneity of the Roma populations within and between countries makes it difficult to draw robust conclusions from small sample surveys; and
- Poor community relationships. Social exclusion of minorities and Roma is a politically sensitive issue and policy and activities developed need to reflect the consensus of all parties involved.

It is within this context that the involvement of a range of pan-European and international institutions needs to be assessed. In addition to the activities undertaken at Member State level there are a number of Pan-European and International bodies that are actively involved with the development of policies and programmes to help reduce the health inequalities set out above including consideration of matters relating to health data.

## **Institutional Overview**

The main actors are the European Commission and its associated agencies including the Consumers, Health and Food Executive Agency (CHAFFEA), the European Centre for Disease Prevention and Control (ECDC), the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), the EU Agency for Fundamental Rights (FRA), the European Commission against Racism and Intolerance (ECRI), and Eurofound. Other European institutions of note include the European Parliament (EP) the European Council and the Council of Europe (CoE). In addition a key role is also played by international organisations including the United Nations Development Programme (UNDP), the World Bank, World Health Organization (WHO) as well as the International Organization for Migration (IOM). A more detailed assessment of the role of each of these organisations is set out below.

## **European Commission**

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<sup>6</sup> Please see

<http://de.scribd.com/doc/197718148/Migration-of-Roma-and-Non-Roma-from-Central-and-Eastern-Europe>.

This research was published after the data collection phase for this study and is therefore not analysed as part of these project findings.

Within the European Union citizens have the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices (article 35 of the Charter of Fundamental Rights of the European Union).

Whilst health policy is still mainly a Member States' competency, the EU is required to take into account the protection of human health when defining and implementing all its policies and activities (articles 9 and 168 of the Treaty on the Functioning of the European Union – TFEU) as well as having a shared competence with Member States in relation to common safety concerns in public health (article 4 TFEU). The Commission also has the competence to carry out actions to support, coordinate or supplement the actions of Member States in relation to the protection and the improvement of human health (article 6 TFEU).

The European Commission's most recent policies to support the integration of Roma date back to the 1990s, as it was a key issue throughout the accession process of the Central and Eastern European Countries. Initiatives from the European Commission targeting Roma Health issues should consequently be viewed within the context of a wider programme of policies related to anti-discrimination, integration and social inclusion.

Issues relating to the health needs of the Roma population are addressed within a range of general and specific policies. Two of the most important elements of the European Commission's response to the health needs of the Roma population form part of wider programmes to support Roma in Europe.

Since 2008, the European Commission has organised a **European Roma Summit on Roma Inclusion**, which provides the opportunity to discuss Roma issues at the highest decision-making levels of the EU, including national and regional authorities, with the involvement of civil society.

The first European Roma Summit took place in 2008 in Brussels and the proposal was put forward to set up a European Roma Platform: an open and flexible environment where all key actors are expected to come together to exchange knowledge, experience and good practice. The second Roma Summit took place in April 2010 and its aim was to take stock of the achievements undertaken at EU level for Roma inclusion over the past two years, and to renew the commitments. Particular attention was paid to the issue of Roma health, to which a plenary discussion was fully dedicated on the second day of the Summit. The Trio of the Spanish, Belgian and Hungarian Presidencies adopted a declaration highlighting the joint commitment for the mainstreaming of Roma issues into all relevant policies, a roadmap for the actions of the European Platform for Roma inclusion, the effective use of the EU Structural and Investment Funds to this end and the follow up of the Summit in Council<sup>7</sup>.

Following the first Roma Summit, the European Platform for Roma Inclusion was launched in April 2009<sup>8</sup>. During this meeting the European Commission presented the 10 Common Basic Principles on Roma Inclusion<sup>9</sup>, which are a tool for both policy-

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<sup>7</sup> Spanish Presidency of the Council, Report on the II European Roma Summit, Promoting Policies in favour of the Roma population (2010). And <http://ec.europa.eu/social/main.jsp?catId=88&langId=en&eventsId=234&furtherEvents=yes>

<sup>8</sup> [http://ec.europa.eu/justice/discrimination/roma/roma-platform/index\\_en.htm](http://ec.europa.eu/justice/discrimination/roma/roma-platform/index_en.htm)

<sup>9</sup> 1. Constructive, pragmatic and non-discriminatory policies; 2. Explicit but not exclusive targeting; 3. Inter-cultural approach; 4. Aiming for the mainstream; 5. Awareness of the gender dimension; 6. Transfer of evidence-based policies; 7. Use of European Union instruments; 8.

makers and practitioners managing programmes and projects<sup>10</sup>. In the same year, one of the major efforts made by the European Commission Parliament was the launch of the pilot project '**Pan-European Coordination of Roma Integration Methods - Roma Inclusion**', which was financed and commissioned by the European Parliament to the Commission (DG REGIO).

Based on the undergoing international initiative the Decade of Roma Inclusion 2005-2015, the experiences of the Roma Summit and the European Platform for Roma; the European Commission published a **Communication on the economic and social integration of the Roma in Europe**<sup>11</sup> (2010) which recognised the importance of addressing the health, education, employment and housing situation for Roma. It was the first time the European Commission adopted a policy Communication dedicated specifically to Roma and was released on the same day as the Progress Report on the implementation of the EU instruments and policies for Roma inclusion 2008-2010.<sup>12</sup> In the Communication the Commission committed itself to assist policy makers by developing a set of model approaches which would identify the key players and legal and financial instruments needed to implement a local, regional or national integration agenda.

A year later (April 2011) the European Commission adopted an **EU Framework for National Roma Integration Strategies up to 2020**<sup>13</sup>, calling on Member States to prepare or revise National Roma Integration Strategies in order to address more effectively the challenges of Roma inclusion to improve the situation by the end of the current decade. The EU Framework addressed Roma inclusion for the first time at EU level and is clearly linked to the Europe 2020 strategy.<sup>14</sup> Regarding health issues in particular, the Framework calls on Member States to reduce the gap in healthcare between Roma and non-Roma and to elaborate a set of measures including specific goals in the area of health. In addition, it spells out the need for policies in the fields of access to education, employment, healthcare and housing to be based on 'common, comparable and reliable indicators.'

In response, national governments committed to develop (or revise the existing Action Plans elaborated from the Decade of Roma Inclusion 2005-2015) National Roma Integration Strategies (NRIS) and to establish Roma contact points, whose role is to coordinate national efforts, track the progress made under the national Roma integration strategy and report to the European Commission.<sup>15</sup> The first assessment of the Roma integration policies (i.e. an evaluation of the Member states' approaches to the four key areas of education, employment, health care and housing) was undertaken in 2012<sup>16</sup> and pointed out that the establishment of a systematic, integrated approach to health remains a challenge for (and the primary responsibility

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Involvement of regional and local authorities; 9. Involvement of civil society; 10. Active participation of the Roma.

<sup>10</sup> [http://www.coe.int/t/dg4/youth/Source/Resources/Documents/2011\\_10\\_Common\\_Basic\\_Principles\\_Roma\\_Inclusion.pdf](http://www.coe.int/t/dg4/youth/Source/Resources/Documents/2011_10_Common_Basic_Principles_Roma_Inclusion.pdf)

<sup>11</sup> COM/2010/0133, Commission Communication on the economic and social integration of the Roma in Europe (7 April 2010)

<sup>12</sup> Roma in Europe: A Progress Report on the implementation of the EU instruments and policies for Roma inclusion 2008-2010 (Commission Staff Working Document), SEC(2010)400

<sup>13</sup> COM(2011)173

<sup>14</sup> COM(2012)226

<sup>15</sup> Roma integration: national representatives discuss progress and pool ideas- European Commission - MEMO/12/730 02/10/2012

<sup>16</sup> COM(2012)226, Commission Communication on National Roma Integration Strategies: a first step in the implementation of the EU Framework

of) Member States. In addition, the lack of systems to monitor health needs and outcomes of Roma were pointed out as a common deficiency in MS strategies.

In the Communication "**Steps forward in implementing national Roma integration strategies**"<sup>17</sup>, the Commission specifically identified the lack of registration of Roma in national population registers and the lack of personal identity papers as a key problem for the Roma population. Encouraging greater inclusion in this respect is seen as an absolute pre-condition to ensure equal access to public services, social protection systems, minimum living conditions, housing and healthcare<sup>18</sup>.

The next Commission report on the progress made on Roma Integration in the field of education, employment health and housing is to be expected in 2014.

The Commission made a proposal for a Council Recommendation in 2013 on effective Roma integration measures in Member states<sup>19</sup> which would aim to provide guidance to Member States in enhancing the effectiveness of their measures to achieve Roma integration and to strengthen the implementation of their NRIS or sets of policy measures to improve the situation of Roma, according to the respective size and situation of their Roma population.

In addition to policies supporting Roma integration, there are also a number of health policies and strategies that help to frame the institutional response to the improvement in the health status of Roma in Europe.

The European Commission aims to work alongside Member States to protect human health and improve public health and the current **EU Health Strategy "Together for Health" (2008-2013)** sets out the means to achieve these goals<sup>20</sup>. In addition, specific initiatives on health (including access to health and preventive care) targeted at vulnerable groups such as Roma have been developed.

The **Commission staff working paper on Europe 2020** – public consultation<sup>21</sup>, published in 2010, presents the general view that economic growth needs to be not only sustainable, but also responsive to the needs of equity, social justice, health and well-being for people and society. These call for a more explicit focus in the Europe 2020 strategy on health and well-being, in particular with regard to optimisation of human capital as the most important factor for sustainable growth and fostering innovation in healthcare and health systems.

The **Investing in health Commission staff working document**<sup>22</sup>, from February 2013, is part of the European Social Investment Package for growth and cohesion and proposes the strategic guidance for smart investments in health:

- by investing in sustainable health systems that combines innovative reforms aimed at improving cost efficiency and reconciling fiscal consolidation targets with the continued provision of sufficient levels of public services

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<sup>17</sup> COM(2013) 454 Commission Communication Steps forward in implementing national roma integration strategies, see [http://ec.europa.eu/justice/discrimination/files/com\\_2013\\_454\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/com_2013_454_en.pdf)

<sup>18</sup> COM(2013) 454 Commission Communication Steps forward in implementing national roma integration strategies, p. 10.

<sup>19</sup> COM(2013) 460 final, [http://ec.europa.eu/justice/discrimination/files/com\\_2013\\_460\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/com_2013_460_en.pdf)

<sup>20</sup> COM (2007) 630 final Together for Health: A Strategic Approach for the EU 2008-2013

<sup>21</sup> SEC (2010) 246 final

<sup>22</sup> SWD (2013) 43 final



- by investing in people’s health as human capital aiming to improve the health of the population in general and reinforcing employability, thus making active employment policies more effective, helping to secure adequate livelihoods and contributing to growth
- by investing in reducing health inequalities investments can contribute to social cohesion and break the vicious spiral of poor health contributing to, and resulting from, poverty and exclusion and by investing in health through adequate support from EU funds.

The platform provided by Roma integration strategies alongside health protection and promotion policies has been used by the Commission and its associated agencies to develop further research, policy and development strategies targeted at improving the health status of the Roma population. In the following section consideration is given to how agencies of the European Commission alongside other European and international institutions have sought to support and augment such programmes.

### European Union Agencies

In parallel to the European Commission there are a range of European Union Agencies that have direct involvement in matters relating to the health of Roma in Europe.

#### Consumers, Health and Food Executive Agency (CHAFEA)

CHAFEA is responsible for management of a significant number of projects under the Health Programme relating to migrants and minorities health issues, covering a wide range of dimensions: studying the socio economic determinants of health status, sharing good practice and empowering local actors in providing health services and monitoring health status of migrants and marginalised groups. A summary of some of these studies is set out in Table 1 below.

**Table 1 Indicative Overview of European Roma Health Projects**

<b>Report</b>	<b>Coordinator (with EC co-funding)</b>
Monitoring the health status of migrants within Europe: development of indicators (MEHO) <sup>23</sup>	Institute of Public Policy and Management - EMC (NL)
Innovative Care Against Social Exclusion (ICAASE) <sup>24</sup>	Omega Graz (AT)
Best Practice in Promoting Mental Health in Socially Marginalized People in Europe, PROMO <sup>25</sup>	Queen Mary University of London (UK)
The Health and the Roma Community - Analysis of the Situation in Europe, Roma Health <sup>26</sup>	Fundacion Secretariado Gitano (ES)
The Information network on good practice in health care for migrants and minorities – MIGHEALTHNET <sup>27</sup>	National and Kapodistrian Universit Athens (GR) and Utrecht University (NL)

<sup>23</sup> [www.meho.eu](http://www.meho.eu)

<sup>24</sup> [www.omega-graz.at/projekte/03-icaase.shtml](http://www.omega-graz.at/projekte/03-icaase.shtml)

<sup>25</sup> [www.promostudy.org/project/index.html](http://www.promostudy.org/project/index.html)

<sup>26</sup> [www.gitanos.org/european\\_programmes/health/index.html](http://www.gitanos.org/european_programmes/health/index.html)

<b>Report</b>	<b>Coordinator (with EC co-funding)</b>
CONNECTIONS, Integrated responses to drugs and infections across European criminal justice systems <sup>28</sup>	University of Kent (UK)
Development of Recommendations for Integrating Socio-Cultural Standards in Health Promoting Offers and Services (Healthy Inclusion) <sup>29</sup>	Österreichisches Rote Kreuz (AT)
Aids and mobility Europe 2007-2010 <sup>30</sup>	Ethno-Medizinisches Centrum (DE)
Addressing inequalities interventions in regions (AIR) <sup>31</sup>	<b>Conseil Régional d'Aquitaine (FR) and partners</b>
Addiction prevention within Roma and Sinti Communities <sup>32</sup>	Municipality of Bologna (IT)
Highly active prevention: scale up HIV/AIDS/STI prevention, diagnostic and therapy across sectors and borders in CEE and SEE, Bordernet work <sup>33</sup>	SPI Research/SPI Forschung GmbH (DE)
Empowering Civil Society and the Public Health System to Fight Tuberculosis Epidemic among Vulnerable Groups <sup>34</sup>	TUBIDU, National Institute for Health Development (EE)
HEALTHY-2020 - Reducing health inequalities: preparation for action plans and structural funds projects <sup>35</sup>	Maastricht University <b>(NL) and partners</b>
Fostering health provision for migrants, the Roma, and other vulnerable groups EQUI-HEALTH <sup>36</sup>	International Organization for Migration (IOM)
Training packages for health professionals to improve access and quality of health services for migrants and ethnic minorities, including the Roma Training Health Professionals <sup>37</sup>	La Escuela Andaluza de Salud Pública (ES)

### **The European Union Agency for Fundamental Rights (FRA)**

The FRA started its work on Roma health under its previous institutional set-up as the European Monitoring Centre on Racism and Xenophobia (EUMC). In 2003 it released a joint report<sup>38</sup> with the Council of Europe on Roma women and health. Another report

<sup>27</sup> [www.mighealth.net](http://www.mighealth.net)

<sup>28</sup> <http://connections.accessproject.eu/>

<sup>29</sup> [www.rotekreuz.at/wien/forschungsinstitut-des-roten-kreuzes/projekte/laufende-forschungsprojekte/healthy-inclusion/](http://www.rotekreuz.at/wien/forschungsinstitut-des-roten-kreuzes/projekte/laufende-forschungsprojekte/healthy-inclusion/)

<sup>30</sup> [www.aidsmobility.org](http://www.aidsmobility.org)

<sup>31</sup> [www.healthinequalities.eu](http://www.healthinequalities.eu)

<sup>32</sup> <http://srap-project.eu>

<sup>33</sup> [www.bordnet.net](http://www.bordnet.net)

<sup>34</sup> <http://www.tai.ee/en/tubidu>

<sup>35</sup> [www.healthequity2020.eu](http://www.healthequity2020.eu)

<sup>36</sup> <http://equi-health.eea.iom.int>

<sup>37</sup> <http://www.easp.es>

<sup>38</sup> European Monitoring Centre on Racism and Xenophobia Breaking the barriers – Romani women and access to public health care, Vienna, 2003. Available at <http://fra.europa.eu/fraWebsite/attachments/ROMA-HC-EN.pdf>

on Roma and Travellers in public education<sup>39</sup> followed in 2006. In 2009, the FRA published two further reports on the housing situation of Roma and Travellers<sup>40</sup> and on the situation of Roma EU citizens moving to and settling in other EU Member States<sup>41</sup>.

In 2009 FRA published *Data in focus report* on 'The Roma'<sup>42</sup>. This report was based on the findings of the FRA European Union Minorities and Discrimination Survey (EU-MIDIS). This survey was the first of its kind to produce comparative EU-wide data on different ethnic minority and immigrant groups' experiences of discrimination and criminal victimisation in everyday life, including their rights. Using a random sampling approach, the survey interviewed 23,500 respondents across the 27 EU Member States – including 3,500 Roma respondents in seven EU Member States and, for the purpose of comparison, a further 5,000 people from the majority population in 10 EU Member States. The first in a series of *Data in focus* reports from this survey presented research results concerning Roma interviewees, who emerged from the survey as the group reporting the highest overall levels of perceived discrimination, compared with other groups such as North Africans and sub-Saharan Africans. The EU-MIDIS survey raised key questions about both fundamental rights protection and the real impact of social policies in areas such as employment, housing, healthcare, social services and education.

The FRA currently implements a Multiannual Roma Programme (2012-2020) with the aim of supporting the EU's effort to make "a tangible difference to Roma people's lives". In this regard it cooperates with Governments, EU institutions, the Council of Europe, the UN and other international organisations. Within the multiannual programme, the FRA regularly monitors progress on the ground regarding Roma integration in the area of employment, education, healthcare and housing; does research and provides good practice examples on Roma integration issues; and assists Member States in improving their monitoring of policy outcomes.

Collaboration between the FRA, the UNDP and the World Bank (and supported by the European Commission) has produced a range of new survey data comparing Roma health with that of neighbouring non-Roma. In May 2012 the FRA/UNDP/WB published "The situation of Roma in 11 EU Member States - Survey results at a glance" which presents the first results of the FRA/UNDP/World Bank surveys carried out in 11 EU Member States in 2011. It provides new robust evidence both about the socioeconomic and the human rights situation of Roma surveyed.

Across eleven Member States (Bulgaria, the Czech Republic, France, Greece, Italy, Hungary, Poland, Portugal, Romania, Slovakia, and Spain) survey teams interviewed 22,203 Roma and non-Roma living nearby, providing information on a total of 84,287 household members. Interviews were carried out face-to-face in Roma and non-Roma respondents' homes with people who self-identified as Roma and members of the general population living in the same area as, or in the closest neighbourhood to, the Roma persons interviewed. The results are representative for Roma living in areas in a

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<sup>39</sup> European Monitoring Centre on Racism and Xenophobia Roma and Travellers in public education, Vienna, 2006. Available at [http://fra.europa.eu/fraWebsite/attachments/roma\\_report.pdf](http://fra.europa.eu/fraWebsite/attachments/roma_report.pdf).

<sup>40</sup> FRA (2009), Housing conditions of Roma and Travellers in the European Union, Luxembourg, Publications Office. Available at [http://fra.europa.eu/fraWebsite/attachments/ROMA-Housing-Comparative-Report\\_en.pdf](http://fra.europa.eu/fraWebsite/attachments/ROMA-Housing-Comparative-Report_en.pdf)

<sup>41</sup> FRA (2009), The situation of Roma EU citizens moving to and settling in other EU Member States, Luxembourg, Publications Office. Available at [http://fra.europa.eu/fraWebsite/attachments/ROMA-Movement-Comparative-report\\_en.pdf](http://fra.europa.eu/fraWebsite/attachments/ROMA-Movement-Comparative-report_en.pdf)

<sup>42</sup> FRA (2009), 'The Roma', Data in focus report, Luxembourg, Publications Office. Available at [http://fra.europa.eu/fraWebsite/attachments/EU-MIDIS\\_ROMA\\_EN.pdf](http://fra.europa.eu/fraWebsite/attachments/EU-MIDIS_ROMA_EN.pdf)



higher than national average density. The results for non-Roma are not representative of the general population, but serve as a benchmark for Roma since the non-Roma interviewed share the same environment, labour market and local infrastructure<sup>43</sup>.

The FRA is actively engaged in the European Platform on Roma Inclusion. At its 8th European meeting the FRA underlined the importance of data collection and monitoring outcomes of Roma policies and Roma integration measures. A FRA-Member States ad-hoc working party on measuring Roma integration was also set up, holding meetings which serve to exchange information and good practices between participating Member States on the development of monitoring methods to measure progress and outcomes of national Roma integration strategies.

### **The European Centre for Disease Prevention and Control (ECDC)**

The European Centre for Disease Prevention and Control has published several scientific reports related to health of migrants (including Roma) since 2009, namely on:

- Background note to the ECDC Report on migration and infectious diseases in the EU (2009),
- Access to HIV prevention, treatment and care for migrant populations in EU/EEA countries (2009),
- Epidemiology of HIV and AIDS in migrant communities and ethnic minorities in EU/EEA countries (2009),
- HIV testing and counselling in migrant populations and ethnic minorities in EU/EEA/EFTA Member States (2011),
- Improving HIV data comparability in migrant populations and ethnic minorities in EU/EEA/EFTA countries: findings from a literature review and expert panel (2011).

The ECDC also organised a meeting on Communicable Disease Prevention among Roma in November 2011. The objectives of this meeting were to: (i) share best practices and lessons learned in improving the Roma population's access to public health programmes for the prevention of communicable diseases, by bringing together key stakeholders with experience in working with and for Roma and; (ii) to provide an opportunity to identify ways of improving health and to provide a forum for discussion on how the identified approaches, knowledge and experiences could be used.<sup>44</sup>

As a result of this meeting the ECDC has suggested a few points of action for the ECDC itself (and other organisations) to pursue, like the creation of an information exchange platform with a database of good communicable disease prevention practices in relation to Roma health.<sup>45</sup>

A further meeting took place in Dublin during 4-6 September 2012, involving experts in vaccination, primary health care professionals and representatives of Roma/travellers' non-governmental organisations from 18 Member States. This meeting, building on the needs identified during the meeting in Vienna, provided a forum for discussion on how knowledge and experiences could be used to stimulate the use of preventive services in the area of communicable diseases. The meeting aimed at

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<sup>43</sup> FRA Brief: Data on Discrimination of Roma and anti-Roma crime. Available at: <http://www.statewatch.org/news/2013/mar/eu-roma-fra-briefing.pdf>

<sup>44</sup> ECDC Meeting Report, Communicable Disease Prevention among Roma (27-29 November 2011)

<sup>45</sup> Ibid. Ibid. pp.3-4.

finding practical solutions to achieving the WHO measles and rubella elimination target by 2015 and tackling challenges brought on by the economic crisis. The result of the consultation was a list of the top 10 interventions for increasing MMR vaccination uptake, which was presented during the Conference on childhood immunisation (progress, challenges and priorities for further action) that took place in Luxembourg, 16-17 October 2012.

ECDC has contracted a Romanian non-governmental organisation – Romani CRISS to conduct a multi-country qualitative study on barriers to immunisation among Roma in five countries with large ethnic Roma population groups.

ECDC is currently finalising practical guidance for health care providers to enhance childhood vaccination uptake. The guide, entitled "*Let's talk about protection*", provides practical peer-reviewed advice and evidence-based guidance for health care providers (HCPs) involved with vaccination services on ways to increase childhood vaccination uptake. The key messages in the guide are developed based on focus groups with parents including from so called "hard to reach" groups, and other health professionals by "giving voice" to their thoughts, knowledge and insights and thus allowing a two-way conversation between the provider and the client. The guide also reframes the focus of the discussion on the benefits of vaccination by being protected and protecting others from a disease (positive) rather than being oriented on the side effects of vaccination (negative). A desk flipbook is also offered to HCP to be used during these conversations as a communication tool. The "*Let's talk about protection*" set was adapted to the needs of Member States (four MS involved in a pilot project), producing country-tailored communication. As a result of the project, all MS can access the English version guide and flip book, as well as an adaptation methodology.

### **The European Foundation for the Improvement of Living and Working Conditions (Eurofound)**

In 2011, the promotion of social inclusion and sustainable social protection was included in the Annual Programme of the European Foundation for the Improvement of Living and Working Conditions (Eurofound); planning research targeting Roma specifically. It is in this light that in 2012 Eurofound carried out a literature review and secondary analysis of survey data, of which the results were published in a report on the Living conditions of Roma, including housing and health<sup>46</sup>. The 2013 annual report, however, does not mention Roma specifically.

### **Other European Institutions**

Whilst the role of the European Commission and associated agencies constitute the most substantive element of the response, there are a number of other institutions and agencies that undertake work within the field of Roma health.

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<sup>46</sup> Eurofound, Living conditions of the Roma: Substandard housing and health

## The European Parliament

The European Parliament (EP) follows the implementation of the NRIS. Within the European Parliament the Committee of Civil Liberties, Justice and Home Affairs (LIBE) is responsible for the EU Strategy on Roma Inclusion. Ahead of International Roma Day, on 8 April this year (2013), the President of the European Parliament Martin Schulz called for clearer targets, closer monitoring of progress, increased participation in decision-making and better use of EU funds as necessary steps to promote Roma inclusion<sup>47</sup>. Between 2005 and 2010 the Parliament adopted several resolutions aiming to improve the situation of the Roma population in Europe<sup>48</sup>.

## The European Council

The European Council supports the efforts made by the EU, stressing the need for Member States to improve the social and economic situation of Roma by pursuing a mainstreaming approach in the fields of healthcare, taking into account the Common Basic Principles on Roma Inclusion, as well as by ensuring equal access to quality services, and make the best use of the funds and resources available<sup>49</sup>. The Council conclusions of May and June 2011<sup>50</sup> on Roma integration, following the proposal from the European Commission on an EU Framework for national Roma integration strategies, mark an unprecedented commitment by EU Member States to promote the inclusion of Roma at national level.

In December 2013 the Council adopted and published a recommendation on effective Roma integration measures in the member states<sup>51</sup>. Its aim is to support the EU countries in effectively implementing the Roma National Integration Strategies. This concluded that "[m]any Roma in the Union still face deep poverty, social exclusion, discrimination and barriers to exercising their fundamental rights which leaves them vulnerable to exploitation, for example through trafficking in human beings. Therefore, more effective social inclusion measures adapted to their situation and needs should

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<sup>47</sup> Press Release 8 April 2013, see

[http://www.europarl.europa.eu/the-president/en/press/press\\_release\\_speeches/press\\_release/2013/2013-april/html/schulz-on-the-international-roma-day](http://www.europarl.europa.eu/the-president/en/press/press_release_speeches/press_release/2013/2013-april/html/schulz-on-the-international-roma-day)

<sup>48</sup> Resolution of 28 April 2005 on the situation of the Roma in the European Union (OJ C 45 E, 23.2.2006, p. 129); Resolution of 1 June 2006 on the situation of Roma women in the European Union (OJ C 298 E, 8.12.2006, p. 283); Resolution of 15 November 2007 on application of Directive 2004/38/EC on the right of EU citizens and their families to move and reside freely within the territory of the Member States (OJ C 282 E, 6.11.2008, p. 428); Resolution of 31 January 2008 on a European Strategy on the Roma (OJ C 68 E, 21.3.2009, p. 31); Resolution of 10 July 2008 on the census of the Roma on the basis of ethnicity in Italy (OJ C 294 E, 3.12.2009, p. 54); Resolution of 11 March 2009 on the social situation of the Roma and their improved access to the labour market in the EU (OJ C 87 E, 1.4.2010, p. 60); Resolution of 25 March 2010 on the Second European Roma Summit (OJ C 4 E, 7.1.2011, p. 7); Resolution of 9 September 2010 on the situation of the Roma and on freedom of movement in the European Union (Texts adopted, P7\_TA(2010)0312).

<sup>49</sup> Council Conclusions on an EU Framework for National Roma Integration Strategies up to 2020, 3089th Employment, Social Policy, Health and Consumer Affairs Council meeting, 19 May 2011.

<sup>50</sup> See <http://register.consilium.europa.eu/pdf/en/11/st10/st10658.en11.pdf> and <http://register.consilium.europa.eu/pdf/en/11/st00/st00023.en11.pdf>

<sup>51</sup> Council of the European Union Council recommendation on effective Roma integration measures in the member states, Employment, Social Policy, Health and Consumer Affairs Council meeting Brussels, 9 and 10 December 2013. Available at [http://www.consilium.europa.eu/uedocs/cms\\_data/docs/pressdata/en/lsa/139979.pdf](http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/139979.pdf)

be considered”<sup>52</sup>. These measures also encompass improved data collection. The access to health care recommendations commits the Commission to “take effective measures to ensure equal treatment of Roma in access to universally available healthcare services on the basis of general eligibility criteria”<sup>53</sup>.

## **Council of Europe**

### **The Council of Europe and the European Commission against Racism and Intolerance (ECRI)**

In order to promote minority rights across Member States, the Council of Europe established the European Commission against Racism and Intolerance (ECRI) in 1993. ECRI is an independent human rights monitoring body covering issues related to racism and racial discrimination. It mainly acts through the documentation of the situation of Roma on a country-by-country basis<sup>54</sup>. In the 2009 Council Conclusions on inclusion of Roma, the Council already identified the need for additional action on the health needs of Roma<sup>55</sup>.

More recently, a Resolution was adopted by the Parliamentary Assembly of the Council of Europe on ending discrimination against Roma children<sup>56</sup> on 23 April 2013. The Resolution is accompanied by an Explanatory memorandum that focuses on integrated interventions in the early ages, including maternal and child health, as well as on measures to improve access to inclusive and quality education.<sup>57</sup>

Furthermore, the Council of Europe launched the European Alliance of Cities and Regions for Roma Inclusion during the 24th Session of the Congress of Local and Regional Authorities (19-21 March), of which health is one the four working areas.<sup>58</sup>

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<sup>52</sup> Council of the European Union Council recommendation on effective Roma integration measures in the member states, Employment, Social Policy, Health and Consumer Affairs Council meeting Brussels, 9 and 10 December 2013. Available at [http://www.consilium.europa.eu/uedocs/cms\\_data/docs/pressdata/en/lsa/139979.pdf](http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/139979.pdf)

<sup>53</sup> Council of the European Union Council recommendation on effective Roma integration measures in the member states, Employment, Social Policy, Health and Consumer Affairs Council meeting Brussels, 9 and 10 December 2013. Available at [http://www.consilium.europa.eu/uedocs/cms\\_data/docs/pressdata/en/lsa/139979.pdf](http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/139979.pdf)

<sup>54</sup> [http://www.coe.int/t/dghl/monitoring/ecri/default\\_en.asp](http://www.coe.int/t/dghl/monitoring/ecri/default_en.asp)

<sup>55</sup> Council Conclusions on inclusion of the Roma, 8 June 2009. Available at [http://www.consilium.europa.eu/uedocs/cms\\_data/docs/pressdata/en/lsa/108377.pdf](http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/108377.pdf)

<sup>56</sup> *Resolution 1927 (2013) of the Parliamentary Assembly of the Council of Europe on ending discrimination against Roma children*

<sup>57</sup> Council of Europe (Parliamentary assembly), *Ending discrimination against Roma children* (4 April 2013). Available at

<http://assembly.coe.int/ASP/Doc/XrefViewPDF.asp?FileID=19545&Language=EN>

<sup>58</sup> WHO Roma Health Newsletter, Issue 4, May 2013.

## **International Institutions**

### **The International Organization for Migration (IOM)**

The International Organization for Migration has promoted a rights-based approach since its inception, and the following relevant to minorities and migrants\_areas have been identified by the Organization as crucial: (i) Protection and advocacy of human rights; (ii) De-stigmatization and inclusion; and (iii) Migrant assistance and protection. In line with identified priorities, IOM has implemented a number of projects on Roma with different scope: reparation programmes (Central Europe), humanitarian and social programmes, labour market integration, combating trafficking in human beings, capacity building and Information campaigns, etc. In terms of health, IOM MHD (Migration Health Division) RO Brussels implemented the "Building Healthy Roma Communities Pilot Project" in 2006-2009, funded by the Government of Belgium in Hungary, Poland, Slovakia and Romania. The objectives were: to build human capacity to deal effectively with minority group needs; to reduce discrimination and support Roma access to health and social services; and to provide opportunities for exchange and learning and pilot a community assistance model with community mediators (Equality Support Unit). IOM is also part of the Inter-Agency Coordination Initiative on Roma Health (Millennium Development Goals 4 and 5), existing in the context of the Decade of Roma inclusion and in support of National Roma Integration Strategies, facilitated by WHO and with the participation of UNFPA, OHCHR, UNDP and UNICEF.

In February 2013, IOM launched the European Commission co-funded "Equi-Health" a three-year action with the objective to improve the access and quality of health care services, health promotion and prevention to meet the needs of migrants, Roma and other vulnerable minority groups, including irregular migrants. The action is prioritised within the EC 2012 Public Health Programme.

The Equi-Health sub-action on Roma Health aims at supporting national authorities in monitoring, sharing and strengthening national approaches to Roma health. To this end, it will develop a coherent network and promote dialogue among key stakeholders on Roma health related issues and delineate strategies and interventions to support capacity building and cooperation within and between participating states. Progress country reports on the implementation of the Roma Integration Strategies and other national commitments to improve Roma health are planned to support EU Member States to better monitor, share and strengthen their national approaches. EU countries with high proportions of Roma and Member States with high proportions of Roma migrants will participate in project activities. Priorities and actions identified jointly with participating MS will be further supported in the framework of Equi-Health.

In 2013, National consultative committee meetings were organized in Romania, Slovakia, Croatia, Italy; and a Regional Expert Working Group "Health in the EU Framework for National Roma Integration Strategies: Implementation, Challenges and the Way Forward" was held in Sofia, Bulgaria. The meeting was organised along four thematic blocks: (i) status and challenges to implementation of the health component of National Roma Integration Strategies; (ii) methodology/template for two-step progress reports; (iii) identification of priority areas for further collaboration; and (iv) exchange of good practices and synergies between initiatives. As a follow up to one of the priorities for cooperation between Member States identified at that meeting, IOM organised a Regional Working Group "Health Mediation and the Roma" in Huelva, Spain, which initiated discussions and exchange of experiences among governmental

and non-governmental experts from Belgium, Bulgaria, Croatia, France, Italy, Spain, and Romania on Roma health mediator programs in different EU Member States<sup>59</sup>.

## **United Nations Agencies**

### **The World Health Organisation (WHO)**

In 2012 the WHO opened two collaborating centres: one on social inclusion and health at the University of Alicante, and another on vulnerability and health at the University of Debrecen, Hungary. The WHO's work with the Collaborating Centre will include the documentation of promising practices and the production of normative guidance materials/tools to improve the health of populations experiencing poverty and social exclusion, with a specific focus on Roma and migrants and due attention to gender equity; information exchange and awareness raising among stakeholders, using electronic/web-based platforms to improve the health of socially excluded populations; and co-organizing capacity-building activities for health policy-makers, programme managers and other stakeholders, on approaches to improve the health of populations experiencing social exclusion and poverty.

Since 2012, together with this centre, the WHO Regional Office for Europe (WHO/Europe) has published a Roma Health Newsletter, in cooperation with the Commission's DG SANCO. The purpose of this newsletter is to share information and resources relevant to improving Roma health, and thereby support current efforts to strengthen the health components of national Roma integration strategies or sets of policy measures in the EU and action plans for the Decade of Roma Inclusion. It is produced as an output of the Interagency Coordination Initiative "Scaling up action towards MDGs 4 and 5 in the context of the Decade of Roma Inclusion and in support of the EU national Roma integration strategies", which is facilitated by WHO in cooperation with other United Nations agencies and the International Organization for Migration (IOM). In June 2013, the WHO/Europe together with the Office of the High Commissioner for Human Rights (OHCHR) organised the second meeting of the Roma civil-society group on the right to health.

### **The United Nations Development Programme (UNDP)**

In 2003, the United Nations Development Programme (UNDP) report "Avoiding the dependency trap"<sup>60</sup> provided for the first time robust statistical evidence showing that a significant number of Roma in the EU face severe challenges in terms of illiteracy, infant mortality and malnutrition. The report was based on a survey conducted by UNDP on the status of Roma and the general population living in close proximity in central and south-eastern Europe<sup>61</sup>.

As mentioned above, in 2011 the FRA, in coordination with the UNDP and the World Bank, and supported by the European Commission, carried out a Roma survey in 11 EU Member States and in neighbouring European countries. The idea behind the survey was to fill the data gap on *marginalised* Roma as part of the Millennium

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<sup>59</sup> For further information and updates please visit Available at

<http://equi-health.eea.iom.int/>

<sup>60</sup> UNDP, Roma in Central and Eastern Europe 2002 – Avoiding the Dependency Trap, Bratislava, UNDP (2003),

<http://hdr.undp.org/en/reports/regional/europethesis/name,3203,en.html>

<sup>61</sup> FRA, UNDP, European Commission, The situation of Roma in 11 EU Member States – Survey results at a glance (2012), Luxembourg, Publications Office, p. 8. Available at [http://fra.europa.eu/sites/default/files/fra\\_uploads/2099-FRA-2012-Roma-at-a-glance\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/2099-FRA-2012-Roma-at-a-glance_EN.pdf)



goals.<sup>62</sup> The UNDP released a separate working paper in 2013 on the health situation of Roma communities, which comprises the health analysis of the UNDP/World Bank/EC Regional Roma Survey 2011<sup>63</sup>.

The UNDP has developed methods suitable and how to better use existing data, taking into account other vulnerable groups and community cohesion<sup>64</sup>. An example of such a method is paying special attention to regions where Roma are concentrated. Work has been done to this effect in four Member States (BG, HU, RO and SK)<sup>65</sup>.

### **The World Bank**

The World Bank (WB) addresses Roma issues in the context of its work on poverty and economic development in the region, by building evidence through data collection, analysis and field work, and providing evidence-based policy lessons for Roma Inclusion, developing partnerships and strengthening institutions and scaling up viable approaches and mainstreaming ethnicity into policy. The World Bank provides specific support in Eastern Europe. It provides capacity building for two flagship initiatives of Roma inclusion in Eastern Europe: the Decade of Roma Inclusion and the Roma Education Fund<sup>66</sup>.

### **Conclusions**

The purpose of this chapter has been to set out how over the last decade addressing the health needs of the Roma population has increasingly become a priority for a range of European and International institutions. This has emanated from programmes targeted at promoting Roma inclusion as well as from broader health development strategies. Increasing evidence of partnerships has been highlighted, particularly in relation to the issue of health data relating to Europe's Roma population.

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<sup>62</sup> Interview with the UNDP as part of this study 13 June 2013. Unpublished.

<sup>63</sup> UNDP, The Health Situation of Roma communities: analysis of the data of the UNDP/World Bank/EC Regional Roma Survey 2011 (2012), see [http://issuu.com/undp\\_in\\_europe\\_cis/docs/health\\_web](http://issuu.com/undp_in_europe_cis/docs/health_web)

<sup>64</sup> Interview with the UNDP as part of this study 13 June 2013. Unpublished

<sup>65</sup>Ibid. Ibid.

## Methodology (Part 1 Roma health data)

The overview of methodology outlined in this section concerns Report 1 Roma health data: Preparing a report assessing the health status and health-related lifestyle attributes of the Roma population. In detail, this report has assessed the status and health related life style attributes of the Roma population in 31 countries across the seven indicators:

1. Mortality and life expectancy
2. Prevalence of major infectious diseases
3. Healthy life styles and related behaviours
4. Access and use of health services and prevention programmes
5. Prevalence of major chronic diseases
6. Health factors related to the role of women in the Roma community
7. Environmental and other socio-economic factors.

The purpose of the first report, according to the Terms of Reference, was to produce a descriptive analysis of the seven above-mentioned indicators. The study covered 31 countries<sup>67</sup> but also required a focus on 11<sup>68</sup> countries with large (migrant) Roma populations. The latter countries were subject to more granular indicators (see Table 5).

As per the request of Chafea and DG SANCO, the indicators of the study clearly take stock of the European Community Health Indicators<sup>69</sup>. The ECHI indicators are grouped according to five main headings: (i) demographic and socio-economic situation (i.e. population, birth rate, total unemployment); (ii) health status (i.e. Infant mortality and HIV/AIDS), (iii) health determinants (smoking consumption/availability of fruit), (iv) health services (i.e. Vaccination of children, hospital beds, health expenditure) and (v) health promotion (policies on healthy nutrition)<sup>70</sup>.

The table below illustrates the research questions developed from the seven indicators, which are the foci of the study and the subsequent indicators. The table also outlines the geographical scope of each indicator and their comparability against the general population.

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<sup>67</sup> The EU-28 along with Iceland, Liechtenstein and Norway

<sup>68</sup> Bulgaria, Croatia, the Czech Republic, France, Greece, Italy, Hungary, Romania, Slovakia, Spain, and the United Kingdom.

<sup>69</sup> Kramers PGN, on behalf of the ECHI team. The ECHI project: Health indicators for the European Community. *European Journal of Public Health* 2003; 13 (no. 3, supplement): 101-106.

<sup>70</sup> [http://ec.europa.eu/health/indicators/echi/index\\_en.htm](http://ec.europa.eu/health/indicators/echi/index_en.htm)



**Table 2 Research Questions (Indicators)**

Research Questions	Geographical Scope	Data Compared to General Population
A. What are the mortality and life expectancy rates among the Roma population?	EU 28 and EEA/EFTA	No
1.1 What are overall infant mortality rates?	11 Case Studies	Yes
1.2 What are overall maternal mortality rates?	11 Case Studies	Yes
B. What is the prevalence of major infectious diseases among the Roma population?	EU 28 and EEA/EFTA	No
2.1 What is the prevalence of tuberculosis?	11 Case Studies	Yes
2.2 What is the prevalence of Multi Drug Resistant Tuberculosis?	11 Case Studies	Yes
2.3 What is the prevalence of measles?	11 Case Studies	Yes
2.4 What is the prevalence of HIV?	11 Case Studies	Yes
2.5 What is the prevalence of Hepatitis A/B/C?	11 Case Studies	Yes
2.6 What is the uptake of vaccination among children?	11 Case Studies	Yes
C. What are the most prevalent healthy life styles and related behaviours among the Roma population?	EU 28 and EEA/EFTA	No
3.1 What is the prevalence of (illicit) drug use?	11 Case Studies	Yes
3.2 What is the prevalence of alcohol abuse?	11 Case Studies	Yes
3.3 What is the prevalence of tobacco use?	11 Case Studies	Yes

Research Questions	Geographical Scope	Data Compared to General Population
3.4 What is the prevalence of obesity?	11 Case Studies	Yes
D. What is the general level of access and use of health services and prevention programmes of the Roma population?	EU 28 and EEA/EFTA	No
4.1 What are the known barriers to access to health care?	11 Case Studies	Yes
E. What is the prevalence of major chronic diseases among the Roma population?	EU 28 and EEA/EFTA	No
5.1 What is the prevalence of diabetes?	11 Case Studies	Yes
5.2 What is the prevalence of hypertension?	11 Case Studies	Yes
5.3 What are the prevalence rates for cancers?	11 Case Studies	Yes
F. What is the overall health status of women in the Roma population?	EU 28 and EEA/EFTA	No
6.1 What is the timing of first ante-natal visit among pregnant women?	11 Case Studies	Yes
6.2 What is the uptake of cancer screening among women?	11 Case Studies	Yes
G. What are the Environmental and other socio-economic factors, which might affect the health status of Roma population (such as housing, sanitation, employment, education)?	EU 28 and EEA/EFTA	No
7.1 What are the overall housing conditions?	11 Case Studies	Yes

## Development of the research

In order to answer the research questions, the methodology was based on two steps:

- Desk Research based on the review of secondary data (literature review).
- Fieldwork collection of primary data through semi-structured interviews.

### Desk Research activities

The Research Team<sup>71</sup> used a systematic and robust search and appraisal methodology to identify and synthesise relevant studies.

The key features of the systematic review methodology are summarised below:

- **Searching:** Each researcher searched for national and international studies on health relevant to the study's 7 indicators. The search for literature was done via Chafea and the FRA<sup>72</sup>, through online searchers, citation chasing and via contact with professional networks.
- **Screening:** Studies from all over Europe were included in the review. A relatively wide timespan gave us the possibility of including the most recent analyses and also having a sense of the changes that occurred in the pre- and post-accession period in countries that joined the European Union in 2004, 2007 and 2013 respectively.
- **Data Extraction:** We used a data extraction tool to capture the data available and the literature it stemmed from. Given the poor systematic data collection on Roma health and the limited possibility of comparing data, we included qualitative studies in our review.

We not only considered the outcomes of the studies, but also observed the solutions implemented to solve the limitations present in research on health and ethnicity<sup>73</sup>. Data from studies were extracted into our Excel-based Data Extraction Tool (DET) per country and indicator and used for the individual country reports produced. The figures below summarise the information collected respectively for the references and for each indicator within the references.

**Table 3 Multi country reference spreadsheet**

Ref #	Language of Publication	Author	Year of Publication	Country of Study	Source	Title	Web site link	Description of Paper	Method Used	1st Parameter	2nd Parameter ...	Non-Parameter Information	Comments
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<sup>71</sup> The Research Team was coordinated by Matrix Knowledge and included EPHA, CSD and individual researchers.

<sup>72</sup> Please see the FRANET studies published at

<http://fra.europa.eu/en/country-data/2013/country-thematic-studies-situation-roma>

<sup>73</sup> This part of the analysis is mainly conveyed in the Report on Member States' current and future activities in data collection and development of specific surveys aiming to monitor the progress in the implementation of the NRIS in the area of health, which dovetails this report.

**Table 4 Indicator spreadsheet**

Background Information on the Indicator				Value of Interest									
Ref #	Parameter Code	Country	Reference Date (this is the date of when the data refers to which might be different from the publication date)	Operational Definition of Indicator	Value of Indicator in Roma Population in #	Value of Indicator in Roma Population in %	Comparative value of Indicator in General Population in #	Comparative value of Indicator in General Population in %	Gender of people in the indicator	Age group of people in indicator (in years)	Roma Nationality of people in the indicator	Roma Residency Status for the people in the indicator	Area of the country for which the indicator applies (towns/cities /regions)

Among the 190 sources analysed, the selected sources below express innovative approaches to overcome the issues regarding data collection on the basis of ethnicity.

**Table 5 Selected studies from the literature review**

Name of the study	Methods	Positive aspects and limitations
The Situation of Roma in 11 EU Countries (the FRA, the UNDP and supported by the European Commission)  Regional Roma survey 2011 (the FRA, in coordination with the UNDP and the World Bank, and supported by the European Commission)	Survey: Face-to-face interviews based on sampling methods in concentrated Roma population Roma Households 22,203; estimated household members: 84,287. Non-Roma households: 7,278; estimated household members 20,024.	Exhaustive nature of the study due to its scale.  External and self-identification of Roma population to overcome bias and distortion.  Comparability among Roma population and general population living in the same (segregated) areas. Territorial proximity considered. However data presented for general population differ from statistical data about the general population which calls into question the representativeness of the general population chosen. The representativeness of the general population seems limited.  Unclear to what extent survey is sustainable or can be reproduced in the future.
Health and the Roma Community, analysis of the situation in Europe: Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain (Fundación Secretariado Gitano)	Survey: face to face interviews 7,604 Roma.	In order to quantify and locate the target population the study used proportional figures provided by the groups of experts created in each of the countries where the study was conducted based on official figures and significant studies undertaken in this regard. This ensured representativeness of the Roma population sample considered in each country.  The study only considered Roma populations and made no comparisons to the general population.  Unclear to what extent survey is sustainable or can be reproduced in the future.
Housing Conditions of Roma (Raxen network of national focal points – coordinated by the FRA)	Desk work and fieldwork research	The research subject is housing conditions rather than health, but it is a good example of a comprehensive review of existing studies and data collected at local level (i.e. social housing agency and administrative registers) on a country by country basis.  Comparisons with the general population are provided.

Name of the study	Methods	Positive aspects and limitations
		<p>Limited use of interviews involving only a small group of stakeholders/ experts.</p> <p>Unclear to what extent survey is sustainable or can be reproduced in the future.</p>
Roma from Romania, Bulgaria, Italy and Spain between social inclusion and migration (Soros Foundation Romania)	<p>Representative survey based on health self-perception of the interviewees. The sampling method used is probabilistic, multi-stage and stratified.</p> <p>On site visits related to projects targeting Roma.</p>	<p>Comparative study resulted from analysis of the common database, accomplished by means of unifying four national databases.</p> <p>Use of European Social Fund to carry out the research.</p> <p>The level of comparability against the general population is unclear.</p>
All Ireland Traveller Health Study (Our geels - University College Dublin)	<p>Survey: questionnaire – semi-structured interview and focus groups have then been used, with the questions modelled on the basis of the existing surveys' targeting the general population.</p> <p>(The Travellers count was based on the number of Traveller families enumerated at the census multiplied by the average family size - four members for each family).</p>	<p>The survey investigates several aspects of Roma health including factors determining health status and health care access.</p> <p>A comparison between Roma and the general population in a longitudinal perspective is carried out by using existing studies on the general population's health.</p> <p>The only limitation of the study is that it does not consider migrant Roma.</p> <p>Unclear to what extent the survey is sustainable or can be reproduced in the future.</p>

## Field work activities

In parallel to the desk work activities Matrix Knowledge launched a fieldwork programme which was based on semi-structured interviews with stakeholders at EU / International and national levels.

The aim of the interview programme was threefold. First, interviews enriched the set of references that the Research Team planned to review in order to assess Roma health status. Second, respondents were invited to provide insights on how to overcome methodological limitations and sensitivities of collecting data on ethnic minorities. Third, interviews were used to validate the initial findings emerging from desk research.

Matrix Knowledge also liaised with EPHA to establish contact with Roma NGOs and organisations that would be willing to provide input to the study. The study team made valuable contact with the following organisations and individuals, who have generously given their time and effort toward this study:

- Dr Gindrovel Dumitra, family physician in a rural community in Romania (Sadova) with a large Roma population
- The Roma Center for Health Policies – Sanatate – SASTIPEN, Romania
- The Roma Health Project Public Health Program of the Open Society Foundations in Hungary
- The National Network of the Health Mediators in Bulgaria
- Dr Stefan Panayotov MD and General Practitioner and chair of the Health of Roma Foundation in Bulgaria

This list focuses heavily on organisations and individuals with expertise of Roma in Romania and Bulgaria. Thus to balance this and to compensate for the networking difficulties experienced, the study team also worked to use the national researchers' professional networks to secure feedback and support from local/national stakeholders, for example the Black Health Agency in Manchester, an NGO that works to improve the lives and health of black and ethnic minority communities and other marginalised communities across the United Kingdom.

The table below lists the lead researchers for each of the 11 countries of focus.

**Table 6 National researchers and coordinators**

<b>Country</b>	<b>Coordinator</b>	<b>Lead researcher</b>	<b>Affiliation</b>
Bulgaria	CSD	Kamelia Dimitrova	Centre for Study of Democracy (CSD)
Croatia	CSD	Kamelia Dimitrova	Centre for Study of Democracy (CSD)
Hungary	CSD	Zsusanna Vidra	Centre for Study of Democracy (CSD)
Italy	CSD	Mario Battaglini	Independent Consultant
Romania	CSD	Pascal Descarpes	Independent Consultant
Slovakia	CSD	Timea Stranska	People in Need
Greece	Matrix Knowledge	Andreas Kyriakou	Support Centre for Children and Family
Czech Republic	Matrix Knowledge	Hana Janatova	National Institute of Public Health
France	Matrix Knowledge	Frank Vanbiervliet	Médecins du Monde
Spain	Matrix Knowledge	Maite Teresa Andrés Martín	Secretariat Gitanos
United Kingdom	Matrix Knowledge	Phil Brown	University of Salford

A total of 20 individuals were interviewed or produced written statements; the names and affiliations of interviewees can be found appended to this report. The Research Team aimed to interview representatives of the most active international organisations in the Roma health field as well as Member State representatives from as many countries as possible, however we did not commit to producing a representative sample of interviewees.

The data collected through the research activities were then conveyed in the country reports where the researchers synthesised the information by identifying trends and drew conclusions across the body of evidence reviewed.

## Results

This chapter presents the findings of this study's Report 1 Roma health in terms of the following seven indicators and 19 additional detailed sub-indicators (not listed).

- Mortality and life expectancy
- Prevalence of major infectious diseases and immunisation
- Healthy lifestyles and behaviour
- Access and use of health services and prevention programmes
- Prevalence of major chronic diseases
- Health factors related to the role of women in the Roma community
- Environmental and socioeconomic factors; and

Analysis is based on the 31 country reports which are annexed to this report. Following a brief introduction, the findings are first presented for each indicator and sub-indicator, then individually for the 11 countries<sup>74</sup> subject to specific considerations, and with a brief aggregated summary for the remaining 20 countries.

Finally, the chapter presents conclusions and recommendations.

## Introduction

This study has focused on data collected on seven indicators, six of which are public health centred, and a seventh which encompasses broader environmental and other socio-economic factors.

Links between Roma health and living circumstances are commonly referred to. However, high quality evidence of the specific causal links is often lacking, and generally lacks granularity in terms of the diversity of Roma communities across Europe<sup>75</sup>. Despite these considerations, a body of evidence demonstrates, among other things, that the Roma population has considerably shorter life expectancy compared to the non-Roma population and face a range of barriers in accessing health care.

This study and other research papers<sup>76</sup> report substantial limitations in the comprehensiveness and quality of the available European or nationwide data on the Roma population. A particular challenge is that Roma health studies are often local or small-scale, and thus have a small sample size. Subsequently, concluding what precise links there are between Roma ethnicity and health is difficult. Other determinants, including poverty and lack of education, also impact on health and affect not only Roma but other neighbouring and disadvantaged groups<sup>77</sup>.

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<sup>74</sup> Bulgaria, Croatia, the Czech Republic, France, Greece, Italy, Hungary, Romania, Slovakia, Spain, and the United Kingdom.

<sup>75</sup> M.E Foldes and A. Covaci Research on Roma health and access to healthcare: state of the art and future challenges *Int J Public Health*. 2012 February; 57(1): 37–39. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3282005/>

<sup>76</sup> See for example: Open Society Foundations No Data–No Progress Data Collection in Countries Participating in the Decade of Roma Inclusion 2005–2015. Available at [http://www.opensocietyfoundations.org/sites/default/files/no-data-no-progress-country-reports-20100628\\_0.pdf](http://www.opensocietyfoundations.org/sites/default/files/no-data-no-progress-country-reports-20100628_0.pdf)

<sup>77</sup> Masseria et al The socio-economic determinants of the health status of Roma in comparison with non-Roma in Bulgaria, Hungary and Romania, 2010 *European Journal of Public Health* , Vol. 20, No. 5, 549–554. Available at <http://eurpub.oxfordjournals.org/content/20/5/549.full.pdf+html>

What the research findings and data are less able to do is to demonstrate the causes of differences between Roma and non-Roma health and to sufficiently explore issues around the impact of specific social determinants on particular health outcomes.

Research on Roma health is developing and is moving from a focus on communicable diseases to encompass broader questions and indicators, including health inequalities. Although somewhat improving, there is still an urgent need for more research that can further explore the link between Roma health issues and social determinants and reverse current trends. This research should also be able to link findings to policy<sup>78 79</sup> and evaluations which can gauge the impact of policy change.

## Demographics

The European Roma population can be found everywhere in most European countries including Russia. The greatest numbers of Roma live in Central Eastern Europe – Romania, Slovakia, Bulgaria, Hungary, and the former Yugoslavia. Less than 20% of Roma in Europe are nomadic<sup>80</sup>.

Since the Accession of eight new Member States (A8) in 2004, Bulgaria and Romania in 2007 and Croatia in 2013, the EU's eastward expansion has made European governments responsible for granting Roma the same rights as other new EU citizens. EU enlargement also means that, pending original EU Member States' temporary migration restrictions, Eastern European Roma can live and work freely in the EU<sup>81</sup>.

When this report speaks of migrant, it is referring to Roma from European countries (EU Members and non-EU Members alike) who are currently living – a nomadic or sedentary life – in another European state and who have the right to do so. There are also non-EU Roma living in the EU. Most Roma migrate under the framework of the right to freedom of movement under European Union law<sup>82</sup>.

Migrant Roma may face discrimination as a result of their migrant status, their Roma status or both. As individuals with migrant status, Roma risk receiving inferior health care compared to host communities as a result of administrative and language barriers. According to the International Organization for Migration, different health practices, lack of empathy and lack of cultural sensitivity of medical personnel also play a part<sup>83</sup>. For irregular or undocumented migrants, the situation is often more severe as in most EU countries these migrants can only access emergency health services with few countries offering primary or specialised care<sup>84</sup>.

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<sup>78</sup> M.E Foldes and A. Covaci Research on Roma health and access to healthcare: state of the art and future challenges *Int J Public Health*. 2012 February; 57(1): 37–39. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3282005/>

<sup>79</sup> Interview with the Council of Europe as part of this study 19 July 2013. Unpublished.

<sup>80</sup> A Tanner The Roma of Eastern Europe: Still Searching for Inclusion, May 2005. Available at: <http://www.migrationpolicy.org/article/roma-eastern-europe-still-searching-inclusion>

<sup>81</sup> A Tanner The Roma of Eastern Europe: Still Searching for Inclusion, May 2005. Available at: <http://www.migrationpolicy.org/article/roma-eastern-europe-still-searching-inclusion>

<sup>82</sup> Roma migrants in Europe. Available at: <http://assembly.coe.int/ASP/XRef/X2H-DW-XSL.asp?fileid=18730&lang=EN>

<sup>83</sup> Equi-Health project to address Roma, migrant health issues in Europe. Available at <http://www.iom.int/cms/en/sites/iom/home/news-and-views/press-briefing-notes/pbn-2013/pbn-listing/equi-health-project-to-address-r.html>

<sup>84</sup> Equi-Health project to address Roma, migrant health issues in Europe. Available at



There are four countries with migrant Roma populations estimated to be 50,000 or above (United Kingdom, Greece, Germany, and Italy). France has an estimated population of 10,000-15,000 migrant Roma (2010)<sup>85</sup>. Roma populations also exist in Belgium, the Czech Republic, Ireland and Spain although no estimates for their size were identified.

The largest group appears to be found in the UK, where estimates range between 50,000 and 1 million<sup>86</sup>. No national statistics are collected on migrant Roma but the University of Salford is currently undertaking a survey of Local Authorities which aims to provide the most comprehensive and up-to-date information about the population of Roma from Central or Eastern Europe in the UK. In Italy, approximately 40-45% of the 140,000 Roma are not Italian citizens (56,000-63,000). Informal estimates of the number of immigrant Roma in Greece, provided for a study during 2008, put the figure at tens of thousands, probably close to or possibly even more than 100,000. Some of these are temporary migrants<sup>87</sup>.

In Germany, most estimates suggest that there are between 40,000 and 50,000 Roma, who are refugees or migrants without full citizenship<sup>88</sup>. These groups have been arriving to Germany from the Central or Eastern European countries since the 1990s<sup>89</sup>.

In Finland, Roma who have arrived in recent years from the former Yugoslavia have been estimated to be somewhere in the hundreds<sup>90</sup>. In the Netherlands the population is estimated at approximately 500, although this estimate dates back to a study from

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<http://www.iom.int/cms/en/sites/iom/home/news-and-views/press-briefing-notes/pbn-2013/pbn-listing/equi-health-project-to-address-r.html>

<sup>85</sup> Halfen, S. (2012) Situation sanitaire et sociale des « Roms migrants » en Île-de-France, Rapport de l'Observatoire régional de santé d'Île-de-France  
There seems to be an increase in the research focus after 2008. See for example: AŠAV. (2011) Synthèse des activités à visée d'insertion sociale et citoyenne, Gens du voyage et Roms migrants. Year 2010, juin 2011

Collectif national droits de l'homme Romeurope (2011) Santé materno-infantile des populations roms migrantes vivant en situation de précarité, June 2011.

Collectif national droits de l'homme Romeurope. (2010) Rapport 2009-2010 sur la situation des Roms migrants en France, septembre 2010

Gamonet J. "So dukhal tut ?", "Qu'est-ce qui te fait mal ?". Réflexions sur la traduction des entretiens médicaux avec les Roms migrants. *Études Tsiganes*, 2005; 22 pp. 120-125.

<sup>86</sup> Smolinska-Poffley, G., Ingmire, S. (2012) Roma Mental Health Advocacy Project Evaluation Report, Roma Support Group

<sup>87</sup> Cahn, Claude and Guild, Eslpeth (2008) Recent migration of Roma in Europe. Second edition 2010. Commissioned by the Commissioner for human rights of the Organisation for Security and Co-operation in Europe High Commissioner on National Minorities. P. 38 Available at:

<http://www.osce.org/hcnm/78034?download=true>

<sup>88</sup> European Parliament (2011) Measures to promote the situation of Roma EU citizens in the European Union – Country Reports. Available from: <http://www.europarl.europa.eu/committees/en/libe/studiesdownload.html?languageDocument=EN&file=34328>

<sup>89</sup> Peucker, M. et. al. (2009) Germany RAXEN National Focal Point – Thematic Study – Housing Conditions of Sinti and Roma, European Forum for migration studies. Available from: [http://fra.europa.eu/sites/default/files/fra\\_uploads/581-RAXEN-Roma%20Housing-Germany\\_en.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/581-RAXEN-Roma%20Housing-Germany_en.pdf)

<sup>90</sup> FRA (2009) FRANET Housing conditions of Roma and Travellers – Finland RAXEN National Focal Point – Thematic Study. Available from: [http://fra.europa.eu/sites/default/files/fra\\_uploads/579-RAXEN-Roma%20Housing-Finland\\_en.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/579-RAXEN-Roma%20Housing-Finland_en.pdf)

2002<sup>91</sup>. In Ireland, it is estimated that there are 2,500–3,000 Roma from Central or Eastern Europe<sup>92</sup> with the majority originating from Romania<sup>93</sup>, but also from the Czech Republic, Bulgaria, Hungary, the Former Republic of Yugoslavia, Lithuania and Poland<sup>94</sup>. In Luxembourg none of the estimated 300-500 Roma are indigenous and originate mostly from the Western Balkans<sup>95</sup>.

Information is available in only a few countries on the geographical distribution of migrant Roma. A study from Ireland illustrates an urban concentration of Roma from Central or Eastern Europe, mainly residing in private rented houses in the Irish capital, in Monaghan (North of Ireland) and Carlow (South-East)<sup>96</sup>. In France approximately 5,000 (one third or one half of the total population) migrant Roma are estimated to be based in Île de France (Greater Metropolitan Paris area) half of which are found in the district of Seine-Saint-Denis. The majority of this group is from Romania with some originating from Bulgaria<sup>97</sup>.

In all of the countries assessed, the availability of data regarding migrant Roma is even scarcer than in the case of national Roma minorities. This is not surprising given that one of the defining features of this group is that they are undocumented by the authorities. This does not only influence their access to social entitlements but also the extent to which data about them is being collected.

In Ireland, data on Roma from Central or Eastern Europe is based on estimations. Even if the Irish Central Statistics Office collects data on ethnicity, this is taken as a proxy from nationality. In other words, data on Roma are collected only for those that identifying as Roma/Travellers, but who are also Irish citizens. This difficulty in obtaining reasonably accurate figures is also exacerbated by the fact that many Roma do not reveal their ethnicity because of a fear of persecution<sup>98</sup>. Moreover there is a lack of data about their legal status in Ireland (i.e. asylum seekers and/or refugees). Uncertainty about their legal status can act as a barrier to access public health services because of a lack of awareness of rights of access<sup>99</sup>.

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<sup>91</sup> European Commission (2010) Ethnic minority and Roma women in Europe: A case for gender equality? Luxembourg: Publications Office of the European Union, 2010. Available from: [ec.europa.eu/social/BlobServlet?docId=4833&langId=enhttp://www.romaninet.com/ROMANINE\\_T\\_Cultural\\_report.pdf](http://ec.europa.eu/social/BlobServlet?docId=4833&langId=enhttp://www.romaninet.com/ROMANINE_T_Cultural_report.pdf)

<sup>92</sup> Estimate supplied by the Roma Support Group and Pavee Point Travellers Centre, in *Report on Educational need on Roma population*.

<sup>93</sup> The Roma Support Group and Pavee Point Travellers Centre estimate that 90% of Roma currently living in Ireland are from Romania, in Lesovitch, L. (2005) *Report on Educational need on Roma population*. City of Dublin VEC in association with Pavee Point Travellers Centre and the Roma Support Group. Available at:

[http://www.paveepoint.ie/pdf/Roma\\_Report.pdf](http://www.paveepoint.ie/pdf/Roma_Report.pdf)

<sup>94</sup> <http://www.nccri.ie/cdsu-travellers.htm>

<sup>95</sup> Council of Europe, ECRI Rapport (2012),

<http://www.coe.int/t/dghl/monitoring/ecri/country-by-country/luxembourg/LUX-CbC-IV-2012-004-FRE.pdf>

<sup>96</sup> The Roma Support Group and Pavee Point Travellers Centre estimate that 90% of Roma currently living in Ireland are from Romania, in Lesovitch, L. (2005) *Report on Educational need on Roma population*. City of Dublin VEC in association with Pavee Point Travellers Centre and the Roma Support Group. Available at: [http://www.paveepoint.ie/pdf/Roma\\_Report.pdf](http://www.paveepoint.ie/pdf/Roma_Report.pdf)

<sup>97</sup> Halfen, S. (2012) Situation sanitaire et sociale des « Roms migrants » en Île-de-France, Rapport de l'Observatoire régional de santé d'Île-de-France pp. 17-18

<sup>98</sup> Lesovitch, L. (2005) *Report on Educational need on Roma population*. City of Dublin VEC in association with Pavee Point Travellers Centre and the Roma Support Group. Available at: [http://www.paveepoint.ie/pdf/Roma\\_Report.pdf](http://www.paveepoint.ie/pdf/Roma_Report.pdf)

<sup>99</sup> Council of Europe, Parliamentary Assembly. 2012. Roma Migrants in Europe. Report prepared by Rapporteur Ms Anette GROTH, Germany, Group of the Unified European Left. Available at:

In Germany, there are no official ethnically disaggregated statistics. Furthermore, documentation of the demography of migrant Roma with a weak legal status is even scarcer<sup>100</sup>. Also in Italy there is a shortage of research comparing Italian Roma with migrant Roma.

**Table 7 Roma population and policymaking<sup>101</sup>**

*"The debate over the size of the Roma population is a direct consequence of the lack of clarity regarding Roma identity, as it makes counting the Roma difficult or even impossible. This is why it is only possible to talk about estimates. Estimates indicate that between 6.8 and 8.7 million Roma live in Europe, 68 per cent of whom live in Central and Eastern Europe and the Balkans. As a consequence, it is impossible to make use of random sampling in research. A general lack of statistical data on the situation of Roma in all sectoral fields makes the planning, design, monitoring and evaluation of policy and programmes difficult if not impossible. It is not possible to identify Roma ethnicity from national surveys, national demographic data or any kind of national health statistics. As a consequence it is difficult, and even impossible to identify them in these datasets. The main reason is the risk of stigmatization. Marking or labelling "Roma ethnicity" in any kind of official documentation could lead to the discrimination of Roma populations on various levels, be it political, social, cultural, economic, health care or a combination".*

As a whole, the Roma population is demographically different from the European populations insofar as it is noticeably younger – and consistently so across Europe. Using the average for the EU-27, the European Roma population has an average age of 25.1 in comparison with 40.2 for the non-Roma population<sup>102</sup>.

An illustration of the age distribution of the Roma population when compared to the non-Roma population is shown below.

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<http://assembly.coe.int/ASP/Doc/XrefViewPDF.asp?FileID=18730&Language=EN>

<sup>100</sup> European Parliament (2011) Measures to promote the situation of Roma EU citizens in the European Union - Study. Available from:

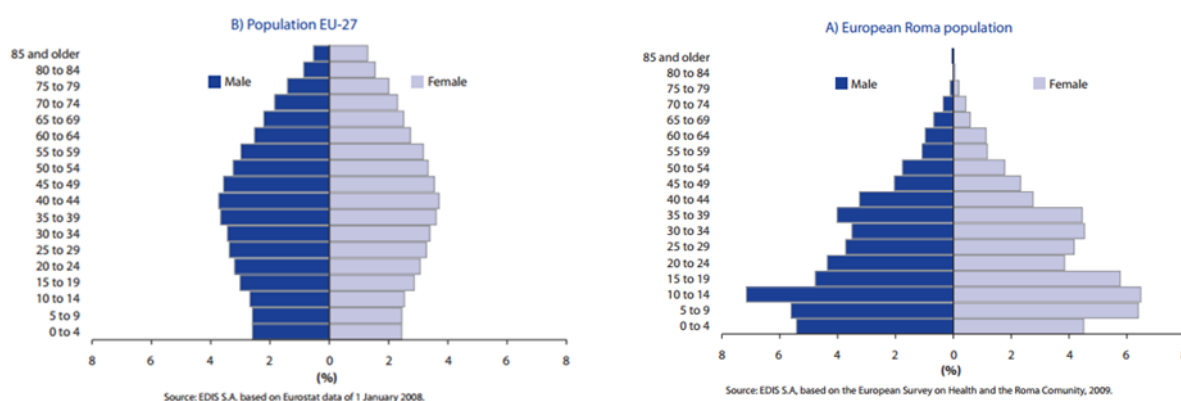
<http://www.europarl.europa.eu/committees/en/libe/studiesdownload.html?languageDocument=EN&file=34328>

<sup>101</sup> MEHO Project K. Rimárová, University P. J. Safarik, Košice Work package n°10: The Health of Roma people in Central and Eastern Europe. Available at:

[http://www.meho.eu.com/health\\_of\\_roma\\_people\\_in\\_cee.php](http://www.meho.eu.com/health_of_roma_people_in_cee.php)

<sup>102</sup> Health and The Roma Community, Analysis of the Situation in Europe: Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain, Fundación Secretariado Gitano et al 2009. Available at [http://ec.europa.eu/justice/discrimination/files/roma\\_health\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_health_en.pdf)

**Table 8 EU-27 vs Roma population**



Source: screenshots taken from *Health and the Roma Community, analysis of the situation in Europe – Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain, Fundación Secretariado Gitano, 2009*<sup>103</sup>

The longevity rate – i.e. the proportion aged 75 and over – is 25.7% for the EU-27 Roma population and 51% for the EU-27 non-Roma population<sup>104</sup>. In Croatia life expectancy of Roma (not gender disaggregated) is 66.6 years – 10 years less than the non-Roma population<sup>105</sup>.

Whilst the birth rate in the Roma population has been reported as being notably higher than for the majority populations, a recent European study (2009)<sup>106</sup> reported a shift in the socio-economic behaviour of the Roma population with a change in the age structure in the countries studied (BG, CZ, GR, PT, RO, SI, ES). The index for the number of children aged less than 5 years of age, for every 100 children aged between five and nine is 82.7 when compared to 101 for the EU-27. This suggests a reversing trend with a fall in replacement rate in children under five. The authors of this study found this to be the case in all the countries they studied. This may indicate that the Roma population is mirroring the decline in birth rate that took place in the European non-Roma population several decades ago<sup>107</sup>.

<sup>103</sup> [http://ec.europa.eu/justice/discrimination/files/roma\\_health\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_health_en.pdf)

<sup>104</sup> Health and The Roma Community, Analysis of the Situation in Europe: Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain, Fundación Secretariado Gitano et al 2009. Available at [http://ec.europa.eu/justice/discrimination/files/roma\\_health\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_health_en.pdf)

<sup>105</sup> Government Office for Human Rights and Rights of National Minorities, Croatia, NACIONALNA STRATEGIJA ZA UKLJUČIVANJE ROMA, ZA RAZDOBLJE OD 2013. DO 2020.GODINE/ National Strategy for Roma Inclusion for 2013-2020, 2012

<sup>106</sup> Health and The Roma Community, Analysis of the Situation in Europe: Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain, Fundación Secretariado Gitano et al 2009. Available at [http://ec.europa.eu/justice/discrimination/files/roma\\_health\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_health_en.pdf)

<sup>107</sup> Health and The Roma Community, Analysis of the Situation in Europe: Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain, Fundación Secretariado Gitano et al 2009. Available at [http://ec.europa.eu/justice/discrimination/files/roma\\_health\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_health_en.pdf)

## Indicator A: Mortality and life expectancy

### Key Findings

- The Roma population is demographically different from the majority European populations insofar as it is noticeably younger – and consistently so across Europe.
- Life expectancy data is very limited on a national and regional level. Most data are based upon estimates. The most widely cited data stems from the Council of Europe.
- Roma experience substantially lower life expectancy compared to non-Roma (up to 20 fewer years).
- Some evidence exists suggesting that shorter life expectancy in Roma populations occurs as a result of the broader environmental conditions they experience.
- Higher rates of infant mortality are reported in some Roma populations (those living in poor housing, with low educational levels and migrant Roma) compared to non-Roma in countries including Bulgaria, the Czech Republic, Hungary, Italy and Slovakia.

Mortality rates and life expectancy data refer to the number of deaths in a population, relative to the size of that population per unit of time; and the expected number of years remaining at a given age (usually at birth).

For many years, published information has persistently shown<sup>108</sup> that the Roma population has a markedly lower life expectancy than the general population and the Council of Europe information for this indicator is widely cited in reports and grey literature. The gap in typical length of life can vary from a decade to many more years. These differences are considerable but are not consistent across the EU as illustrated below.

This study's review of largely quantitative estimates<sup>109</sup> from international studies confirm previous assessments that the Roma population die earlier than the non-Roma population, and also draws attention to links between shorter life expectancy and wider determinants of health. Further anecdotal evidence drawn from secondary reviews is used to provide further context as well as highlighting areas of data weakness, such as migrant and undocumented Roma.

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<sup>108</sup> e.g., the Council of Europe, the World Bank

<sup>109</sup> The Research team have no data from Cyprus, Denmark, Estonia, Finland, France, Germany, Greece, Latvia, Lithuania, Luxembourg, the Netherlands, Norway, Portugal, and Slovenia.

**Table 9 Roma and non-Roma life expectancy in Czech Republic**

According to the data collected for this study in the Czech Republic<sup>110</sup>, Roma life expectancy is about 10-15 years less than the majority population. This estimate is generally accepted for the Roma population in Europe. More precise data has not been found (very probably are not available). In the Czech Republic life expectancy at birth in 2011 is estimated to be 74.3 years for men and 80.5 years for women<sup>111</sup>, and 64 years for Roma men and 70 years for Roma women. However, the recorded average age of death in 2011 was 59.2 years for Roma men compared to 65.6 years for non-Roma men and 63 years for Roma women compared to 80.2 for non-Roma women<sup>112</sup>. Differences between age of death and/or predicted life expectancy are more pronounced for women at 17 years. This suggests that the life expectancy of Roma women is 17 years shorter than for non-Roma women, but that life expectancy is increasing for both Roma and non-Roma groups.

If we compare life expectancy of the Czech population in terms of socio economic determinants such as education, we find that less educated men live 18 years less than university educated men<sup>113</sup>. For women, the difference in education appears to have a lesser influence on life expectancy – only three years. It is generally observed that social determinants have a gender gradient in that they influence men more than they do women. Poor education is a typical social determinant for Roma communities and one would expect that mortality and life expectancy would affect Roma men more than women. In reality, the opposite seems to occur; women appear to be more vulnerable to social economic determinants of health than men in Roma communities in the Czech Republic in general<sup>114</sup>.

Precise and comprehensive national data on Roma population life expectancy is generally not available across Europe, often because national authorities do not collect ethnically disaggregated health data<sup>115</sup>. Moreover, the Research Team found little data on Roma life expectancy disaggregated by gender (Hungary and the Czech Republic are exceptions) which would have helped with the understanding of Roma women's health in particular. In addition, when estimates are given, it is not clear whether these are based on solid data collection or are derived from assumptions.

The table below shows the difference in life expectancy between Roma and non-Roma men and women in the two countries where disaggregated data is available.

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<sup>110</sup> See further the Czech country report in Appendix A.

<sup>111</sup> [www.csu.cz](http://www.csu.cz) (Czech Statistical Office official website)

<sup>112</sup> Davidova E. a kol. Kvalita života a sociální determinanty zdraví u Romů v České a Slovenské republice (The Quality of Life from the Aspect of Health Determinants in the Roma in the Czech and Slovak Republics), TRITON, 2010

<sup>113</sup> Eurostat online database 20.4.2012

<sup>114</sup> Czech Republic country report, please see Appendix A.

<sup>115</sup> See for example Structural Funds: Investing in Roma Brief on Ethnic Data Collection. Available at [http://www.euromanet.eu/upload/29/80/BRIEF\\_ON\\_ETHNIC\\_DATA\\_COLLECTION.pdf](http://www.euromanet.eu/upload/29/80/BRIEF_ON_ETHNIC_DATA_COLLECTION.pdf)

**Table 10 Life expectancy at birth by gender in the CZ and HU**

	<b>Roma Men</b>	<b>Non-Roma Men</b>	<b>Roma Women</b>	<b>Non-Roma Women</b>
<b>Czech Republic</b> <sup>116</sup>	64 ( <i>estimate</i> )	74.3	70 ( <i>estimate</i> )	80.5
<b>Hungary</b> <sup>117</sup>	59	68	58	76

Beyond this data, information on life expectancy and mortality for the Roma community within Europe is disjointed and ad hoc. Inter-country differences are found in measurement scales and quality. The information contained in national reports and other sources includes estimates by (sometimes unnamed) experts, region specific information, anecdotal reports from various healthcare providers and estimates from population pyramid statistics. Health data collection in many countries does not include ethnicity, nor do the Roma population always categorise themselves in this way for fear of discrimination. Forming a conclusion or definitive answer on this topic is therefore difficult and involves an element of estimation and a wide margin for error. Despite these limitations the following table shows estimates from other countries where available.

**Table 11 Estimates of Roma life expectancy years compared to non-Roma by country**

<b>Country</b>	<b>Estimated Roma life expectancy compared to non-Roma</b>	<b>Source</b>
Austria	Estimated but not quantified	WIFO working paper
Belgium	Estimated but not quantified	Cijfers pric Limburg 2009, HIVA, Kwantitatieve bevraging van de maatschappelijke en economische positie van woonwagenbewoners, 2010, Vlaams Strategisch Plan voor woonwagenbewoners
Bulgaria	-10 years	National Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities
Croatia	-10 years	Government Office for Human Rights and Rights of National Minorities, Croatia
The Czech Republic	-5 to -10 years	Council of Europe estimate
Finland	Estimated but not quantified	Ministry of Social Affairs and Health, The (2009) The proposal of the working group for a national policy on Roma – working group report
Hungary	-9 years	Eduinvest (2009) "The Roma population's state of health survey
Ireland	-5 to -10 years	All Ireland Traveller Health Study (2010)
Italy	-20 years	CEPS, (2011), Promoting the Social Inclusion of Roma
The Netherlands	-12 years	Dokters van de Wereld (2010) Roma and Sinti op weg... naar een beter welzijn
Poland	Estimated but not quantified	Poland National Roma Integration Strategy
Romania	-12 years	Social Observatory for Roma (Bucharest University) and the World Bank
Slovakia	-5 to -10 years	Slovakia Regional office of public health survey, (2008)
Slovenia	Estimated but not	Belović, B. (2011), 'Health-Related Lifestyle of Roma' in:

<sup>116</sup> www.csu.cz ( Czech Statistical Office official website)

<sup>117</sup> Eduinvest (2009) The Roma population's state of health survey

Country	Estimated Roma life expectancy compared to non-Roma	Source
	quantified	Belović, B. and Krajnc Nikolić, T. (eds) Determinants Affecting the Health of Roma in Pomurje, Murska Sobota, Zavod za zdravstveno varstvo Murska Sobota
Spain	-7 years	FSG Health Area, (2009). Health and the Roma Community, analysis of the situation in Europe. Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain. Madrid. Fundación Secretariado Gitano,
The United Kingdom	-2 to -10 years	FRA (2012) "FRANET National Focal Point: Social Thematic Study: The Situation of Roma", University of Nottingham, UK

In Belgium, the Brussels municipal social services (CPAS) estimate that Roma have a life expectancy of 55 years and that Roma health is poor, even when compared to refugees and undocumented migrants; and suggests this to be linked to housing conditions<sup>118</sup>. Irish data also suggests that travellers have a lower life expectancy than the general population, estimated at 5-10 years<sup>119</sup>.

In Austria regional estimates suggest the mortality rate for Roma is 14% higher than for the rest of the country<sup>120</sup>. This study found similar calculations elsewhere. Whilst there is a noticeable lack of consistent, national Roma life expectancy data at country level, there was however some regional and/or estimated data in Bulgaria, Croatia, the Czech Republic, Italy, Hungary, Poland, Romania, Slovakia, Spain, and the United Kingdom.

In Slovakia the biggest gap in life expectancy is present in segregated and secluded areas of Roma settlements with poor living conditions, and it is estimated that mortality rate in such settlements is twice or three times higher compared to integrated Roma.<sup>121</sup>

Although quantifications of higher mortality and/or shorter life expectancy are largely not available, almost two-thirds of the 31 countries in this study (60%) estimate or can evidence poorer Roma health compared to the non-Roma population.

Overall life expectancy years for the Roma community are estimated to be between 5 and 20 years lower.

### Indicator A1: Infant mortality

As reported below, data exist in several Member States regarding Roma infant mortality; however these rates are often not comparable over time or with other data, as they tend to come from smaller-scale studies.

<sup>118</sup> Belgium country report, please see Appendix A.

<sup>119</sup> Ireland country report, please see Appendix A.

<sup>120</sup> Austria country report, please see Appendix A.

<sup>121</sup> Fundación Secretariado Gitano Zdravotná starostlivosť v sociálne vylúčených rómskych komunitách, 2007, p. 28. Available at: [http://ec.europa.eu/health/ph\\_projects/2004/action3/docs/2004\\_3\\_01\\_manuals\\_sk.pdf](http://ec.europa.eu/health/ph_projects/2004/action3/docs/2004_3_01_manuals_sk.pdf)



**Table 12 Infant mortality in Italy**

Italian data pertaining to infant mortality rates are scarce, outdated and somewhat inconsistent. In addition, there is no available data on maternal mortality. According to a Save the Children report<sup>122</sup> that presents data from 1992-1995 in the Lazio region, the rate of infant mortality at birth for Roma equalled 6.5/1,000 as opposed to 3.5/1,000 for Italians, while infant mortality within the first week equalled 15.3/1,000 for the Roma, as opposed to 4.4/1,000 for Italians. The main causes of death are infections and hypoxia. The European Monitoring Centre on Racism and Xenophobia<sup>123</sup> estimates that in 1991 the infant mortality rate for Roma in Italy was almost three times the rate of the wider population.

Studies suggest that least in some Roma groups, these higher rates of infant mortality appear to be associated with poorer living conditions (housing, low educational attainment and migrant Roma).

Along with Italy, data reporting higher infant mortality rates for Roma children have also been found in Bulgaria, Slovakia, Hungary, and the Czech Republic. In the latter country, at least one study<sup>124</sup> illustrates the relationship between higher infant mortality among Roma and the socio-economic conditions and high incidence of risk factors among pregnant women, especially smoking during pregnancy (57%<sup>125</sup>), and poor environmental conditions, especially housing. These socio-economic conditions and health behaviours increase the relative risk of lower birth weight and other non-favourable outcomes<sup>126 127</sup>.

In Hungary, studies also suggest a link between Roma infant mortality and social determinants. Although there is no national data disaggregated for ethnicity, regional disaggregated data<sup>128</sup> allows for some approximations and shows that there are regional differences in the rate of infant mortality.

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<sup>122</sup> Save the Children (2008) Studio sulla Salute Materno Infantile nelle comunità Roma. Il caso di Roma.

<sup>123</sup> European Monitoring Centre on Racism and Xenophobia, (EUMC)) *Breaking the barriers—Romani women and access to public health care*, 2003.

<sup>124</sup> Rambouskova J. a kol. Stravovací zvyklosti romských těhotných žen, (Eating habit of Gypsy pregnant women), *Hygiena*,48,2003, No.4,p.187-193

<sup>125</sup> Ibid.

<sup>126</sup> Bobak, M.,et all Unfavourable birth outcomes of the Roma women in the Czech Republic and the potential explanation: a population – based study, *BMC Public health*,2005,5,106

<sup>127</sup> Mihailov, D. The Health Situation of Roma Communities, Analysis of the UNDP/World Bank/EC Regional Roma Survey Data, UNDP, 2011

<sup>128</sup> For full bibliography please see the Hungarian country report in Appendix A.

## Indicator B: Prevalence of major infectious diseases & immunisation uptake

### Key Findings

- Recent comprehensive data regarding infectious diseases within Roma communities is not readily available, and the data available are often old, small-scale or, in a few cases, collected during disease outbreaks.
- Some of the available studies show higher rates of infectious diseases or risk of infectious disease outbreaks amongst Roma (including Measles and Hepatitis A), particularly segregated Roma compared to the majority population
- Evidence relating to rates of HIV/Aids is more mixed, though there are some reports of faster disease progression.
- There is a lack of data on vaccination uptake in the Roma population.
- The available evidence suggests that with some exceptions (Croatia, Hungary, and the Czech Republic) the Roma population, particularly migrant Roma, have lower or much lower rates of childhood vaccination uptake.

Infectious diseases (also known as communicable diseases) are caused by pathogenic microorganisms, such as bacteria, viruses, parasites or fungi; they can therefore be spread, directly or indirectly, from one person to another<sup>129</sup>. Major infectious diseases include Hepatitis A, B and C, HIV/Aids, Measles, Meningitis and Tuberculosis (TB). Where data is available, these are all covered in this study. However, it is important to note that variations in diagnosis and reporting of infectious diseases between countries are substantial, and consequently even where data exists it may not be reliable or comparable.

Interviews undertaken for this study as well as the review of existing literature have highlighted that research into infectious diseases in the Roma population has been a long-standing focus of public policy; however there is now evidence of a shift in focus away from infectious diseases and towards studies on non-communicable diseases, chronic illnesses and associated risk factors<sup>130</sup>.

Yet this study has found that recent comprehensive data regarding infectious diseases within Roma communities is not readily available, and the data available are often old, small-scale or collected during a disease outbreak. The European Centre for Disease Prevention and Control does provide surveillance reports and up-to-date monitoring (monthly) on measles and rubella outbreaks (among others), but this is not ethnically disaggregated, therefore it is not possible to identify whether this is a problem for the Roma population. It might also be argued that Roma with poor access to healthcare are less likely to have their infectious diseases diagnosed and reported to surveillance systems.

As noted in the European Journal of Public Health in 2010 "*Roma health literature focuses mostly on infectious diseases and genetic disorders as the major causes of*

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<sup>129</sup> [http://www.who.int/topics/infectious\\_diseases/en/](http://www.who.int/topics/infectious_diseases/en/)

<sup>130</sup> M.E Foldes and A. Covaci Research on Roma health and access to healthcare: state of the art and future challenges Int J Public Health. 2012 February; 57(1): 37–39. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3282005/>

*differences in Roma health. However, it has been argued that 'the focus on communicable disease may reflect less a concern about the health needs of the Roma but more those of the majority population'. Indeed, historically, Roma have been perceived and often stigmatised as a source of contagion. Poor hygiene and sanitation continue to be viewed to be the main causes of the relatively high rates of infectious disease in Roma*<sup>131</sup>.

## **Immunisation uptake**

On the whole, data on immunisation uptake suggests that in general the Roma population is more likely than the non-Roma population to be below the level required for herd immunity. In particular, migrant Roma have lower vaccination levels and the French country report compiled by Médecins du Monde (Appendix A) provides comprehensive contextual evidence around the dangers of low immunisation uptake.

Levels of Roma immunisation uptake are not consistent across Member States. In Croatia, Hungary<sup>132</sup> and the Czech Republic uptake levels are almost comparable to the general population. However, in others, including Bulgaria, France, Greece, Germany, Italy, Luxembourg, Poland, Romania, Slovakia and the UK, evidence (even if only anecdotal) suggests comparatively low levels. Notably this group of countries includes countries with the highest levels of migrant Roma.

The four substantive examples below provide further insight into low Roma vaccination levels.

1. A little over half of the Roma population in Slovakia have received some sort of vaccination, compared to up to 99% in the majority population. The fact that Roma are far behind the vaccination level of the majority population is likely to be a result of more difficult access to general health services, and thus irregular contact with general practitioners and other health practitioners. Besides this there is also lack of information and awareness on the importance of vaccination. In 2007 Slovakia adopted a programme focusing on improvement of Roma health through assigned health practitioners who visited Roma communities and educated Roma people on health issues, and also vaccination.<sup>133</sup> However, this programme is currently suspended due to lack of financial resources<sup>134</sup>.
2. Romanian data from 2009 suggests that 45.7% of the Roma children did not receive all of the mandatory and free of charge vaccines included in the National Immunisation Programme<sup>135</sup>.
3. According to the Bulgarian National Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities (2005), 15% of Roma children have not

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<sup>131</sup> Masseria et al The socio-economic determinants of the health status of Roma in comparison with non-Roma in Bulgaria, Hungary and Romania, 2010 European Journal of Public Health , Vol. 20, No. 5, 549–554. Available at <http://eurpub.oxfordjournals.org/content/20/5/549.full.pdf+html>

<sup>132</sup> UNDP: UNDP-WB-European Commission regional Roma survey 2011

<sup>133</sup> Program of health support of disadvantaged communities in Slovakia for years 2009 – 2015 – Second phase. Available at [http://www.uvzsr.sk/docs/info/podpora/romovia/romovia\\_2\\_etapa.pdf](http://www.uvzsr.sk/docs/info/podpora/romovia/romovia_2_etapa.pdf)

<sup>134</sup> Slovakia country report, please see Appendix A.

<sup>135</sup> Wamsiedel, M. & al., Health and Roma community – analysis of the situation in Romania, Fundacion Secretariado Gitano, Madrid, 2009.

completed mandatory vaccinations<sup>136</sup>. It is likely that in some isolated communities the rates of Roma children with incomplete vaccinations are much higher. More recent data (2009) collected through questionnaires to parents and guardians of Roma children indicated that 28.9% of Roma minors did not adequately follow the child vaccination programme<sup>137</sup>.

4. In France, evictions of Roma settlements had a significant impact on the health of the population, as the organisation of healthcare and of public health actions became more difficult. The public health actions carried out by NGOs including health care follow-ups, mother and child care and protection, postnatal follow-ups, immunisation, screening for diseases, and the delivery of treatments for chronic diseases were stopped. Evictions of Roma in France have also taken place during immunisation campaigns, making it harder to plan preventive actions and tackle epidemics such as the measles epidemic in France during 2008-2011.<sup>138 139 140</sup>

Thus, French data suggests links between low Roma vaccination uptake and disease outbreaks with wider social conditions. In addition to a very low coverage of BCG (*Bacillus Calmette–Guérin*) vaccinations for TB among Roma in France (38.9% in 2010 in under 30-year-olds<sup>141</sup>), poor living conditions that favour the spread of tuberculosis, a high prevalence of the disease among Roma in Eastern Europe, and low access to prevention and health care in France; communicable diseases such as TB are more easily spread<sup>142 143</sup>. Roma in France often settle in vacant plots or squats and hence are often evicted or compulsorily deported from French territory. For those few who have been diagnosed and are being treated for tuberculosis, there is no continuity of care resulting in poor compliance with medication and a lack of effective monitoring and follow up. This is a matter of great concern, since incomplete treatment can lead to multi-resistant TB<sup>144</sup> and worse outcomes.

An older and small scale study<sup>145</sup> in the UK indicates that Traveller and Gypsy children have lower levels of vaccinations, but these surveys are too local to be representative of the UK Gypsy Traveller population as a whole. Parental choice appears to be the main reason for non-completion of childhood immunisation in the non-Gypsy traveller population. It has also been argued in that study that the low levels of immunisation amongst Gypsy Traveller children are indicative of a range of factors shaped by their

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<sup>136</sup> Council of Ministers of Republic of Bulgaria, "National Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities", 2005, Sofia, Bulgaria

<sup>137</sup> Wamsiedel, M. & al., Health and Roma community – analysis of the situation in Romania, Fundacion Secretariado Gitano, Madrid, 2009.

<sup>138</sup> Médecins du Monde (2011), Rapport d'enquête sur la couverture vaccinale des populations roms rencontrées par les équipes de Médecins du Monde en France, Rapport de la Direction des Missions France, 22p

<sup>139</sup> Laurence, S., Chappuis, M., Rodier, P., Labaume, C., Corty, J-F. (2013), Campagne de vaccination hors centre contre la rougeole des populations précaires en période de pic épidémique, Marseille 2011, *Revue d'Epidémiologie et de Santé Publique* 61, pp.199-203

<sup>140</sup> Laurence S., Chappuis M, Lucas D, Duteutre M, Corty J-F, Campagne de vaccination rougeole des populations précaires: retour d'expérience, (submitted for publication)

<sup>141</sup> Médecins du Monde (2011), Rapport d'enquête sur la couverture vaccinale des populations roms rencontrées par les équipes de Médecins du Monde en France, Rapport de la Direction des Missions France, 22p

<sup>142</sup> Médecins du Monde (2012), Actions mobiles auprès des Roms, 2011, non publié.

<sup>143</sup> Halfen, S. (2012) Situation sanitaire et sociale des « Roms migrants » en Île-de-France, Rapport de l'Observatoire régional de santé d'Île-de-France, 144p.

<sup>144</sup> Ibid.

<sup>145</sup> Feder, G., & Hussey, R. (1990). Traveller mothers and babies. *BMJ: British Medical Journal*, 300(6739), 1536.

culture and lifestyle such as: (i) involuntary mobility as a result of eviction from sites, (ii) difficulties in registering and accessing GPs and, (iii) a lack of information regarding community health.

### **Prevalence of Major Infectious Diseases**

In more than half of the countries with a Roma population the available data on health status and disease prevalence is lacking, while in the other half there is partial data. Despite the paucity of data, the existing studies give indications that Roma health – at least in marginalised Roma communities – is poorer than the non-Roma population with respect to the prevalence of major infectious diseases.

The studies that are available have, since the mid-1990s, shown a higher rate of infectious diseases amongst Roma than the majority population<sup>146</sup>. In 2011, the ECDC hosted a pan-European conference on communicable disease prevention among Roma, undertaking a data collection exercise which drew a number of conclusions. Despite the Roma population being heterogeneous, they are disproportionately affected by communicable diseases. This impact can be linked to social determinants such as living conditions, health perceptions and behaviour, limited inclusion in prevention programmes such as immunisation programmes, and entrenched discrimination<sup>147</sup>. Indeed, a higher prevalence of infectious diseases among Roma appears not to be confined to specific countries but can be observed in a number of Member States with larger Roma populations including France, Spain, Bulgaria, and Romania. A 2011 study carried out in Barcelona amongst injecting drug users found that the highest prevalence of HIV infection and TB was within the Roma cohort within the study sample<sup>148</sup>.

The figure below shows key findings by Lim et al<sup>149</sup> from a 2013 paper reporting an 8-year era of continuous measles transmission in Bulgaria which ended in 2009. It noted that the Roma community were disproportionately affected and that the outbreak was characterised by an unusually high case-fatality rate and ratio of medical complications. The paper summarised that good maternal education, up-to-date child immunisation status and high household income lower the risk of complications like encephalitis or pneumonia. The figure represents the percentage of Roma measles cases compared with non-Roma and GDP, by region. Pie size (in the figure) is proportional to the number of measles cases. It demonstrates how Roma were affected significantly more in all regions bar one (Ruse). This is most aptly demonstrated in Dobrich where all recorded cases were Roma. The figure also shows the inverse proportionality between high incidence of measles and low GDP, for example in Sliven.

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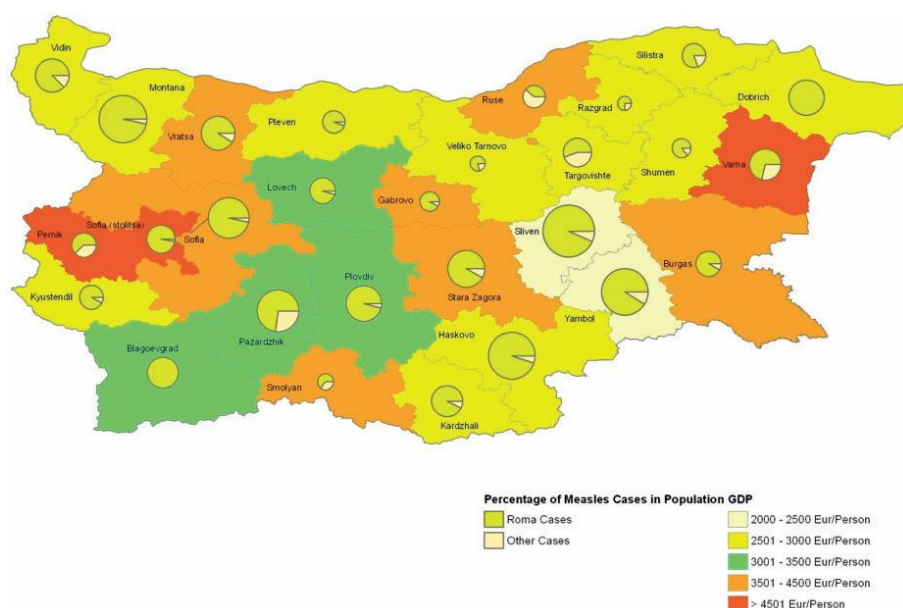
<sup>146</sup> Save the Children via Roma Inclusion Working Papers UNDP Europe and the CIS, Bratislava Regional Centre, The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma Survey, 2012

<sup>147</sup> ECDC Meeting Report Communicable disease prevention among Roma Vienna, 27–29 November 2011

<sup>148</sup> Roma Inclusion Working Papers UNDP Europe and the CIS, Bratislava Regional Centre, The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma Survey, 2012

<sup>149</sup> Lim, T-A et al. (2013). 'Measles outbreak in Bulgaria: poor maternal educational attainment as a risk factor for medical complications'. *European Journal of Public Health*, 1-6.

**Table 13 Percentage of Roma measles cases compared with the general population and GDP, by region, 2010, Bulgaria<sup>150</sup>**



Source: Tek-Ang Lim et al, Measles outbreak in Bulgaria: poor maternal educational attainment as a risk factor for medical complications, *The European Journal of Public Health Advance Access* published January 8, 2013

A significant amount of data on the prevalence of measles and TB within Roma communities relates either to specific outbreaks or to regional cohorts, and may therefore reflect health of marginalised Roma groups. However, the data is not comprehensive; there is limited scope to extrapolate from local or regional data to gauge the health of a national population. Indeed, no country assessed for this study systematically collects and reports comprehensive data or evidence of Roma health status for the major infectious diseases covered in this study.

To fully understand infectious disease prevalence in Roma and non-Roma populations across all countries there is a need for more complete data that more thoroughly record ethnicity or suitable proxies over time.

Outbreaks can nevertheless be used as a proxy for understanding the levels of vaccinations within Roma groups. Outbreaks may indicate poor living conditions – amongst Roma as well as their non-Roma neighbours – which can lead to disease and ill health. Thus the prevalence of infectious disease is also linked to poverty and social exclusion.

There are such examples from a number of countries, including France, Slovakia, Romania, and Italy. In Bulgaria there are significant data gaps on the prevalence of major infectious diseases, yet both quantitative and qualitative data reveals that Roma are especially vulnerable to outbreaks of measles and hepatitis A, while rates of HIV infection have been reported amongst the most socially excluded Roma, such as prisoners, drug users and sex workers. An outbreak of measles in this country registered in 2009 found that 89.3% of the 24,047 people affected were of Roma

<sup>150</sup> Tek-Ang Lim et al, Measles outbreak in Bulgaria: poor maternal educational attainment as a risk factor for medical complications, *The European Journal of Public Health Advance Access* published January 8, 2013

origin and 22 out of the 24 deaths were Roma patients<sup>151</sup>. Qualitative information from interviews with health practitioners working with Roma suggests that there are frequent outbreaks of hepatitis A in geographically isolated Roma communities. Such outbreaks can be linked to the density of Roma settlements and households making it more difficult to isolate hepatitis A virus carriers, and such infections frequently turn into epidemics<sup>152</sup>. This is a clear indication of poor sanitation conditions, including poor access to water. Among the migrant Roma living in the greater Metropolitan Paris area, both infectious diseases (notably Tuberculosis) and chronic diseases are more prevalent than in the population as a whole. The latter is particularly caused by unhealthy living conditions, unhealthy life styles and inadequate or untimely primary medical care<sup>153</sup>.

A 2008 academic study based on face-to-face interviews in five Roma settlements populated by Khorakhané Roma from Kosovo and Macedonia in five Italian cities (Florence, Bergamo, Brescia, Venice and Bolzano)<sup>154</sup> identifies the risk factors associated with diarrhoea, cough and respiratory difficulties. These risk factors are divided into two main categories:

- Camp-related: presence of water stagnating because of ruined paving or inappropriate drainage systems, size of the camp (number of people; size of the camp/ square meters), camp overcrowding (less than 25 m<sup>2</sup> per person), presence of rats in the camp, and prolonged stay in the camp.
- Household-related: poor condition of housing, overcrowding (more than 2.5 people per room), no indoor access to sanitation, use of wood-burning stoves.

#### **Table 14 HIV Infection in Spain**

The Roma population is the largest ethnic minority among HIV-infected patients registered in the Spanish VACH Cohort<sup>155</sup>. This is consistent with the hypothesis that this group constitutes the largest ethnic minority living in Spain, but could also be an indication that the HIV epidemic has severely impacted on the population through the high prevalence of IVDU (Intravenous Drug Use) observed in this population. The transmission of HIV through heterosexual contact seems to have reached a level in Roma similar to that seen in non-Roma. However, the association with IVDU, a characteristic of previous Spanish HIV epidemics, seems to have been significantly stronger for Roma. This population seems to have shared in the progressively decreasing percentage of IVDU-related new HIV diagnoses reported in recent years, but to a lesser extent than non-Roma. Thus, the percentage of Roma within new diagnoses of HIV infection has significantly decreased along the years, as IVDU has become a less predominant mechanism for HIV.

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<sup>151</sup> Mira Kojouharova, NCIPD, Bulgaria, "Measles outbreak in Bulgaria, 2009-2010", 2010, National Center of Infectious and Parasitic Diseases, Bulgaria

<sup>152</sup> Ilona Tomova, "The Health Status of Roma in Europe. National Report on Bulgaria", 2009, Foundation "The health of romany people", Sliven, Bulgaria

<sup>153</sup> Halfen, S. (2012) Situation sanitaire et sociale des « Roms migrants » en Île-de-France, Rapport de l'Observatoire régional de santé d'Ile-de-France pp. 65-75

<sup>154</sup> Monasta, L, N. Andersson, R. J. Ledogar, A. Cockcroft, Minority Health and Small Numbers Epidemiology: A Case Study of Living Conditions and the Health of Children in 5 Foreign Roma ' Camps in Italy, American Journal of Public Health, 2008 available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2636417/pdf/2035.pdf>

<sup>155</sup> The VACH cohort is a prospective-recruited Spanish cohort currently made of 10 800 HIV-infected adult patients from 19 hospitals across Spain.



In this cohort, HIV disease progressed faster to Aids (and to Aids to death) in Roma than non-Roma. Differences in a wide array of intermediate variables are often found in relation to race or ethnic origin. Nonetheless, differences in the rates of disease progression have been only exceptionally reported. In the present study, ethnic origin remained associated with an increased risk of progression after adjusting for other prognostic variables<sup>156</sup>.

**Table 15 Spain: Incidence of Infectious Diseases and Survival among the Roma Population: A Longitudinal Cohort Study<sup>157</sup>**

**Table 1 Incidence of TB, AIDS, imprisonment and injecting drug use according to sex and last living place in a Roma population. Barcelona (1985–2008)**

	Cases	Follow-up (person-years)	Rate/100 000pyf <sup>a</sup> (95% CI)
<b>Global</b>			
TB	7	7702.7	90.9 (68.5–113.2)
AIDS	8	7686.3	104.1 (80.1–128.0)
Imprisonment	45	7009.2	642.0 (579.7–704.3)
IDU	18	7506.3	239.8 (203.0–276.6)
<b>Men</b>			
TB	3	3791.4	79.1 (49.4–108.9)
AIDS	5	3782.3	132.2 (93.7–170.7)
Imprisonment	24	3359.4	714.4 (619.5–809.4)
IDU	17	3359.4	506.0 (426.1–585.9)
<b>Women</b>			
TB	4	3911.3	102.3 (69.0–135.6)
AIDS	3	3904.0	76.8 (48.0–105.7)
Imprisonment	21	3649.8	575.4 (493.6–657.1)
IDU	1	3908.0	25.6 (8.9–42.2)
<b>Last living place</b>			
<b>Barcelona</b>			
TB	5	1097.3	455.7 (323.0–588.3)
AIDS	5	1070.9	466.9 (331.0–602.8)
Imprisonment	10	921.7	1085.0 (861.6–1308.3)
IDU	4	1044.0	383.1 (258.4–507.9)
<b>Elsewhere<sup>b</sup></b>			
TB	2	6464.8	30.9 (16.7–45.2)
AIDS	3	6474.8	46.3 (28.9–63.7)
Imprisonment	35	5946.9	588.5 (523.8–653.3)
IDU	14	6321.7	221.5 (182.9–260.0)

**a: Person-years**  
**b: Place of residence in the follow-up**

<sup>156</sup> Characteristics and outcome of HIV infection in Roma in the Spanish VACH Cohort

<sup>157</sup> Casals M. et al Incidence of infectious diseases and survival among the Roma population: a longitudinal cohort study Eur J Public Health (2011). First published online: January 7, 2011.



A Spanish study from 2009 aimed to track Roma inhabitants of Camp de la Bota since the 1985 TB outbreak until 2008, analysing the incidence of infectious diseases, IDU, imprisonment and survival within this population. The Roma population on the whole was more youthful, although life expectancy within the group was found to be significantly lower than the rest of Spain at 68 years of age. This is most likely a result of the vicious cycle experienced by the Roma including persecution, less access to public services, lower educational levels and consequently increased crime.

The screenshot of the table above demonstrates the empirical findings of the study, which, to summarise, showed that the Roma population had an increased prevalence of AIDS, TB, drug addiction and were more likely to be imprisoned.

The author concludes that future policy needs to focus on reducing inequalities, giving some examples of encouraging policies being carried out by the Spanish government; including recognition of Roma culture as integral and enriching; and creating a plan to assist Roma in the Catalan Autonomous community.

*Source: Casals M. et al Incidence of infectious diseases and survival among the Roma population: a longitudinal cohort study Eur J Public Health (2011). First published online: January 7, 2011.*

The table above shows the number of cases and the prevalence per 100,000 inhabitants for the years 2008-2012 and compares the Roma population and non-Roma populations in Greece. There is a consistently higher prevalence of hepatitis A in the Roma population and a suspected measles outbreak in 2010.

## Indicator C: Healthy life styles and behaviours

### Key Findings

- Roma suffer disproportionately from illnesses that are associated with the social determinants of health.
- While data on health lifestyles and behaviours among Roma populations are generally limited, the available evidence from a large majority of countries included in the project suggests that Roma have poorer health related lifestyles.
- Available data on diet and physical activity consistently suggest that healthy diet and physical activities to stay healthy are less common in Roma.
- Available data on smoking prevalence from Austria, Croatia, the Czech Republic, Slovakia, Bulgaria, Hungary, Ireland, Portugal and Romania consistently show smoking is more common in the Roma population.
- Available evidence on alcohol consumption and illicit drug use amongst Roma communities reports conflicting findings.
- Very few interventions specifically target the health behaviours of Roma, though exceptions include drug rehabilitation programmes in Croatia, Finland, Ireland, Latvia and Lithuania.
- Small scale studies have identified a number of cultural factors which have a negative impact on the health lifestyles of Roma.

This indicator focuses on data on the prevalence of (illicit) drug use, tobacco use, alcohol abuse, and obesity among the Roma population.

### Overview

According to data shared by the FRA, Roma tend to have higher rates of illnesses associated with poor diet and stress<sup>158</sup>. Some Roma also suffer anxiety as a result of traumatic war experiences in the Balkan region, leading to mental health problems and psychosomatic complaints. There is also a high frequency of eye and dental problems, which can be attributed to poor diet and malnutrition<sup>159</sup>.

In Belgium, the Roma population's health is at least partly related to living conditions in their country of origin according to the Belgian municipal services (CPAS). Migrant Roma from Central or Eastern Europe arriving in Belgium already often suffer from poor health, which further deteriorates during their stay in Belgium as a result of poor living conditions<sup>160</sup>.

In some countries, studies have been carried out focusing on all migrants rather than migrant Roma. Such a study from Germany found that migrants living in Germany (including migrant Roma) are more likely to have health problems due to stressful

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<sup>158</sup> FRA (2013) FRANET Country thematic studies on the situation of Roma, Luxembourg, Publications Office Available at:

<http://fra.europa.eu/en/country-data/2013/country-thematic-studies-situation-roma>

<sup>159</sup> Ibid.

<sup>160</sup> Ramón Peña-Casas, Dalila Ghailani and Ides Nicaise (with the assistance of Eva Zemandl) Promoting the Social Inclusion of Roma A Study of National Policies: Belgium, July 2011

living and working conditions<sup>161</sup>. An Italian study of migrants living in Italy found that male Roma were the only group of migrants to have an average Body Mass Index value significantly higher than the average Italian<sup>162</sup>.

There is no data to cover all indicators for all countries (drug use, tobacco use, alcohol abuse and obesity) and studies tend to be small scale rather than covering whole populations. In relation to alcohol consumption there are contrasting trends, with most studies suggesting the Roma population consume less alcohol than non-Roma populations.

Many wider population studies have shown that socioeconomic status, specifically low educational attainment and low income, are associated with unhealthy lifestyles<sup>163</sup>. Some data on this indicator in Roma are robust and illustrative; for example from the UNDP et al<sup>164 165</sup>. Other indicators such as mental health lack quantifications. Indeed, a significant number of countries encompassed by the data collection are missing data on this indicator including Cyprus, Denmark, Estonia, Finland, Germany, Luxembourg, Norway and Poland.

### **Illicit Drug Use**

The studies sourced for this report which describe (illicit) drug use are few and do not cover the majority of the countries. There is still generally a strong correlation between social exclusion and illicit drug use, and evidence on good practice in drug prevention and treatment highlights the need for culturally sensitive service provision if service providers are to engage effectively with ethnic minorities.

The European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) recently published research that examined drug prevention interventions for minority ethnic populations in 29 European countries<sup>166</sup>. Although the report cites limited representation and an inability to generalise about issues due to a low response rate, it may give an indication about the extent to which drug rehabilitation interventions

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<sup>161</sup> See original study at: Federal Commissioner for Migration, Refugees and Integration (Beauftragte der Bundesregierung für Migration, Flüchtlinge und Integration) (2010) Bericht der Beauftragten der Bundesregierung für Migration, Flüchtlinge und Integration über die Lage der Ausländerinnen und Ausländer in Deutschland. Available at: [http://www.bundesregierung.de/Content/DE/\\_Anlagen/2010/2010-07-07-langfassung-lagebericht-ib.pdf;jsessionid=302B1C999D11829D7D54EEABEBEC1CFA.s2t1?\\_\\_blob=publicationFile](http://www.bundesregierung.de/Content/DE/_Anlagen/2010/2010-07-07-langfassung-lagebericht-ib.pdf;jsessionid=302B1C999D11829D7D54EEABEBEC1CFA.s2t1?__blob=publicationFile)

Federal Office for Migration and Refugees (Bundesamt für Migration und Flüchtlinge) (2011) Morbidität und Mortalität von Migranten in Deutschland. Available from: [http://www.bamf.de/SharedDocs/Anlagen/DE/Publikationen/Forschungsberichte/fb09-mortalitaet.pdf?\\_\\_blob=publicationFile](http://www.bamf.de/SharedDocs/Anlagen/DE/Publikationen/Forschungsberichte/fb09-mortalitaet.pdf?__blob=publicationFile)

<sup>162</sup> Geraci, S, F. Motta, A. Ricordy, Salute senza esclusioni Sperimentazione di interventi per la promozione dell'accesso ai servizi sanitari e dell'educazione alla salute per la popolazione Rom e Sinta in Italia, Caritas Roma, Rome, 2009

<sup>163</sup> M. Benzeval, et al Fiscal Studies (2000) vol. 21, no. 3, pp. 375–399 © Institute for Fiscal Studies, 2000 Evidence on the Relationship between Low Income and Poor Health: Is the Government Doing Enough?

<sup>164</sup> Mihailov, Dotcho, The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma Survey 2011. Roma Inclusion Working Papers. Bratislava: United Nations Development Programme, 2012

<sup>165</sup> David M. Cutler and Adriana Lleras-Muney Understanding Differences in Health Behaviors by Education J Health Econ. 2010 January; 29(1): 1–28. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2824018>

<sup>166</sup> Drug prevention interventions targeting minority ethnic populations: issues raised by 33 case studies EMCDDA, Lisbon, April 2013

are accessible to Roma. The study found that only five countries included interventions targeted specifically to Roma: Croatia, Finland, Ireland, Latvia and Lithuania.

Of the limited available data, the Czech Republic found that only 2.5% of the adult Roma population admitted to illicit drug abuse – at least once in their life, in comparison with the non-Roma population; 19% of men and 13% of women reported taking an illicit drug, most often marijuana<sup>167</sup>. In other countries, evidence is conflicting, for instance a recent (2010) but not representative survey of adolescents (age 13-16) in Hungary who already used drugs found the difference between the rate of drug use among Roma and non-Roma is very high: 22% for Roma compared to 2% for non-Roma<sup>168</sup>.

**Table 16 EU Health funded project SRAP: illegal/legal drugs among young Roma**

SRAP – Addiction Prevention within Roma and Sinti Communities – is a network of 11 associated European partners, dedicated to sharing information, promoting mutual learning and carrying out research on prevention and reduction of use/abuse of illegal/legal drugs among young Roma. The research undertaken by the network found that consumption by Roma youth does not differ much from that of their counterparts in the general population but that poverty, segregation, low access to education, employment and health services keep them at higher risk. Exploring cultural factors, one important observation was that such beliefs and values are not always just “ethnic” (limited to Roma culture), but they were also built in interaction with non-Roma peers, at school, or from the media. Nonetheless, in some closed communities, the drug issue was taboo, and people tended to put distance, in their discourse, between themselves, their own community, and drug use.

The research also found profound gender differences characterising young Roma’s experience of the social sphere. Different norms apply for boys and girls, the onset, frequency and contexts of consumption are different between boys and girls. Promiscuity is a trait easily associated to girl consumers, who suffer from stigma, and fear rejection or violent reactions from the family and community. Thus discourses about drugs in Roma communities intersect axes of gender, economic inequalities, age and convey implicit definitions of group belonging.

Awareness and mediation campaigns should be directed towards increasing knowledge of specialized services for health or for addiction, while outreach work and mediation should be at the basis of intervention designs for Roma health. Outreach services frequently established contact with Roma users, but they are mostly limited to IDU harm reduction or treatment, while often legal status (migrant Roma), lack of medical insurance or low school attendance exclude Roma youth from general prevention or health promotion programs. The network noticed that there is high variability not only between contexts but also within communities regarding patterns of consumption.

Results on patterns of consumption of Roma youth supports the idea of specially designed interventions, dedicated to these communities, with interventions aimed at increasing awareness, facilitating access and eliminating barriers in health and social services provision. The network suggests that further research needs to link social

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<sup>167</sup>Ibid

<sup>168</sup> Gerevich J., Bácskai E., Czobor P., Szabó J. (2010) “Substance use in Roma and non-Roma adolescents.” *The Journal of nervous and mental disease* Volume: 198, Issue: 6, Pages: 432-436

inclusion to processes and drug consumption dynamics, and explore their points of contact and mutual implications. The research pointed out how young Roma's access to drugs is linked to breaking down segregation and to participation in non-Roma peer groups. Still, there is a lack of information on how illegal markets and involvement in drug dealing contribute to facilitate consumption and multiply negative consequences for the individuals. Future research should also deepen the understanding of how non-segregated interaction influences service awareness, access rates, competence and knowledge capital. One other central point of interest regards stigma and secrecy and their influence on the possibility of developing family and community level interventions. The network suggests that future research should also reflect on how individual access to specialised services can be designed as an opportunity for dealing with other problems in the families, in a holistic approach, and thus to multiply the impact of individual interventions<sup>169</sup>.

Small-scale qualitative studies in Ireland based on interviews and focus groups show that the Roma population is more likely to exhibit this form of risk behaviour. Even when young people have similar behaviour in consuming drugs in comparison to non-Roma of the same age, the former are less aware of drug side effects and the related health services available<sup>170</sup>.

#### **Table 17 Illicit drug use – the United Kingdom**

A six month study carried out in 2010 by Tower Hamlets (London) Substance Misuse Service and the Roma Support Group<sup>171</sup> draws attention to the rising numbers of young men from Central and Eastern Europe who require intervention for heroin and cocaine dependency. During the two year prior to 2010, young people from the Roma community and non-Roma from Eastern European Countries account for 10% of referrals to the specialist drug treatment centre for heroin dependency.

The report discusses some of the cultural factors which underpin how Roma tend to deal with the issue of drugs within the community, stating that a lack of understanding and awareness of drugs and the harm they can do, has led some young people to using in the first place but that this lack of awareness also impinges on the abilities of young people to discuss drugs with their older relatives. This is further compounded by the taboo that surrounds drug use, particularly for young women, and a lack of access to drugs education reinforced by low levels of school attendance.

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<sup>169</sup> SRAP Project (2012) Understanding drug addiction in Roma and Sinti communities – Research report. Available at

<http://srap-project.eu/files/2012/06/SRAP-Action-research-final-report-Short.pdf>

<sup>170</sup> Van Hout, M. and Connor, S. (2008), 'The Normalisation of Substance Abuse Among Young Travellers in Ireland' *Journal of Ethnicity in Substance Abuse*, Vol. 7, No 1, pp 5-21

Van Hout, M. (2009), 'Irish travellers and drug use – an exploratory study' *Ethnicities and Inequalities in Health and Social Care*, Vol. 2, No 1, pp 42-49

Van Hout, M. (2010a), 'Alcohol use and the Traveller community in the west of Ireland' *Drug and Alcohol Review*, Vol. 29, No 1, pp 59-63

Van Hout, M. (2010b), 'Traveller health and primary care in Ireland: a consultative forum' *Community Practitioner*, Vol. 85, No 5, pp 27-30

Van Hout, M. (2011), 'Assimilation, habitus and drug use among Irish Travellers' *Critical Public Health*, Vol. 21, No 2, pp 203-220

Van Hout, M. and Staniewicz, T. (2012), 'Roma and Irish Traveller housing and health – a public health concern' *Critical Public Health*, Vol. 22, No 2, pp 193-207

<sup>171</sup> Winyard and Felja 2010, *Children of Roma Druglink* Vol 25 Issue 6 November/December 2010

## Tobacco

In general tobacco use follows clear socio-demographic patterns and is becoming increasingly concentrated in lower socioeconomic groups<sup>172</sup>. Across the EU smokers are more likely to be male than female, under 54 years of age, unemployed, manual workers or self-employed. Among the employed, manual workers are the most prevalent smokers (almost 40% smoke). The link between smoking and education exhibits a clear trend; tobacco use has a strong association with lower levels of educational attainment<sup>173</sup>.

Our research demonstrates that these patterns are also reflected in Roma communities, with smoking prevalence generally being high, with Roma tending to smoke more cigarettes and start at a younger age than the non-Roma population. Higher than general population smoking prevalence (sometimes obtained from small study samples) was evidenced in Austria, Croatia, the Czech Republic, Slovakia, Bulgaria, Hungary, Ireland, Portugal and Romania<sup>174</sup>.

The UNDP/WB/EC Regional Roma Survey in Croatia observed 52% more Roma smokers than non-Roma in Croatia<sup>175</sup>. The UNDP et al survey data also shows that across the countries studied the total number of Roma smokers over the age of 16 is significantly higher (by 20%), compared to the neighbouring non-Roma population – 53% and 33% respectively. The survey data found that the highest numbers of Roma who smoke are found in the Czech Republic, Slovakia and Croatia and the fewest number of Roma who smoke are in Bulgaria and Romania; however these Roma populations still smoke significantly more than the non-Roma population<sup>176 177</sup>. For example, in the Czech Republic, the prevalence of adult (aged 16+) Roma smokers was 77% compared with 43% of the non-Roma population<sup>178</sup>. Evidence from UNDP et al also suggests that Roma quit smoking less frequently, but also do it at a later age than non-Roma living in their proximity<sup>179</sup>.

The European Health Interview survey found that in the Czech Republic 56% of women and 65% of men in the Roma population reported smoking every day. Children smoke regularly from the age of 16 but occasionally also at a younger age. Self-reported numbers differ slightly in different sources.<sup>180 181 182 183</sup> Smoking prevalence

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<sup>172</sup> The Aspect Consortium Tobacco or Health in the European Union, Past, Present and Future, for DG for Health and Consumer Protection, October 2004

<sup>173</sup> Eurostat

<sup>174</sup> Yet the Czech profile also suggests that self-reported numbers slightly differ in different sources, which may well be the case in other countries too.

<sup>175</sup> UNDP: UNDP-WB-European Commission regional Roma survey 2011. [http://issuu.com/undp\\_in\\_europe\\_cis/docs/health\\_web](http://issuu.com/undp_in_europe_cis/docs/health_web)

<sup>176</sup> A factor believed to be linked to low income levels in combination with high taxation

<sup>177</sup> Mihailov, Dotcho, The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma Survey 2011. Roma Inclusion Working Papers. Bratislava: United Nations Development Programme, 2012

<sup>178</sup> UNDP: UNDP-WB-European Commission regional Roma survey 2011. [http://issuu.com/undp\\_in\\_europe\\_cis/docs/health\\_web](http://issuu.com/undp_in_europe_cis/docs/health_web)

<sup>179</sup> Mihailov, Dotcho, The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma Survey 2011. Roma Inclusion Working Papers. Bratislava: United Nations Development Programme, 2012

<sup>180</sup> Nesvadbová, L., Sandera, J., Haberova, V.: Romská populace a zdraví, Česká republika - Národní zpráva 2009 (Roma population and health, the Czech Republic, National report 2009)

<sup>181</sup> Davidova E. a kol. Kvalita života a sociální determinanty zdraví u Romů v České a Slovenské republice The Quality of Life from the Aspect of Health Determinants in the Roma in the Czech and Slovak Republics", TRITON, 2010

among the non-Roma population is 30% for men and 19% for women.<sup>184</sup> Among pregnant women, 58% reported smoking during pregnancy and 85% reported smoking before pregnancy. Amongst non-Roma, 20% of women in the Czech Republic report smoking during pregnancy<sup>185</sup>.

Research in the UK<sup>186</sup> shows higher rates of smoking amongst Gypsy Traveller populations compared to the study control group. From a sample of 260, 64% of 16-35 year old Gypsy Travellers were current smokers compared to 26% of the control group. Although no research has been carried out into the smoking habits of Roma coming from Central and Eastern European Countries (CEE) in the UK, a paper<sup>187</sup> on the drug habits of Roma migrants in Tower Hamlets in London suggests that there are also high levels of smoking amongst the migrant Roma population who originate from Central and Eastern European countries.

## Alcohol

Our study's secondary reviews did not identify new trends with respect to alcohol consumption in the Roma population. Alcohol consumption appears to be a variable health risk for Roma. In some cases (e.g. Portugal and the Czech Republic<sup>188</sup>) Roma tend to drink less than the general population, or the difference is not statistically significant (a small-scale study covering Latvia and Lithuania<sup>189</sup>). Alcohol related health problems were however evident elsewhere, e.g. Italy and Sweden for young male Roma<sup>190</sup>.

## Diet

The Research Team's review of existing evidence suggests that Roma generally have a poor diet, most likely a result of poverty. Roma tend to eat fewer vegetables, consume less nutritional food and eat more fatty food. Where studies on diet are available, data on weight and obesity is often available. In addition, Bulgaria, the Czech Republic, Hungary, Portugal and Romania report low numbers of Roma (adults and/or children) who undertake physical activities to stay healthy. The study has been able to highlight examples of cultural factors which may be associated with unhealthy lifestyles;

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<sup>182</sup> Zurovcová, H. Romové v České Republice, občanské sdružení Vzájemné soužití, Ostrava, 2010, zpráva Roma in the Czech Republic, Report of NGO Vzájemné soužití, personal archive

<sup>183</sup> Nesvadbová a kol. Determinanty zdraví romské populace v České republice 1999-2001. (Health Determinants of the Romany Population in the Czech Republic 1999-2001). *Praktický lékař*, 8/3, 2003,3, 139-145

<sup>184</sup> EHIS, European health information survey, 2008, USIS, [www.uzis.cz](http://www.uzis.cz) – official website of Institute of health information and statistics

<sup>185</sup> Davidova E. a kol. Kvalita života a sociální determinanty zdraví u Romů v České a Slovenské republice (The Quality of Life from the Aspect of Health Determinants in the Roma in the Czech and Slovak Republics", TRITON, 2010

<sup>186</sup> Glenys Parry, Patrice Van Cleemput, Jean Peters, Stephen Walters, Kate Thomas, Cindy Cooper, (2007), Health status of Gypsies and Travellers in England, *Journal of Epidemiologic Community Health* 2007; 61:198–204

<sup>187</sup> Winyard and Felja 2010

<sup>188</sup> DR0M: Zdraví versus sociální vyloučení (Health versus social exclusion). Report from the website of NGO DR0M, 2012 [www.drom.cz](http://www.drom.cz)

<sup>189</sup> Virginija Kanapeckienė, Rolanda Valintėlienė, Aušra Beržanskytė, Rimantas Kėvalas, Piotr Supranowicz (2009), Health of Roma children in Vilnius and Ventspils, *Medicina (Kaunas)* 2009; 45(2)

<sup>190</sup> Statens Folkhälsoinstitut (2010) Hur mår Sveriges nationella minoriteter? Kartläggning av hälsosituationen bland de nationella minoriteterna samt förslag till förebyggande och hälsofrämjande åtgärder. Available at: [http://www.fhi.se/Documents/Om-oss/redovisade-ppdrag/2010/Aterrapportering\\_regeringsuppdrag\\_nationella\\_minoriteters\\_halsa.pdf](http://www.fhi.se/Documents/Om-oss/redovisade-ppdrag/2010/Aterrapportering_regeringsuppdrag_nationella_minoriteters_halsa.pdf)



however, it has not been possible to establish how diet or lifestyle vary within particular Member States or nor how variables such as housing conditions or employment contribute to the differences observed.

Although poor diet is believed to be the result of unfavourable socioeconomic factors, a lack of exercise is explained partly in terms of access to recreation services and open spaces, and partly as a cultural factor as the Roma population tends to prioritise short-term over long-term health considerations<sup>191</sup>. The UNDP et al surveys suggest that the real health problems of Roma are only perceived once they become acute emergencies and are strongly linked to access to health services and the level of health knowledge and culture<sup>192</sup>. This conclusion is based on the following:

1. There are substantial differences between the Roma and non-Roma sample populations living in geographical proximity regarding disabilities, smoking patterns and hospital inpatient admission, all of which are indicators of acute forms of health deterioration. Smaller differences between the Roma and non-Roma samples were recorded in general health perceptions and out-patient attendances.
2. Differences between self-reported longstanding illnesses by Roma and non-Roma increase with the age of respondents.
3. Blood diseases, which are normally diagnosed following a medical check-up, are more common in non-Roma living in close proximity to the interviewed Roma, while respiratory infections (which can be more easily self-diagnosed) have higher prevalence among Roma<sup>193</sup>.

Complementary to this regional survey data, small-scale studies in the north of England have highlighted a range of cultural factors within the Roma community which contribute to ill health and which have been found to be resistant to change through health education, due in part to a distrust of health professionals. These include bottle feeding babies with sugary tea and consuming foods with particularly high fat content<sup>194</sup>. These studies have also concluded there is an overall poor awareness of how to maintain a healthy lifestyle amongst Slovak Roma residing in the UK. Research attributes poor diet amongst Central and Eastern European Roma in Leeds to poverty and a lack of money to buy fresh fruit and vegetables<sup>195</sup>.

Regarding data availability on the healthy life styles and related behaviours indicator, comparable data tend to stem from the UNDP/WB/EC survey, with countries not covered in the cohort struggling to produce data. In Italy, data inherent to healthy life styles are particularly scarce and outdated and the studies that do exist only peripherally cover lifestyles. One issue on which there is clear evidence in Italy is the

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<sup>191</sup> FRA Country thematic studies on the situation of Roma, June 2013. Available at: <http://fra.europa.eu/en/country-data/2013/country-thematic-studies-situation-roma>

<sup>192</sup> Mihailov, Dotcho, The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma Survey 2011. Roma Inclusion Working Papers. Bratislava: United Nations Development Programme, 2012

<sup>193</sup> Mihailov, Dotcho, The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma Survey 2011. Roma Inclusion Working Papers. Bratislava: United Nations Development Programme, 2012

<sup>194</sup> Lizzie Moore (2010). A Healthcare Needs Assessment of the Slovak Roma Community in Tinsley, Sheffield, University of Sheffield

<sup>195</sup> Cath Mahoney (2006), Roma Families in Leeds. A social audit of their situation needs and services, Travellers Health Partnership



increased prevalence of low birth weight Roma infants compared with non-Roma<sup>196</sup>. Across the 31 countries there is also poorer data availability for migrant Roma (noted in Belgium and Ireland, for example) but there is far better data availability concerning Irish Travellers.

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<sup>196</sup> Italy country report. Please see Appendix A.

## Indicator D: Access to and use of health services and prevention programmes

### Key Findings

- Patterns of access and use of health services is not homogenous across the Roma populations in the 31 countries, implying different impacts on Roma health and experience of health care. The level of marginalisation or integration of the Roma populations appears to be a crucial factor.
- Where data is available it provides sufficient evidence that there are numerous barriers to health care in the majority of countries.
- Evidence consistently suggests that barriers to access are closely linked to social exclusion factors, and specifically include the following factors:
  - Language and literacy barriers
  - A lack of knowledge of available health care systems
  - Discrimination by health care professionals
  - A lack of trust in health professionals
  - Physical barriers – mobility and distance
  - A lack of identification and/or insurance.
- Evidence also shows that patterns of health care utilisation among Roma differs from the general population, for instance including higher levels of use of acute hospital services, perhaps as the result of lower levels of engagement with or access to preventive care.
- There is evidence that the economic crisis is disproportionately impacting Roma populations' access to health care in the countries studied.

### Overview

Universal access to health care is a fundamental element of public policy in EU Member States. The EU Charter of Fundamental Rights' Article 35 states that

*"[e]veryone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices"<sup>197</sup>.*

Briefly summarised and simplified, universal health care access is delivered in Europe through two main approaches:

- The basic minimum approach which seeks to ensure that no citizen falls beneath a particular level of subsistence.
- The equalizing approach which strives towards delivering the same level or quality of health care to all, regardless of status<sup>198</sup>.

In reality, health care systems combine the two approaches sometimes in complex ways<sup>199</sup>. Consequently, access and use of health services is not homogenous across the Roma populations in the 31 countries, implying different impacts on Roma health

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<sup>197</sup> Quoted in Wörz et al Access to health care in the EU Member States Euro Observer Summer 2006 Volume 8, Number 2

<sup>198</sup> Wörz et al Access to health care in the EU Member States Euro Observer Summer 2006 Volume 8, Number 2

<sup>199</sup> Ibid.

and experience of health care. Equally, the level of marginalisation or integration of Roma populations is a crucial factor.

The Research Team's assessment of existing studies, such as UNDP et al, provides a significant amount of data on these issues; comparing Roma with neighbouring non-Roma populations. They confirm a general picture of Roma having poorer access to health services and prevention programmes than non-Roma.

There are some indications or data for most of the countries. However, the anecdotal nature of the data available make it difficult to draw conclusions, hence for a smaller set of five countries our findings appear mixed.

In turn, this study has also located and collected data in most of the countries covered by the study. Only three of the 28 countries with Roma populations have no data to report, although there is still a strong reliance on anecdotal information.

The data collected by this study identify multiple barriers which impact on Roma access to health care and services. The following section summarises these and provides further context from individual countries.

### **Language, literacy & health system knowledge**

These barriers have been widely reported and are likely to have the highest impact on migrant Roma. Small-scale studies from multiple sources and evaluations in the UK illustrate many of these issues, which are likely also applicable to other countries.

The UK reports that language and literacy barriers profoundly affect the ability of migrant Roma from South-Eastern Europe to access health services. Academic reports highlight difficulties in accessing appropriate interpreters for appointments and a lack of simply written and translated materials regarding health services. In addition, Roma who have recently arrived in the UK are reported to have very little knowledge of how the health system works and the services available to them<sup>200</sup>. This is very likely to be an issue in other countries with high numbers of migrant Roma. The London-based Roma Support Group's evaluation of its three-year Mental Health Advocacy Project (2012)<sup>201</sup> with the Central and Eastern European Roma Community in the UK capital highlights some recurring themes with regards to barriers to mental health services; namely a lack of knowledge of the existence of mental health services; communication, language and literacy barriers and the stigma of mental health issues.

Data collection in Finland indicates that Roma tend to use health services less than the general population and this is attributed to linguistic and cultural differences as well as lack of knowledge of their entitlements concerning welfare related issues and available services<sup>202</sup>. Studies showed that among elderly Roma many were unaware of services available to them. It was also reported that low levels of education and cultural barriers hindered the elderly population's access to public services. Services provided by the third sector were also reported to have been equally unused<sup>203</sup>.

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<sup>200</sup> UK Country Report. Please see Appendix A.

<sup>201</sup> Smolinska-Poffley, G., Ingmire, S. (2012) Roma Mental Health Advocacy Project Evaluation Report, Roma Support Group

<sup>202</sup> Ministry of Social Affairs and Health, The (2009) The proposal of the working group for a national policy on Roma – working group report. Available from: [http://ec.europa.eu/justice/discrimination/files/roma\\_finland\\_strategy\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_finland_strategy_en.pdf)

<sup>203</sup> Ministry of Social Affairs and Health, The (2009) The proposal of the working group for a national policy on Roma – working group report. Available from:

## Discrimination & trust

Again, there are multiple studies from the UK referring both to UK Gypsy Travellers as well as migrant Roma from Central and Eastern Europe, which indicates that barriers to health care are rooted in experiences of racism and discrimination as well as a lack of understanding of Gypsy Traveller culture on the part of many health professionals<sup>204</sup>. German literature also draws attention to mistrust of health providers and personnel, which in turn limits access to health services by Roma and Sinti<sup>205</sup>. Reports on discrimination or fear of discrimination (self-assessed) or cultural barriers preventing access to health care are also found in France<sup>206</sup>, Sweden<sup>207</sup>, Slovakia<sup>208</sup> and Poland<sup>209</sup>.

In Poland there is reported widespread agreement amongst stakeholder groups about the limited level of access to and use of health services in the Roma community. Both institutional documents and academic literature emphasise this problem. Less clear cut is the reasoning for Roma being underrepresented as patients in the health and social care system. An assessment of research based on interviews with experts and practitioners from a range of health agencies in Krakow and Warsaw, points out that the lack of trust of the Roma population in non-Roma individuals and the tradition of taking care of their problems within their own community limit use of the public health system. In addition, access to social services requires residency registration, which in the case of Roma was reported to potentially represent a deterrent, given their nomadic habits<sup>210</sup>. Moreover, it was reported that the Polish health system has recently shifted toward a more private approach; and poor economic conditions faced by the Roma community represent a further obstacle to healthcare.

Despite a right to emergency medical care, regardless of immigration status, Roma illegally residing in Brussels often encounter difficulties accessing medical care. This appears to be the result of incidents where doctors or hospitals refuse to care for fear that they will not be paid for their services<sup>211</sup>. In Italy, irregular third-country nationals may only receive emergency treatments on national territory by the means of a

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[http://ec.europa.eu/justice/discrimination/files/roma\\_finland\\_strategy\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_finland_strategy_en.pdf) (original source: Majaniemi Päivi, Viljanen Anna-Maria, 2008. Romanivanhusten palvelutarvekartoitus ('Survey on the Service Needs of Elderly Roma'). Available from: [http://www.suomenromaniyhdistys.fi/pdf/sry\\_palvelutarvekartoitus.pdf](http://www.suomenromaniyhdistys.fi/pdf/sry_palvelutarvekartoitus.pdf)

<sup>204</sup> UK Country Report. Please see Appendix A.

<sup>205</sup> European Parliament (2011) Measures to promote the situation of Roma EU citizens in the European Union - Study. Available from: <http://www.europarl.europa.eu/committees/en/libe/studiesdownload.html?languageDocument=EN&file=34328>

<sup>206</sup> ASAV, AREAS, Médecins du Monde, Romeurope, (2012) Projet de Médiation santé en direction de femmes et jeunes enfants Roms, Rapport final, 59p

<sup>207</sup> Statens Folkhälsoinstitut (2010) Hur mår Sveriges nationella minoriteter? Kartläggning av hälsosituationen bland de nationella minoriteterna samt förslag till förebyggande och hälsofråamjande åtgärder. Available at:

<http://www.folkhalsomyndigheten.se/documents/livsvillkor-levnadsvanor/nationella-minoriteter/redovisade-uppdrag/aterrapportering-hur-mar-sveriges-nationella-minoriteter.pdf>

<sup>208</sup> Popper, M., Szeghy, P., Sarkozy, S. (2009), Roma population and health: Analysis of situation in Slovakia, p. 70.

<sup>209</sup> Puckett, L.S. "Barriers to access: Social services and the Roma of Poland", *International Social Work* 2005 48: 621.

<sup>210</sup> Ibid.

<sup>211</sup> Ramón Peña-Casas, Dalila Ghailani and Ides Nicaise (with the assistance of Eva Zemandl) Promoting the Social Inclusion of Roma A Study of National Policies: Belgium, July 2011

special card called Tesserino STP (*Straniero Temporaneamente Presente*). However, this card is not granted to EU nationals who are either not in possession of medical insurance from their country of origin (Romania, Bulgaria), or are not regularly employed in Italy. Some regions have provided an alternative card, which puts them on a par with STP holders. However, since Roma with EU citizenship from Romania and Bulgaria face difficulties in being employed, their situation is particularly vulnerable.

**Table 18 Recommendations from Health and the Roma Community - analysis of action proposals<sup>212</sup>**

This document is based on the conclusions reached by means of the qualitative analysis carried out by the "Group of Experts on Health and the Roma Community" within the framework of the collaboration agreement between the Ministry of Health and Consumer Affairs and the Fundación Secretariado Gitano in 2004. The goal of this working group was to come up with an initial diagnosis of the social health status of the Spanish Roma population in order to pinpoint their principal needs and thus contribute to the elimination of existing health inequalities faced by this group. This work was based on the realisation that there was very little available data upon which to base tailored intervention within the Roma community. Until ad hoc research is available, it is up to experts in the field who work with and meet the needs of the Roma population (in the areas of health and social action) to help raise awareness about the situation, prioritise actions and tailor methodologies.

Having taken stock of this situation, the Ministry of Health and Consumer Affairs (Directorate-General for Public Health) and the Fundación Secretariado Gitano (FSG) have put together a joint collaboration project aimed at promoting health care equality for the Roma population in Spain. At European level, the FSG heads a project financed by the European Union and supported by the Ministry of Health and Consumer Affairs targeting the same objectives.

The report discusses (i) Health, Health Equality and Health Promotion, (ii) The Roma community and health: a diagnosis for action, and (iii) The Roma community and health: recommendations for action.

**Summary of recommendations**

Actions that could be taken by health care professionals working with Roma

- Work with the network of family members - Bear in mind the close relationship among extended Roma family members
- Priority should be put on group work when dealing with the Roma community, its perceptions, habits, knowledge or attitudes regarding health
- The diagnosis indicated that factors such as human warmth in the treatment process, perceived empathy and the feeling of being listened to and understood were among the most important criteria for the Roma population in assessing the quality of health-care services
- Learn how to deal with conflict and the development of a mediator's mind-set. Mutual feelings of prejudice and the influence of cultural differences when assessing a situation or interpreting certain codes, could give rise to significant conflict.

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<sup>212</sup> Spanish Directorate-General for Public Health Ministry of Health and Consumer Affairs Area of Health and Fundación Secretariado Gitano (2004) Health and the Roma Community Analysis of action proposals. Available at: [http://www.gitanos.org/upload/32/41/1.7-HEA\\_Health\\_and\\_the\\_Roma\\_Community.pdf](http://www.gitanos.org/upload/32/41/1.7-HEA_Health_and_the_Roma_Community.pdf)

#### Training of health-care professionals

Priority should be put on including the following material in training schemes:

- Background knowledge on Roma culture
- Knowledge of the ideas that the Roma community has with regard to health
- Awareness of the cultural elements involved in the relationship that exists between Roma men and women and health
- Information regarding the health status of the Roma population
- Insight into the internal diversity of the Roma community
- Analysis of prior intervention experiences regarding the health-Roma community relationship.

From the very outset it is important to point out that everyone must contribute to the intercultural mediation effort; i.e. mediation efforts must be made from all sectors of the community and all health-care service providers (in the case at hand) should receive training in mediation skills and attitudes.

#### The need for Roma community capacity building in the area of health

The Roma community must participate and be given a leadership role throughout all of the planning phase (diagnosis of needs, implementation and evaluation). Participation should take place at all levels; on a broad scale when defining strategic lines of action and on a more concrete level when assigning these strategic lines to specific areas and individual pockets of the population.

#### Intervention programmes focusing on the health-Roma community relationship

The ultimate goal of health programmes should be mainstreaming; that the needs of the Roma population should be met by the same service providers and the same resources as the rest of the population. That should be the objective of the stable programmes referred to in the recommendations; to guarantee that the specific needs and peculiarities of the Roma community can be met through the operation of these mainstream resources and the efforts of service providers.

#### Studies focusing on the health-Roma community relationship

The lack of studies and research on the health of the Roma population is a factor which complicates the planning of specific programmes that can be tailored to the reality and needs of this group. The following considerations should be kept in mind:

- Studies which constitute an affront to individual privacy should be avoided and efforts should be made to seek alternative techniques
- Whenever Roma collaboration is requested for a study, participants must be 'rewarded' by being sent the results
- A number of questions must be posed prior to the start of any study: Are the expected results of the study going to be significant? In other words, is the information sought necessary for advancement in that sector? If the answer to the latter question is affirmative, do we have the necessary resources to carry out a sufficiently serious and high-quality study? If the answer to one or both of the above questions is negative, it would be better to dedicate our efforts and resources to other objectives<sup>213</sup>.

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<sup>213</sup> Spanish Directorate-General for Public Health Ministry of Health and Consumer Affairs Area of Health and Fundación Secretariado Gitano (2004) Health and the Roma Community Analysis of action proposals. Available at: [http://www.gitanos.org/upload/32/41/1.7-HEA\\_Health\\_and\\_the\\_Roma\\_Community.pdf](http://www.gitanos.org/upload/32/41/1.7-HEA_Health_and_the_Roma_Community.pdf)

## Physical barriers – mobility & distance

Barriers to health care are also linked to the practicalities of a way of life which is, at least some of the time, mobile. Issues such as a lack of a postal address, having to travel long distances to visit their GP and evictions due to a lack of authorised sites are all relevant<sup>214</sup>.

Another reported barrier is a lack of health insurance cards or ID documents for countries without universal health care access. Non-insured Roma may have access only to emergency care but cannot use other health services. Countries where health insurance data suggest Roma are disadvantaged include Belgium<sup>215</sup>, Bulgaria<sup>216</sup>, Croatia<sup>217</sup>, and France<sup>218 219 220</sup>, and there are also indications this is the case in Germany<sup>221</sup>.

Patterns of Roma & non-Roma insurance from the recent FRA study are shown in the figure below.

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<sup>214</sup> Clark, C., and Greenfields, M (2006) Here to Stay. The Gypsies and Travellers of Great Britain, University of Hertfordshire Press

<sup>215</sup> Regional Integration Centre - Le Foyer (RIC-Le Foyer) (2004), Les Roma de Bruxelles, RIC-Le Foyer, Bruxelles.

<sup>216</sup> UNDP UNDP-WB-European Commission regional Roma survey 2011

<sup>217</sup> Ibid.

<sup>218</sup> Romeurope (2012), « Les Roms, boucs-émissaires d'une politique sécuritaire qui cible les migrants et les pauvres », Rapport 2010-2011 Collectif National Droits de l'Homme Romeurope,30p

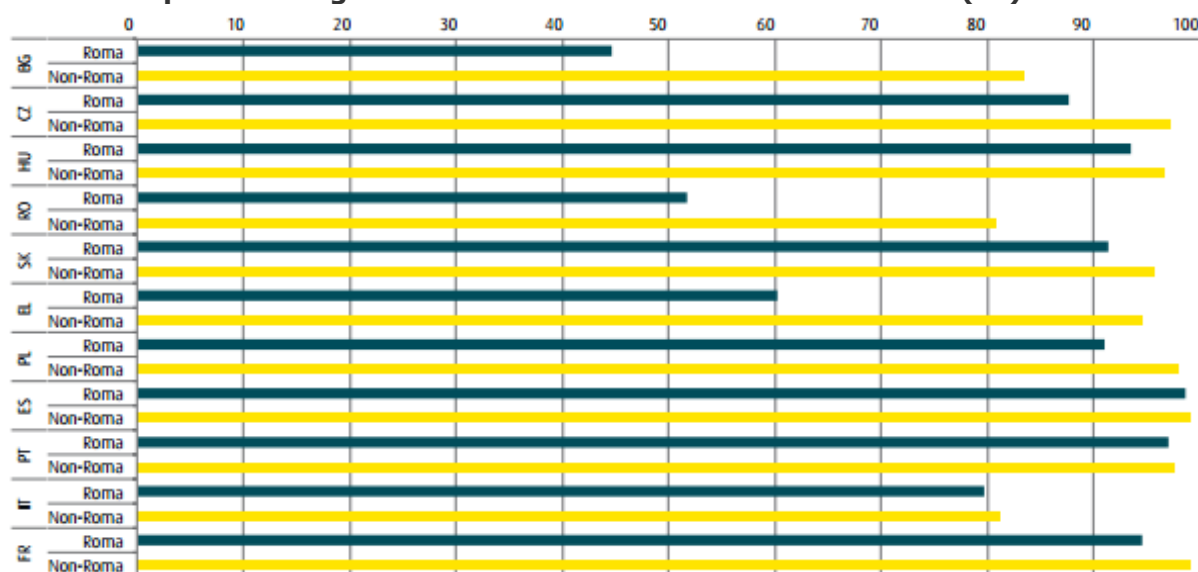
<sup>219</sup> Halfen, S. (2012) Situation sanitaire et sociale des « Roms migrants » en Île-de-France, Rapport de l'Observatoire régional de santé d'Île-de-France, 144p.

<sup>220</sup> JORF (2012). Arrêté du 1er octobre 2012 modifiant l'annexe de l'arrêté du 18 janvier 2008 relatif à la délivrance, sans opposition de la situation de l'emploi, des autorisations de travail aux ressortissants des Etats de l'Union européenne soumis à des dispositions transitoires, JORF n°0240 du 14 octobre 2012 page 16060, texte n° 14

<sup>221</sup> Bundesministerium des Innern (2011) An EU Framework for national Roma Integration Strategies up to 2020 – Integrated packages of measures to promote the integration and participation of Sinti and Roma in Germany. Available from:

[http://ec.europa.eu/justice/discrimination/files/roma\\_germany\\_strategy\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_germany_strategy_en.pdf)

**Table 19 Respondents aged 18 and above with medical insurance (%)**



Source: FRA Roma pilot survey 2011, UNDP/World Bank/EC regional Roma survey 2011

**Table 20 France. Barriers to access health care**

In France, the current French legislation concerning Romanians and Bulgarians is a primary barrier for Romanian and Bulgarian Roma to access health care. Although both countries joined the European Union in 2007, their nationals are only allowed to stay in France for over three months if they either hold a valid work permit or prove they have enough funds to live in France without being a burden to the French social security system, which means subscribing to private health insurance<sup>222 223 224 225 226</sup>.

Associated evictions for political and sanitary reasons have major negative consequences for Roma health, for their eligibility for social health protection and thus their access to health services and effective use of health care<sup>227 228</sup>. The instability resulting from evictions and compulsory departures moves Roma further away from accessing social health protection and health care. The administrative steps required for social health protection and the links with health professionals are interrupted and broken. Families and groups are dispersed by evictions and compulsory departures. As they resettle they either miss some members or are aggregated to new groups.

<sup>222</sup> Romeurope (2012), « Les Roms, boucs-émissaires d'une politique sécuritaire qui cible les migrants et les pauvres », Rapport 2010-2011 Collectif National Droits de l'Homme Romeurope, 30p

<sup>223</sup> Amnesty International (2013), « Facts of shame. Discrimination, forced evictions, segregation and violence against Roma in the European Union », Public Statement, 04.04.2013, AI Index: 01/008/2013, 2p

<sup>224</sup> Halfen, S. (2012) Situation sanitaire et sociale des « Roms migrants » en Île-de-France, Rapport de l'Observatoire régional de santé d'Ile-de-France, 144p.

<sup>225</sup> Médecins du Monde (2011), Parias, les Roms en France, Dossier de Presse, 15p

<sup>226</sup> Amnesty International (2013), "The rhetoric and reality of Roma rights", OP-ED, 04.04.2013, AI Index EUR 01/009/2013, 2p

<sup>227</sup> Médecins du Monde (2011), Parias, les Roms en France, Dossier de Presse, 15p

<sup>228</sup> Médecins du Monde (2007), Les Roms que l'Europe laisse à la porte, 30p.



The first consequence of evictions and compulsory deportations is that it is increasingly difficult to organise health care and public health interventions in a continuous and constructive way. Interventions that are stopped include health care follow up, improving settlement hygiene, mother and children care and protection, postnatal follow-up, vaccination, screening for diseases or the delivery of treatments for chronic diseases.

### Patterns of health care utilisation

This study's secondary review can also confirm already existing indications that the Roma population tend to use health care services differently from the non-Roma population, with higher use of acute hospital services perhaps as the result of lower levels of engagement in preventive primary care. There are several illustrations of this.

In the Czech Republic, Roma reported more obstacles accessing health care, however they use services proportionately more than the majority population: 44% every month (28% for majority population 18+), 34% at least once a year and 23% less than once a year. The number of visits does not differentiate between GPs or specialists<sup>229</sup>. Some studies state that inpatient ward or emergency wards are more frequently used by Roma than the majority population, others conclude higher frequency doctor visits by Roma, but that this is true only for General Practitioner visits<sup>230</sup>. Visits to specialists and dentists are less frequent in comparison to the majority population. The data are very similar across the majority population and dependent on socio-economic group; the less wealthy people visit GPs more often than more wealthy parts of the population but make fewer visits to dentists and specialists<sup>231</sup>. Roma visit health care facilities more often than non Roma (78% visit a GP or a specialist at least once a year). This is true in spite of the age distribution. There are fewer seniors (60+) in the Roma population; however they are the most health care consuming population group among non-Roma<sup>232</sup>.

An Irish study<sup>233</sup> found that the Traveller population makes greater use of Accident and Emergency (A&E) services. FRA also<sup>234</sup> confirms that there is a higher utilisation rate of A&E services and paediatrics and obstetrics. But the All Ireland Travel Health Study reports that a lower level of assistance was granted to Traveller children for a problem that needed attention (8.3%) in comparison with similar situation in the general population (2.8%)<sup>235</sup>. The reason given is paying for the care.

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<sup>229</sup> Nesvadbová, L., Sandera, J., Haberova, V.: Romská populace a zdraví, Česká republika - Národní zpráva 2009 Roma population and health, the Czech Republic, National report 2009

<sup>230</sup> Davidova E. a kol. Kvalita života a sociální determinanty zdraví u Romů v České a Slovenské republice (The Quality of Life from the Aspect of Health Determinants in the Roma in the Czech and Slovak Republics", TRITON, 2010

<sup>231</sup> Devaux M. and M.de Looper: Income-Related Inequalities in Health Service Utilisation in 19 OECD Countries. 2008-2009, OECD Health Working Pápera No 58, OECD Publishing, 2012, <http://dx.doi.org/10.1787/5k95xd6stnxt-en>

<sup>232</sup> Nesvadbová, L., Sandera, J., Haberova, V.: Romská populace a zdraví, Česká republika - Národní zpráva 2009 (Roma population and health, the Czech Republic, National report 2009

<sup>233</sup> All Ireland Traveller Health Study (2010) Technical Report I. Available at: [http://www.dohc.ie/publications/aiths2010/TR1/AITHS2010\\_TechnicalReport1\\_LR\\_All.pdf?direct=1](http://www.dohc.ie/publications/aiths2010/TR1/AITHS2010_TechnicalReport1_LR_All.pdf?direct=1)

<sup>234</sup> FRA (2013) FRANET Country thematic studies on the situation of Roma, Luxembourg, Publications Office Available at: <http://fra.europa.eu/en/country-data/2013/country-thematic-studies-situation-roma>.

<sup>235</sup> National Longitudinal Study of Childhood

Mediation programmes to facilitate access to health care for Roma is a mechanism used in countries such as France, Bulgaria, Slovakia and Romania. These interventions have been particularly successful in increasing vaccination rates among Roma, and in supporting Roma to obtain identification and insurance documents to facilitate health care access<sup>236</sup>.

**Table 21 Spain. New situation due to the economic crisis 2009-2013<sup>237</sup>**

The most pressing issue in Spain has been the impact of the economic crisis since 2009. Whilst the research team did not find evidence of any significant deterioration of health of the Roma population since 2009, problems were highlighted with regard to certain reductions in health spending, increasing bureaucracy in accessing health cards and pharmaceutical co-payment. Of greatest concern are the reported direct effects on health within the most vulnerable families, especially for children's diet and chronic disease monitoring and management within elderly disabled groups. Stakeholders also reported cases of worsening mental health of Roma, especially women with depression and rising levels of anxiety.

Fundación Secretariado Gitano also reported that a new law on health in 2012 has resulted in Roma of Eastern European origin facing severe restrictions in their right to health care. Impact was reported as affecting children and pregnant women.

According to information collected in 54 cities of Spain in 2013 by Fundación Secretariado Gitano, the economic crisis and austerity measures that are being implemented in Spain are directly affecting a large part of the Roma community, reducing their income levels and quality of life, and increasing the poverty rate of many Roma families who were already in a precarious situation, as well as families who had previously been in a more stable situation.

The reported consequence of the austerity measures is that many Roma families are now caught in a complex circle of interactions between inability to access services related to health, employment, education and housing, which ultimately produces greater social exclusion and consequently leads to a decline in their situation.

Measures that have been taken recently to tighten the conditions for payment of basic income and social assistance are severely affecting many Roma families; there are reported cases of people who were independent but now have to return to the social protection system. The social protection system itself is reported by stakeholders as not meeting the basic needs of the most vulnerable and excluded in Spanish society. Moreover, reducing aid dependency affects many Roma families who have disabled people in their care, resulting in serious situations of poverty and instability in these families as the costs of health care and daily life are high and the care of people is incompatible with employment. This in turn is reported as having long-term effects on carers because it is limiting their educational and employment promotion.

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<sup>236</sup> Interview with the Open Society Foundations as part of this study 14 June 2013, unpublished.

<sup>237</sup> Please see the Spanish country report in Appendix A

## Indicator E: Prevalence of major chronic diseases

### Key Findings

- Once allowance is made for demographic differences with the general population, Roma communities appear to suffer higher rates of chronic disease (i.e. asthma, diabetes, cardiovascular disease, hypertension) and the associated disability and limitations on daily activities.
- A range of small scale studies highlight dramatically higher and more complex cases of chronic disease amongst Roma across a range of European Countries – Germany, Finland, Poland, the UK (migrant Roma), Romania, Ireland, Italy, Spain and France.
- Some evidence reports links between these higher rates of chronic disease, and higher prevalence of risk factors (e.g. diet, exercise, stress), poor access to and uptake of primary care and preventive health programmes among Roma.
- A number of studies again highlight the disproportionate impact of the economic crisis on Roma populations and its relevance to chronic disease risk factors.

### Overview

In the context of this report, the following major chronic diseases have been considered: heart disease, stroke, cancer, diabetes, and arthritis.

Earlier studies suggest Roma suffer higher rates of major chronic disease than non-Roma, and more recent evidence and interviews<sup>238</sup> included in this study confirms higher rates of chronic diseases and associated risk factors compared to the majority population<sup>239</sup>.

The Regional Roma Survey data produced by the UNDP/World Bank/European Commission in 2011 found that Roma's perceived<sup>240</sup> health status<sup>241</sup> is comparatively close to that of the non-Roma sample group. The data even suggested that – looking at prevalence of chronic disorders<sup>242</sup> – 17% of the Roma sample suffered from one or more of these, while the equivalent number was 18% for the non-Roma sample<sup>243</sup>.

Prevalence of many chronic health conditions increases with age, thus it can be expected that, as a population ages, the proportion with one or more such conditions

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<sup>238</sup> Interview with the Council of Europe as part of this study 19 July 2013. Unpublished.

<sup>239</sup> Masseria et al The socio-economic determinants of the health status of Roma in comparison with non-Roma in Bulgaria, Hungary and Romania, 2010 European Journal of Public Health , Vol. 20, No. 5, 549–554. Available at <http://eurpub.oxfordjournals.org/content/20/5/549.full.pdf+html>

<sup>240</sup> Perceived – i.e. replies to surveys are based on personal perception and attitudes

<sup>241</sup> covering EU countries the Bulgaria, Croatia, Czech Republic, Hungary, Romania and Slovakia

<sup>242</sup> Asthma; Chronic bronchitis, chronic obstructive pulmonary disease (COPD), or emphysema; Hypertension (high blood pressure); Long-standing problems with muscles, bones and joints (rheumatism, arthritis); Chronic anxiety or depression; Diabetes

<sup>243</sup> Roma Inclusion Working Papers UNDP Europe and the CIS, Bratislava Regional Centre, The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma Survey, 2012

would rise<sup>244</sup>. The UNDP findings indicate that Roma in the older age groups (65 years old) report a much steeper increase in chronic disease-related problems – 70% compared with 56% of the non-Roma<sup>245</sup>.

Hence the demography of the Roma and non-Roma populations is important in this context. Roma – as a younger population on average – appear to suffer slightly less from chronic illnesses – but for Roma over 65 their vulnerability to long term chronic conditions may be greater than non-Roma.

The age factor is also highlighted in this study's data collection. The findings of the UNDP et al survey are, for example, mirrored in a Madrid study published in 2006, which surveyed a range of health problems (cholesterol, depression, stomach ulcers, and migraine headaches). It found that Roma over the age of 35 (both men and women) suffer from these conditions in greater proportions than the general population. And in some cases this was also true for younger age groups as well<sup>246</sup>.

The epidemiology of chronic disease is addressed and given further context in the UNDP et al surveys. The 2012 UNDP/FRA/EC report assessing, inter alia, the living conditions of the Roma population in 11 EU Member States<sup>247</sup> reported on the extent of their sub-standard housing conditions; about 45% of Roma live in households that lack at least one basic housing amenity, about 90% of households have an income below national poverty lines, and around 40% live in households where somebody had to go to bed hungry at least once in the last month and lacked the financial resources to buy food. These are well known conditions that contribute to the prevalence of chronic diseases; poor diet and malnutrition can contribute to diseases such as obesity, hypertension, diabetes and chronic heart disease, while damp, cold and poor quality housing can contribute to respiratory diseases such as asthma and bronchitis or musculoskeletal diseases such as rheumatoid arthritis<sup>248</sup>.

Some illustrations from literature identified for this study are highlighted below:

- In Germany, existing literature suggests that poor living conditions result in a higher risk of health problems<sup>249</sup>. According to one study in particular, specific health problems suffered by Roma in Hamburg seem to be heart disease, asthma and rheumatism. Another study shows that obesity and associated

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<sup>244</sup> Chronic health conditions: changing prevalence in an aging population and some implications for the delivery of health care services *Can J Aging*. 2010 Mar; 29(1):11-21.

<sup>245</sup> Roma Inclusion Working Papers UNDP Europe and the CIS, Bratislava Regional Centre, The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma Survey, 2012

<sup>246</sup> Hacia la Equidad en Salud. Disminuir las Desigualdades en una Generación en la Comunidad Gitana. Estudio comparativo de las Encuestas Nacionales de Salud a población gitana y población general de España. 2006. Available at [http://ec.europa.eu/health/social\\_determinants/docs/spain\\_rd03\\_en.pdf](http://ec.europa.eu/health/social_determinants/docs/spain_rd03_en.pdf)

<sup>247</sup> FRA, UNDP, European Commission, The situation of Roma in 11 EU Member States – Survey results at a glance (2012), Luxembourg, Publications Office, p. 8. Available at [http://fra.europa.eu/sites/default/files/fra\\_uploads/2099-FRA-2012-Roma-at-a-glance\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/2099-FRA-2012-Roma-at-a-glance_EN.pdf), p. 12.

<sup>248</sup> FRA, UNDP, European Commission, The situation of Roma in 11 EU Member States – Survey results at a glance (2012), Luxembourg, Publications Office, p. 8. Available at [http://fra.europa.eu/sites/default/files/fra\\_uploads/2099-FRA-2012-Roma-at-a-glance\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/2099-FRA-2012-Roma-at-a-glance_EN.pdf), p. 12.

<sup>249</sup> Eurofond (2012) Living conditions of the Roma: Substandard housing and health. Available from: <http://www.eurofound.europa.eu/pubdocs/2012/02/en/1/EF1202EN.pdf>

health problems such as metabolism disorder and hypertension are of concern within the migrant Roma population<sup>250</sup>.

- In Finland, the Ministry of Social Affairs and Health reported that, compared with the majority population, elderly Roma often have a higher incidence of respiratory disease and diseases of the musculoskeletal system, such as rheumatic diseases and asthma. It is believed that poor housing, damp, cold and malnutrition contribute to the high incidence of these diseases in elderly Roma living in Germany<sup>251</sup>.
- According to the Polish NRIS<sup>252</sup>, based on the information provided by the representatives of the Roma community, individuals are especially at risk of developing diabetes, cardiovascular and respiratory diseases; such as asthma, bronchitis and pneumonia. The study emphasises that Roma health problems appear to be the result of bad, and in many cases catastrophic social situations, such as the lack of water supply, sewage systems, heating in homesteads, or disastrous technical conditions of the heating system, as well as poor diet, limited access to health services (to name just a few examples stated in the report).
- Another study<sup>253</sup>, previously cited in relation to lifestyle aspects, highlights that in the UK, a nurse working closely with Slovak Roma in Sheffield has observed high rates of type two diabetes mellitus, cardiovascular disease, premature myocardial infarction, obesity and asthma and that it is common for Roma to have undiagnosed health conditions. Nearly half of Roma respondents to a survey in Leeds reported that someone in their house was suffering from a long term health condition<sup>254</sup>.
- A 2009 study<sup>255</sup> of Romanian Roma concluded that over half of the population age 45 and over suffered from disabilities or chronic disease irrespective of their gender.
- The 2011 Census in Ireland reports that Irish Travellers had higher rates of disability than the general population. Amongst Irish Travellers, the most common type of disability was 'difficulty caused by pain, breathing or any other chronic illness' (7.7%). This was followed by 'difficulty with remembering, learning or concentrating' (6.6%) and 'difficulty with basic physical activities' (6.3%)<sup>256</sup>. This is confirmed by the All Ireland Travel Health Study: "regarding the incidence of specific illnesses, the Traveller group appears to have a

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<sup>250</sup> FRA (2013) FRANET Country thematic studies on the situation of Roma, Luxembourg, Publications Office Available at: <http://fra.europa.eu/en/country-data/2013/country-thematic-studies-situation-roma>.

<sup>251</sup> Ministry of Social Affairs and Health, The (2009) The proposal of the working group for a national policy on Roma – working group report. Available from: [http://ec.europa.eu/justice/discrimination/files/roma\\_finland\\_strategy\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_finland_strategy_en.pdf)

<sup>252</sup> Poland National Roma Integration Strategy, Annex 6. Available at <http://ec.europa.eu/justice/discrimination/roma/national-strategies/>

<sup>253</sup> Lizzie Moore (2010). A Healthcare Needs Assessment of the Slovak Roma Community in Tinsley, Sheffield, University of Sheffield

<sup>254</sup> Cath Mahoney (2006), Roma Families in Leeds. A social audit of their situation needs and services, Travellers Health Partnership

<sup>255</sup> Wamsiedel, M. & al., Health and Roma community – analysis of the situation in Romania, Fundacion Secretariado Gitano, Madrid, 2009

<sup>256</sup> Central Statistics Office, Information Section, Profile Central Statistics Office, Information Section (2011) Profile 7: Religion, Ethnicity and Irish Travellers.

greater burden of chronic diseases than the general population, with conditions such as back conditions, diabetes, and heart attack increased by a factor of two in the Traveller group, and respiratory conditions such as asthma and chronic bronchitis increased by a factor of two to four, in comparison with the general population"<sup>257</sup>. FRA confirms this kind of data too, explaining that the Traveller population is affected by nutrition related illnesses, such as higher rates of diabetes mellitus, hyperlipidaemia, coronary artery disease and obesity<sup>258</sup>.

- In Italy<sup>259</sup> respiratory difficulties and asthma prevalence were found in children aged 0-5 in the five Roma settlements under assessment. Twenty-three per cent of the children had respiratory difficulties or wheezing; 17% of the children had respiratory difficulties in the past 12 months; 5% had recurrent respiratory difficulties (at least four times in the previous 12 months). Asthma prevalence was 17%.

Research undertaken for this study supports existing findings highlighted above and also provides further insight. For example, the Spanish country report<sup>260</sup> points to the role of social factors and concludes that the Roma population with a higher level of education have a better perception of their health status and are less likely to develop hypertension, asthma, eye problems or smoke (the latter only applying to men). Equally, Roma women and men who live in sub-standard housing have a greater tendency to describe their health as bad or very bad in comparison with those who live in standard housing. They likewise refer more frequently to problems such as hypertension, asthma, cardiovascular disease, hearing problems, dental problems and accidents<sup>261</sup>. It should also be noted that more socially excluded Roma living in poor conditions seem to use health services less frequently and are thus more likely to have undiagnosed chronic diseases.

Similarly, the French country profile concluded that chronic diseases for Roma are often related to living conditions, a lack of health education and difficulties in accessing health care. Roma in France do not seem to have access to tailored prevention programmes for chronic diseases in their own language. Without prevention and regular medical follow-up, and considering the sub-optimal conditions they experience, Roma who suffer from chronic diseases are likely not to be diagnosed or are diagnosed at a late stage. Even if they are diagnosed, they have a lower chance of being followed up by a general practitioner and receiving periodic investigations and treatment reviews to ensure that the disease is kept under control. With delays in

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<sup>257</sup> All Ireland Traveller Health Study (2010) Technical Report I. Available at: [http://www.dohc.ie/publications/aiths2010/TR1/AITHS2010\\_TechnicalReport1\\_LR\\_All.pdf?direct=1](http://www.dohc.ie/publications/aiths2010/TR1/AITHS2010_TechnicalReport1_LR_All.pdf?direct=1)

<sup>258</sup> FRA (2013) FRANET Country thematic studies on the situation of Roma, Luxembourg, Publications Office Available at:

<http://fra.europa.eu/en/country-data/2013/country-thematic-studies-situation-roma>

<sup>259</sup> Monasta, L, *Difficoltà respiratorie e prevalenza d'asma in bambini da zero a cinque anni in cinque insediamenti Rom*, Centro de Investigación de enfermedades tropicales (CIET), Universidad autónoma del Guerrero, Acapulco, México, 2004 available at [http://www.epidemiologiaeprevenzione.it/materiali/ARCHIVIO\\_PDF/2004/E&P4-5/E&P4\\_258\\_art6.pdf](http://www.epidemiologiaeprevenzione.it/materiali/ARCHIVIO_PDF/2004/E&P4-5/E&P4_258_art6.pdf)

<sup>260</sup> Hacia la Equidad en Salud. Disminuir las Desigualdades en una Generación en la Comunidad Gitana. Estudio comparativo de las Encuestas Nacionales de Salud a población gitana y población general de España.

<sup>261</sup> Spain country report. Please see Appendix A.

follow-up care, chronic diseases are not managed effectively, flare up will be more frequent and this leads to worsening of the overall health status of patients<sup>262 263 264</sup>.

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<sup>262</sup> Halfen, S. (2012) Situation sanitaire et sociale des « Roms migrants » en Île-de-France, Rapport de l'Observatoire régional de santé d'Île-de-France

<sup>263</sup> Médecins du Monde (2012), Rapport 2011 de l'Observatoire de l'Accès aux Soins de la Mission France

<sup>264</sup> Médecins du Monde (2010), Synthèse - forum « La santé des Roms en France : une urgence sanitaire? », Médecins du Monde - 25 février 2010



## **Indicator F: Health factors related to the role of women in the Roma community**

### Key Findings

- The recent (2013) FRA data on Roma women's health is the most comprehensive European source and underlines that Roma women are generally in worse health and more disadvantaged than Roma men and non-Roma alike.
- Available evidence suggests a range of additional barriers to improved health amongst Roma women, including expectations to fulfil traditional gender roles, limited educational and employment opportunities, physical and social isolation, and poor living conditions.
- Maternal health risks (i.e. early and late pregnancies, large families, poor access to and low uptake of antenatal care), and poor outcomes (i.e. miscarriage and still birth) are more common in Roma women.
- Evidence suggests that Roma women are at higher risk of domestic violence and associated mental health risks.
- A Spanish study suggests that the position of Roma women had improved as a result of lower birth rates, but also reported that they suffered more from obesity, depression, metabolic diseases, and sexual health problems, exercised less and had lower uptake of breast and cervical cancer screening.
- A French study suggests Mediation Programmes appear to offer a potentially effective means to engage with Roma women about health issues.

In the last decade more attention has been given to Roma women and to improving their situation<sup>265</sup>. However, research still concludes that Roma women continue to be discriminated against and are not given sufficient attention in health-related research, partly due to methodological challenges<sup>266</sup>.

In September 2012, an event organised by the OSCE Office for Democratic Institutions and Human Rights and the European Roma Rights Centre again stated that poor housing, the lack of access to education opportunities and the exclusion of Roma from public health insurance schemes were noted as having a negative impact on Roma health. In addition to this, the disadvantaged position of Roma women compared to Roma men means that they are disproportionately affected<sup>267</sup>. As Roma women's health issues are under-explored, including related factors such as the specific needs of Roma girls and women in education and housing, their needs are not routinely considered in policy-making and programme development<sup>268</sup>.

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<sup>265</sup> Gabriela Hrabanova The right to health: Challenges for Roma Women, Contribution to the 11th International Women Health Meeting (IWHM) Brussels, 13-17 September 2011. Available at <http://www.ergonetwork.org/media/userfiles/media/egro/The%20right%20to%20Health%20-20Challenges%20for%20Roma%20women%20Gabriela%20Hrabanova.pdf>

<sup>266</sup> M.E Foldes and A. Covaci Research on Roma health and access to healthcare: state of the art and future challenges Int J Public Health. 2012 February; 57(1): 37-39. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3282005/>

<sup>267</sup> <http://www.osce.org/odihr/94320>

<sup>268</sup> European Monitoring Centre on Racism and Xenophobia Breaking the Barriers – Romani Women and Access to Public Health Care, 2003



Research undertaken for this study again confirms that there are few substantial studies or data on the health of Roma women. Austria, Belgium and Sweden among others present anecdotal or unquantifiable evidence that Roma women's health is poor, but data are not consistently comparable and not particularly robust. Our findings suggest the most comparable and quantifiable data on Roma women's health stem from the UNDP et al survey. The research performed by FRA spanning eleven EU Member States also produces comparable findings, notably that "when looking at gender differences across all EU Member States, more Roma and non-Roma women than men said that their daily activities are limited because of health problems"<sup>269</sup>.

A very recent FRA study, published in the autumn of 2013 also contains important gender disaggregated data on Roma and non-Roma on important wider determinants of health. Due to the timing of its publication, the study has not been analysed in full here, but can be found summarised below. The indicators and results presented by FRA are illustrations of the links between health and social determinants, as discussed in this report in the Background and Context section, (Health inequalities in the Roma population) as well as in the following section on Environmental and other socio-economic factors. For instance, poor educational outcomes reduce chances of integration in the labour market, which locks individuals into lower socio-economic groups where poverty also means poor housing conditions, which in turn impact negatively on health. Disadvantaged situations also hamper access to health services.

**Table 22 FRA Report – Analysis of FRA Roma survey results by gender<sup>270</sup>**

The self-declared health status of Roma women and the ability to access healthcare facilities are also covered in the FRA report. It is important to note, however, that women generally report a lower self-perceived health status than men. Therefore these data have been compared with non-Roma women. Regarding women in 'bad' or 'very bad' health, all but one of the countries covered reported higher occurrence of these indicators in Roma women (16+) compared with non-Roma women. When discussing women aged 50+, Roma women declare themselves to be in significantly worse health than their non-Roma counterparts. For instance, in Poland 75% of Roma women stated that they were in 'bad' or 'very bad' health and in Italy a 58% difference exists between the self-declared health status of Roma and non-Roma women. Roma women also encounter greater limitations in their daily activities. On average 23% of Roma women experience limitations compared with 17% of non-Roma women. This is most evident in Poland where a 17% gap exists between the self-declared limitations of Roma women versus non-Roma women. Regarding medical insurance, 18% of Roma women compared with 8% of non-Roma women declared having no medical insurance. Three countries in particular show large differences in this respect. Bulgaria, Romania and Greece have differences of 37%, 25% and 31% respectively regarding lower coverage of Roma compared to non-Roma women with respect to medical insurance. Within Roma communities, women have slightly higher levels of medical insurance than men as 82% of Roma women are covered compared with 80% of Roma men. With regards to accessing healthcare, Roma, on the whole, did not encounter any issues as only 5% of women and 4% of men declared not receiving medical assistance when it was required.

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<sup>269</sup> European Union Agency for Fundamental Rights, 2012 UNDP, 2012 The situation of Roma in 11 EU Member States Survey results at a glance. Luxembourg: Publications Office of the European Union, 2012. [http://fra.europa.eu/sites/default/files/fra\\_uploads/2099-FRA-2012-Roma-at-a-glance\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/2099-FRA-2012-Roma-at-a-glance_EN.pdf)

<sup>270</sup> FRA for the European Parliament Analysis of FRA Roma survey results by gender, 2013. Available at: <http://fra.europa.eu/en/publication/2013/analysis-fra-roma-survey-results-gender>

<b>Healthcare Indicator</b>	<b>Countries that state poorer health in Roma women vs. non-Roma women</b>
Self-declared health status as 'bad' or 'very bad'	<i>PL, PT, RO, IT, CZ, BG, ES, FR, SK, EL</i>
Limitations in daily activities due to health status	<i>PL, PT, RO, IT, CZ, BG, FR, SK, EL</i>
Medical insurance coverage	<i>BG, RO, EL, SK, CZ, PL, FR</i>

There are notably few data on domestic violence. Two UK reports make the general statement that there is significant pressure within Gypsy Roma Traveller communities to conform to traditional gender roles, that domestic violence is relatively common and that this has an impact on the mental health of Roma women such as low self-esteem and depression<sup>271</sup>. This research includes quantifications of levels of domestic violence experienced by Roma women, although very little is known about the sample, and the data are not compared to a control group.

Largely the data available from existing studies on Roma women focus on sexual and maternal health. There are also a few qualitative studies available on mental health issues affecting Roma women. However, FRA studies have found that in Slovenia, Roma women are reported to experience stress, loneliness and depression as a result of their subordinate role in the Roma community<sup>272</sup>. In a study by the Swedish National Institute of Public Health, Roma women reported stress due to the overwhelming burden in their families<sup>273</sup>. A major study on this topic is still outstanding and is likely to shed further light on this issue – the Swedish government has commissioned the Swedish National Institute of Public Health to assess the health of Roma girls and women which is to be published in March 2014<sup>274</sup>. Survey research from 2009 covering Bulgaria, the Czech Republic, Greece, Portugal, Romania, Slovakia, and Spain revealed that in over 90% of the households with minors Roma women take responsibility for their care<sup>275</sup>.

Findings by our Research team in Spain (Fundación Secretariado Gitano) indicate that external factors may be leading to changes in Roma women's roles. Roma women are developing a key role within their community as educators, caregivers of children and the elderly, and are the transmitters of the norms and values of Roma Culture<sup>276</sup>.

<sup>271</sup> See the UK country report for full references

<sup>272</sup> FRA Country thematic studies on the situation of Roma, June 2013. Available at: <http://fra.europa.eu/en/country-data/2013/country-thematic-studies-situation-roma>

<sup>273</sup> Statens Folkhälsoinstitut (2010) Hur mår Sveriges nationella minoriteter? Kartläggning av hälsosituationen bland de nationella minoriteterna samt förslag till förebyggande och hälsofrämjande åtgärder. Available at: [http://www.fhi.se/Documents/Om-oss/redovisade-uppdrag/2010/Aterrapportering\\_regeringsuppdrag\\_nationella\\_minoriteters\\_halsa.pdf](http://www.fhi.se/Documents/Om-oss/redovisade-uppdrag/2010/Aterrapportering_regeringsuppdrag_nationella_minoriteters_halsa.pdf)

<sup>274</sup> Presentation to EU-Expert group on social determinants and health (2013) Sweden's Strategy for Roma Inclusion 2012-2032. Luxembourg. Available at: [http://ec.europa.eu/health/social\\_determinants/docs/ev\\_20130121\\_co05\\_en.pdf](http://ec.europa.eu/health/social_determinants/docs/ev_20130121_co05_en.pdf)

<sup>275</sup> Health and The Roma Community, Analysis of the Situation in Europe: Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain, Fundación Secretariado Gitano et al 2009

<sup>276</sup> García, C. (2005). *Guía para la actuación con la Comunidad Gitana en los Servicios Sanitarios*. Madrid. Fundación Secretariado Gitano.

**Table 23 Health Status of Roma Women in Spain<sup>277</sup>**

**Table 2 Distribution of Roma women and non-Roma women included in Spanish National Health Survey 2006 and National Health Survey in Roman Population 2006, by comorbidity**

	Roma women % (95% CI)	Non-Roma women % (95% CI)	OR (95% CI)
<b>High blood pressure</b>			
Yes	17.08 (14.10–20.54)	13.09 (11.19–15.27)	0.55 (0.29–1.02)
No	82.92 (79.46–85.90)	86.91 (84.73–88.81)	1
<b>High cholesterol</b>			
Yes	12.52 (9.96–15.64)	8.54 (6.99–10.39)	1.77 (0.84–3.72)
No	87.48 (84.36–90.04)	91.46 (89.61–93.01)	1
<b>Diabetes</b>			
Yes	7.02 (5.13–9.54)	3.23 (2.31–4.48)	1.42 (0.64–3.15)
No	92.98 (90.46–94.87)	96.77 (95.52–97.69)	1
<b>Obesity</b>			
BMI ≤ 30	75.55 (71.59–79.11)	89.78 (87.71–91.53)	1
BMI > 30	24.45 (20.89–28.41)	10.22 (8.47–12.29)	1.91 (1.05–3.50)
<b>Allergy</b>			
Yes	15.56 (12.71–18.91)	14.33 (12.34–16.58)	1.31 (0.76–2.26)
No	84.44 (81.09–87.29)	85.67 (83.42–87.66)	1
<b>Depression/anxiety</b>			
Yes	21.44 (18.14–25.16)	14.23 (12.25–16.48)	1.95 (1.09–3.48)
No	78.56 (74.84–81.86)	85.77 (83.52–87.75)	1
<b>Migraine</b>			
Yes	37.76 (33.72–41.98)	14.42 (12.43–16.68)	2.05 (1.27–3.33)
No	62.24 (58.02–66.28)	85.58 (83.32–87.57)	1
<b>Menopauses period</b>			
Yes	8.35 (6.27–11.04)	4.08 (3.04–5.46)	2.87 (1.15–7.12)
No	91.65 (88.96–93.73)	95.92 (94.54–96.96)	1
<b>Osteoporosis</b>			
Yes	5.69 (4.01–8.03)	3.13 (2.23–4.37)	1.96 (0.82–4.68)
No	94.31 (91.97–95.99)	96.87 (95.63–97.77)	1
<b>Respiratory disease</b>			
Yes	8.92 (6.76–11.67)	7.78 (6.31–9.56)	1.13 (0.57–2.24)
No	91.08 (88.33–93.24)	92.22 (90.44–93.69)	1

OR adjusted by educational level.

A 2010 paper "Health Status of Roma Women in Spain"<sup>278</sup> utilised a descriptive cross-sectional epidemiological study on health status, lifestyle and preventive practices among Roma women. Findings were based on secondary data from two similar surveys carried out in 2006, one on the Roma population and the other on the general population.

<sup>277</sup> Casals, M. Pila, P. Langohr, K. Millet, J.P. Caylà, J.A. Roma Population Working Group, (2011), "Incidence of Infectious Diseases and Survival among the Roma Population: A Longitudinal Cohort Study", European Journal of Public Health, Vol. 22, No. 2, pp. 262-6.

<sup>278</sup> Carrasco-Garrido, P. López de Andrés, A. Hernández Barrera, V. Jiménez-Trujillo, I. Jiménez-García, R. (2010), "Health Status of Roma Women in Spain", European Journal of Public Health, Vol. 21, No. 6, pp. 793-8.

Statistically significant differences were observed in a variety of different factors, with much of this evidenced in the accompanying table. Certain differences included the following: 71.91% of Roma women had no formal education compared to 6.41% non-Roma women; Roma women were found to be more likely to suffer from obesity, depression and migraines; Roma women had significantly higher values of alcohol consumption than non-Roma women and exercised less, although the study found that they did smoke less; and despite more serious health problems, healthcare resources were not used more by Roma women and the use of certain preventative measures, such as smear tests and mammograms, were in fact lower for Roma women.

Findings from the study generally match the outcomes of similar studies, pointing to the Roma population as an unhealthy demographic with lower educational levels that underuse public services. Roma women appeared to be most significantly affected by specific metabolic diseases or problems related to sexual health. The only direct contradiction between this study and similar work concerned smoking levels. It is thought that up to 70% of Roma adults were reportedly smokers, whereas the Carrasco-Garrido et al. study found smoking levels among Roma women to be below the national average.

*Source: Casals, M. Pila, P. Langohr, K. Millet, J.P. Caylà, J.A. Roma Population Working Group, (2011), "Incidence of Infectious Diseases and Survival among the Roma Population: A Longitudinal Cohort Study", European Journal of Public Health, Vol. 22, No. 2, pp. 262-6*

The Research Team's assessment of available secondary evidence also suggests that the role of many women has shifted from exclusively performing household tasks and childcare to work in the labour market or to take on other roles formerly assigned to men. The impact of education, demographic changes, information technology and urban life are contributing to intense and ambivalent cultural transformation, reflected particularly in younger Roma, but also in women. In Spain, a falling birth rate was reported as meaning smaller families, children having a new position in the family, education being valued and a new relationship between the sexes being developed, as many women are not solely dedicated to motherhood; thus they could have more autonomy and be in better health. Nevertheless, Roma women were still reported to suffer more health problems in comparison to Roma men and women in the general population. The Spanish data also identified problems associated with early and late pregnancy, poor uptake of gynaecological prevention services and health problems caused by work overload<sup>279</sup>.

The Open Society Institute, which works across Central and Eastern Europe, maintains that many Roma women have limited educational opportunities and live in inadequate housing and receive poor healthcare, take on traditional gender roles and are thus socially excluded from mainstream society<sup>280</sup>. In addition, the FRA and UNDP survey (2012) highlights that unemployment rates for Roma women are on average one third higher than for Roma men<sup>281</sup>.

There is also a significant evidence gap in the research around the health of migrant and undocumented Roma women, and our findings are therefore very limited.

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<sup>279</sup> García, C. (2005). Guía para la actuación con la Comunidad Gitana en los Servicios Sanitarios. Madrid. Fundación Secretariado Gitano.

<sup>280</sup> Open Society Institute's Network Women's Program Initiative. Available at [http://www.opensocietyfoundations.org/sites/default/files/z\\_romani\\_women\\_0.pdf](http://www.opensocietyfoundations.org/sites/default/files/z_romani_women_0.pdf)

<sup>281</sup> Luxembourg FRANET National Focal Point Social Thematic Study The situation of Roma (2012) Etudes et Formation S.A. Available at: <http://fra.europa.eu/sites/default/files/situation-of-roma-2012-lu.pdf>

Anecdotal evidence from Luxembourg via the FRA study<sup>282</sup> suggests that there is a high ratio of medically uncontrolled pregnancies among Roma women that have recently arrived in the country. Although not comparable, survey data from Médecins du Monde's beneficiaries of a prenatal information and follow up programme<sup>283</sup> may give an indication of the situation of undocumented Roma women in France.

The same French research shows that Roma women are seldom aware that they can be followed up during their pregnancy and do not know where to go for care, although France offers free prenatal care in specific Mother and Child Protection health care facilities for those without social health protection. Consequently, MdM has documented complications such as miscarriages, in-utero foetal deaths and many other preventable complications<sup>284 285</sup>. In 2011, 50% of pregnant women who came to MdM Roma Programmes were not being followed up during their pregnancy. The study found 70.8% delayed starting their antenatal care and were more than 12 weeks pregnant when such care was first received<sup>286</sup>. There was an average of 1.88 miscarriages in the 12.7% of Roma women who had already had at least one miscarriage in 2011, and there was an average of 1.44 stillborn babies per woman<sup>287</sup> among the 6.3% of Roma women who had already had at least one stillborn baby. Among Roma women, only two out of four pregnancies result in a living infant on average<sup>288</sup>.

The absence of antenatal care in France was also reported to be a matter for concern, since Roma women tend to have their first child at a very young age; 17 years on average in the 2008 survey and 17.27 years on average in 2011<sup>289 290</sup>. It should be noted that the median age of both surveys' population was 22 years old<sup>291 292</sup>. The 8.3% of pregnant women, who benefit from being treated in public health care facilities, can seldom complete prenatal care as a result of evictions that force them to move further away from the health care facility where they were being treated. Stress from the fear of evictions, identity checks and the experience of living and coping in informal settlements without water, electricity or sanitation also results in higher proportions of women not able to access prenatal care<sup>293 294</sup>.

Many countries' data indicate that Roma women start having children at a younger age than the majority population. Irish census figures analysed in 2010 reported that among the 40-49 year olds (women who are no longer fertile), those with no children made up just 11.6% of women amongst Irish Travellers compared to 18.7% of women generally. 26.9% of Irish Traveller women had given birth to five or more children in contrast to just 2.6% of women overall. Furthermore, just over one in eight (13%)

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<sup>282</sup> Ibid

<sup>283</sup> Médecins du Monde (2008), Médecins du Monde auprès des femmes Roms, 8p

<sup>284</sup> Ibid

<sup>285</sup> Médecins du Monde (1999), Données médicales et socio-démographiques: les populations Roms/ Tsiganes migrantes en situation de grande exclusion dans trois pays d'Europe. Espagne, France, Grèce. Etude Quantitative. Projet Romeurope, 93p.

<sup>286</sup> Médecins du Monde (2012), Actions mobiles auprès des Roms, 2011, non publié.

<sup>287</sup> Ibid

<sup>288</sup> Médecins du Monde (2010), Synthèse - forum « La santé des Roms en France: une urgence sanitaire ? », Médecins du Monde - 25 février 2010, 10p.

<sup>289</sup> Médecins du Monde (2012), Actions mobiles auprès des Roms, 2011, non publié.

<sup>290</sup> Médecins du Monde (2008), Médecins du Monde auprès des femmes Roms, 8p

<sup>291</sup> Médecins du Monde (2012), Actions mobiles auprès des Roms, 2011, non publié.

<sup>292</sup> Médecins du Monde (2008), Médecins du Monde auprès des femmes Roms, 8p

<sup>293</sup> Médecins du Monde (2007), Les Roms que l'Europe laisse à la porte, 30p.

<sup>294</sup> Romeurope (2000), Roms, Sintés, Kalés, Tsiganes en Europe, promouvoir la santé et les droits d'une minorité en détresse, Actes du colloque européen, Paris, 19 et 20 octobre 2000, 129p.



Irish Traveller women had given birth to seven or more children, compared with 0.4 % of women generally<sup>295</sup>. There is also a higher level of spontaneous delivery among pregnant Traveller women (37%) than the matched groups. In 2008, a higher level of infant mortality was also registered (+10.8%) compared with infant mortality in the population as a whole. Notably, artificial feeding is higher among Irish Roma women (96%) than the matched population (57%)<sup>296</sup>.

Health Mediation is reported to be an increasingly successful method of supporting Roma health. Roma health mediators are almost exclusively women and provide a key bridge between Roma women and health care systems. They facilitate access to services such as antenatal care and vaccination.

#### **Table 24 Health Mediation in France**

Health mediation between Roma and health care facility representatives is a tool to address the lack of information and barriers to accessing health care. The MdM Roma mission in Nantes and other associations working with Roma in Lille and the Parisian outskirts have participated in a 24-month pilot programme of health mediation<sup>297 298</sup>. This pilot programme has been positively evaluated and has illustrated that health mediation is a useful method for closing the access gap for Roma and the health care system in France.

Mediation professionals speak both Romanian and French but have a larger scope of action than just translation; they are linked to a network of social workers and health care professionals and notify these actors on social factors (housing, living conditions, marginalisation, education) and barriers of access to health institutions. A range of interventions were undertaken to inform Roma and help them understand how to acquire health care, accompany them to surgery and provide health education. The mediators also worked with practitioners and staff of health care facilities in order to increase their awareness of Roma health issues, clarify the barriers to access health care and how to avoid stigmatising this population<sup>299</sup>.

The pilot programme was focused on mother and child health, but families also benefited from the mediators' actions. After the mediators' intervention 86% of Roma women participating in the programme had acquired state medical aid AME (aide médicale d'état)<sup>300</sup>, whereas only 37% had AME at the beginning of the programme. Consequently, there was an increase in the frequency of medical visits per 100 persons, from 22% to 57%. Moreover, Roma women alone accounted for 40% of the visits at the end of the 18-month pilot programme. The mediators' action had thus helped them to achieve autonomy over their health care, although the language

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<sup>295</sup> All Ireland Traveller Health Study (2010) of Technical Report I. Available at: [http://www.dohc.ie/publications/aiths2010/TR1/AITHS2010\\_TechnicalReport1\\_LR\\_All.pdf?direct=1](http://www.dohc.ie/publications/aiths2010/TR1/AITHS2010_TechnicalReport1_LR_All.pdf?direct=1)

<sup>296</sup> All Ireland Traveller Health Study (2010) of Technical Report I. Available at: [http://www.dohc.ie/publications/aiths2010/TR1/AITHS2010\\_TechnicalReport1\\_LR\\_All.pdf?direct=1](http://www.dohc.ie/publications/aiths2010/TR1/AITHS2010_TechnicalReport1_LR_All.pdf?direct=1)

<sup>297</sup> Médecins du Monde (2012), Rapport 2011 de l'Observatoire de l'Accès aux Soins de la Mission France, 215p

<sup>298</sup> ASAV, AREAS, Médecins du Monde, Romeurope, (2012) Projet de Médiation santé en direction de femmes et jeunes enfants Roms, Rapport final, 59p

<sup>299</sup> Ibid

<sup>300</sup> Aide Médicale d'Etat (AME) is a free of charge social health protection granted to legal or illegal immigrants who can justify residence in France for an uninterrupted period of over three months and lack financial resources to pay for health care

barrier and the lack of knowledge of the health care system still constituted a barrier for Roma to access general practitioners<sup>301</sup>.

Several positive impacts were thought to be due to the mediators' action. At the beginning of the programme, 16% of Roma needing health care had not been to a surgery, and at the 18-month evaluation this figure had dropped to just 9%, with other barriers to access health care also reduced, such as lack of AME, fear of being misunderstood by practitioners and transport issues<sup>302</sup>. The mediator was also able to support health institutions to visit the areas where Roma live to promote services such as vaccinations campaigns<sup>303 304 305</sup>.

### **Table 25 Evaluation of Romania's Health Mediation Programme<sup>306</sup>**

A World Health Organization case study report from 2013 provides a critical overview of the Roma health mediation programme in Romania. It looks at the social and political context in which the programme developed, the general characteristics of mediation, as well as the lessons learnt after 10 years of implementation. Health mediation was designed to improve the health status of Roma and their access to health care services. Compared to the general population, Roma have higher infant mortality rates, lower life expectancy at birth and lower rates of childhood immunisation. Roma fare worse than other ethnic groups with respect to the use of health care facilities and are more likely to experience discrimination in the medical system.

The objectives of the programme are to facilitate communication among medical personnel and Roma communities, and to increase the efficacy of public health interventions. Mediators are usually Roma women with an average level of education, who have been recommended by local communities, approved by medical practitioners and who have successfully completed brief training.

The programme's successes include:

- collaboration between government and non-government structures in the planning and implementation of health mediation
- high number of women trained and hired as health mediators
- a high number of beneficiaries
- broad geographical coverage
- transferability of the model to other European countries that have significant Roma populations, such as Bulgaria and the former Yugoslav Republic of Macedonia
- a focus on preventive, instead of curative care

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<sup>301</sup> Ibid

<sup>302</sup> Ibid

<sup>303</sup> Médecins du Monde (2011), Rapport d'enquête sur la couverture vaccinale des populations roms rencontrées par les équipes de Médecins du Monde en France, Rapport de la Direction des Missions France, 22p

<sup>304</sup> Laurence S., Chappuis M, Lucas D, Duteutre M, Corty J-F, Campagne de vaccination rougeole des populations précaires : retour d'expérience, (submitted for publication)

<sup>305</sup> ASAV, AREAS, Médecins du Monde, Romeurope, (2012) Projet de Médiation santé en direction de femmes et jeunes enfants Roms, Rapport final,

<sup>306</sup> Spanish Directorate-General for Public Health Ministry of Health and Consumer Affairs Area of Health and Fundación Secretariado Gitano (2004) Health and the Roma Community Analysis of action proposals. Available at: [http://www.gitanos.org/upload/32/41/1.7-HEA\\_Health\\_and\\_the\\_Roma\\_Community.pdf](http://www.gitanos.org/upload/32/41/1.7-HEA_Health_and_the_Roma_Community.pdf)



- contributions to knowledge pertaining to health among Roma
- assistance provided to some of the most vulnerable categories of Roma, particularly persons lacking identity documents.

Some of the challenges encountered during programme implementation have been insufficient initial training, modest remuneration of mediators, difficult working conditions and changes brought about by the decentralisation of health care. The programme has often been criticized for shortcomings in the supervision of health mediators and the insufficient use of data collected by mediators in the communities. Lack of transparency in programme funding and limited opportunities for continuous training of mediators have also attracted criticism<sup>307</sup>.

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<sup>307</sup> WHO (2013) Roma health mediation in Romania ROMA HEALTH – Case Study Series No. 1. Available at: [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0016/235141/e96931.pdf](http://www.euro.who.int/__data/assets/pdf_file/0016/235141/e96931.pdf)

## Indicator G: Environmental and socio-economic determinants of health

### Key Findings

- European institutions (the FRA and Eurofound) publish the most comprehensive data on environmental and other socio-economic determinants of health.
- The housing situation of Roma families is generally worse than the housing situation of non-Roma citizens, though in a minority of countries some evidence suggested that access to social housing and standards were comparable to the general population (Germany, Lithuania and Sweden).
- The Eurofound study reported that accommodation overcrowding is most severe in Slovakia and Hungary with additional problems such as poor sanitation and segregation.
- Roma usually have a lower level of education than non-Roma. Comparatively low educational attendance (Bulgaria, Greece and Romania) and segregation remain challenges (Estonia and Germany).
- In all Member States that have statistics on Roma employment, unemployment rates of Roma are higher than those of non-Roma. Particularly stark differences between Roma and non-Roma levels of employment have been found in Bulgaria, Croatia, Ireland, Lithuania, and Hungary.

In this section the key environmental and socio-economic factors affecting the health, and by extension; housing, employment and education of Roma are discussed. These factors are inter-related. Low levels of education or (undocumented) migrant situations lead to high rates of unemployment. High levels of poverty lead to poor housing conditions. Furthermore living in segregated areas makes it more difficult for Roma to gain employment and education.

A large amount of data was found to be available for these indicators; however it is not always comparable between Roma and non-Roma. Regarding overall environmental and other socio-economic conditions for Roma, they were, in all cases, poorer than non-Roma, or regarded as notably poor.

A recent and comprehensive Eurofound report<sup>308</sup> outlines the major environmental problems facing Roma including lack of access to forms of sanitation, overcrowding and segregation in cities. These conditions affect both the physical and mental health of those experiencing these conditions.

The UNDP et al survey<sup>309</sup> also provides context and comparable data on Roma living conditions, employment and education. FRA's Raxen studies<sup>310</sup> provide substantial (largely qualitative) data on Roma housing conditions.

In most Member States, the housing situation of Roma families is worse than the housing situation of non-Roma citizens. Only in a few countries was (anecdotal) evidence found that the housing conditions of Roma were comparable to those of the

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<sup>308</sup> Eurofound, Living conditions of the Roma: substandard housing and health, 2012. Available at: <http://www.eurofound.europa.eu/pubdocs/2012/02/en/1/EF1202EN.pdf>

<sup>309</sup> UNDP UNDP-WB-European Commission regional Roma survey 2011

<sup>310</sup> FRANET, [Online], Available: <http://fra.europa.eu/en/research/franet>

rest of the country and included access to social housing (Germany<sup>311</sup>, Lithuania<sup>312</sup> and Sweden<sup>313</sup>).

Roma also face difficulties in accessing social housing; either as migrants they lack documentation (France<sup>314</sup>) or they experience feelings of discrimination (reported in Finland<sup>315</sup>, Lithuania<sup>316</sup> and Luxembourg<sup>317</sup>). In all the main host countries of migrant Roma (Italy, Germany, UK and Finland), the limited access to housing is highlighted as a key concern with further implications for the health status of this group.

**Table 26 Hungarian study: Environmental Survey of Segregated Habitats of Roma in Hungary: A Way to be Empowering and Reliable in Minority Research<sup>318</sup>**

This aim of this 2009 study was to identify 'segregated habitats' of Roma in Hungary and evaluate them according to their development, infrastructure and hygiene levels. The definition of a segregated settlement was given as "separate entities or parts of human settlements consisting of at least four dwelling units distinguishable by lower quality, higher population density and unfavourable environmental conditions compared with other dwelling units of the same or neighbouring settlement." The data collected included the location, number and type of housing unit, type of wall, access to paved roads and public utilities, environmental danger and ethnic minorities within dwellings. Primary research was carried out by a selection of predominantly Roma persons and the habitats were ranked according to a scoring system based on housing conditions with 10 being the worst and 0 the best.

A major finding from the paper was that the 2001 Hungarian Census was believed to significantly underestimate the Roma population because its methods were based on self-determination. In three Hungarian counties, Roma had five times the number of recorded inhabitants in the Kosa et al. study compared to official data. Using Roma to undertake much of the fieldwork helped to reduce suspicion, increase local knowledge and provide more reliability to the study.

Other findings include: 94% of the colonies studied were found to be mostly Roma inhabited; 1.6% of the Hungarian population is said to live in segregated habitats in 19 counties of Hungary; 33% of these live in the Northern Great Plain Region; the

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<sup>311</sup> Bundesministerium des Innern (2011) An EU Framework for national Roma Integration Strategies up to 2020 – Integrated packages of measures to promote the integration and participation of Sinti and Roma in Germany. Available from: [http://ec.europa.eu/justice/discrimination/files/roma\\_germany\\_strategy\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_germany_strategy_en.pdf)

<sup>312</sup> RAXEN (2009), Lithuania National Focal Point Thematic Study Housing Conditions of Roma and Travellers

<sup>313</sup> Sweden RAXEN National Focal Point Thematic Study Housing Conditions of Roma and Travellers. Centre for Equal Opportunities and Opposition to Racism, March 2009

<sup>314</sup> BILAN D'APPLICATION DE LA CIRCULAIRE INTERMINISTERIELLE DU 26 AOÛT 2012 RELATIVE A L'ANTICIPATION ET A L'ACCOMPAGNEMENT DES OPERATIONS D'EVACUATION DES CAMPEMENTS ILLICITES. AOÛT 2012-MAI 2013. Available at <http://www.defenseurdesdroits.fr/sites/default/files/upload/rapport-roms-2013-06-25.pdf>

<sup>315</sup> FRA (2009) Housing conditions of Roma and Travellers – Finland RAXEN National Focal Point – Thematic Study.

<sup>316</sup> <http://ces.lt/en/>

<sup>317</sup> Council of Europe, ECRI Rapport (2012), <http://www.coe.int/t/dghl/monitoring/ecri/country-by-country/luxembourg/LUX-CbC-IV-2012-004-FRE.pdf>

<sup>318</sup> Kósa, K. Daragó, L. Ádány, R. (2009), "Environmental Survey of Segregated Habitats of Roma in Hungary: A Way to be Empowering and Reliable in Minority Research", European Journal of Public Health, Vol. 21, No. 4, pp. 463-8.

northern-most county (Borsod-Abauj-Zemplen) houses 21% of all colony dwellers; in Heves county 4.3% of total population were colony dwellers and 20-26% of the Roma population in Hungary are thought to be 'colony dwelling'.

Source: Kósa, K. Daragó, L. Adány, R. (2009), "Environmental Survey of Segregated Habitats of Roma in Hungary: A Way to be Empowering and Reliable in Minority Research", *European Journal of Public Health*, Vol. 21, No. 4, pp. 463-8

In Germany it is observed that many Roma live in segregated communities in German cities<sup>319</sup>. A report from the Finnish Ministry of Interior finds the same to be the case in Finland<sup>320</sup>. However, the report also found that Roma preferred to be integrated into society, and saw authorities' attempts to house many Roma in the same neighbourhood as discriminatory and problematic<sup>321</sup>.

According to the Eurofound study<sup>322</sup>, overcrowding is most severe in Slovakia and Hungary. Roma live on average with two persons per room. According to a UNDP survey<sup>323</sup> in 2004, Roma in Bulgaria live in 0.76 rooms per household member, compared to 1.58 rooms per household member of non-Roma. The average size of housing units was 34m<sup>2</sup> in Bulgaria, while Roma live in housing units of 15m<sup>2</sup>. Overcrowding is a known risk factor for the spread of infectious diseases<sup>324</sup>.

#### Table 27 Living conditions in Belgium

A main source of data for housing is the 2009 study commissioned by the Fundamental Rights Agency – the Raxen National Focal Point for Belgium<sup>325</sup>. This study undertook a thorough assessment of the housing situation of both Roma and Travellers. Two main issues arose:

**Travellers:** A significant lack of encampment sites and related access to basic facilities. According to the report, there were 416 residential lots spread out over 28 official encampment sites in Flanders and Brussels. Despite regional plans to increase this number, the number of halting sites per family actually decreased in Flanders from 2003 to 2007<sup>326</sup>. In the Walloon Region only one camp has been created. The alternative to public accommodation is private encampments. However they reportedly lacked sufficient water and sanitation facilities. Other alternatives include renting or purchasing a caravan plot, yet Travellers often faced legal difficulties and discrimination when trying to rent or purchase. With the exception of Flanders, caravans are not considered proper dwellings by regional housing laws. In Wallonia and Brussels, building permits are still needed in order to permanently settle caravans. Hence, Travellers are very dependent on the regional authorities.

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<sup>319</sup> European Parliament (2011) Measures to promote the situation of Roma EU citizens in the European Union - Study. Available from:

<http://www.europarl.europa.eu/committees/en/libe/studiesdownload.html?languageDocument=EN&file=34328>

<sup>320</sup> Carrasco-Garrido, P. et al. (2007) Health profiles, lifestyles and use of health resources by the immigrants population resident in Spain. *European Journal of Public Health*. 17:5, 503-507

<sup>321</sup> Carrasco-Garrido, P. et al. (2007) Health profiles, lifestyles and use of health resources by the immigrants population resident in Spain. *European Journal of Public Health*. 17:5, 503-507

<sup>322</sup> Eurofound, Living conditions of the Roma: substandard housing and health, 2012

<sup>323</sup> UNDP (2004) Faces of Poverty, Faces of Hope, p. 16, in: FRA (2009), Housing conditions of Roma and travellers in the European Union, comparative report, p.72

<sup>324</sup> 'Removing obstacles to healthy development' Report on Infectious Diseases WHO, 1999

<sup>325</sup> Belgium RAXEN National Focal Point Thematic Study Housing Conditions of Roma and Travellers Belgian NFP Centre for Equal Opportunities and Opposition to Racism, March 2009

<sup>326</sup> Ibid

According to the report, less than half of the Travelling families have access to the existing encampment facilities, leaving a significant proportion to live on illegal sites<sup>327</sup>. Yet many Travellers are Belgian citizens<sup>328</sup>.

**Roma:** Belgian Roma tend to be sedentary and live in urban neighbourhoods. Housing conditions are generally poor, which impact on their physical and mental health. Moreover, Roma often live side by side with other immigrant communities and tensions between different communities can arise. Roma are often in a weaker position with respect to other groups, and their relocations and displacements can make it difficult to maintain social links which are a lifeline for Roma<sup>329</sup>.

Roma usually have a lower level of education than non-Roma. Roma women usually have a lower level of education than Roma men. According to FRA<sup>330</sup>, on average only one out of two Roma children attend pre-school or kindergarten. Although a large percentage (90%) of Roma children between 7 and 15 years are reported to be in school<sup>331</sup> (except for Bulgaria, Greece and Romania), poor school attendance and high dropout rates were reported in this study. These are more pressing problems among Roma than the number of school enrolments (i.e. Bulgaria, Cyprus, and Lithuania).

Findings from our study also include reports of educational segregation (Estonia<sup>332</sup> and Germany<sup>333</sup>).

#### **Table 28 Education Germany**

Reports from NGOs working with Roma and Sinti in Germany have recorded a high school dropout rate at the primary school level. The report stated that in some cases almost 50% of all school age Roma and Sinti children do not finish primary school. The majority of those who go to school attend "special schools". Girls are more likely to drop out than boys, as they marry early and have subsequent obligations within the family as wife, mother and homemaker. Attaining education more difficult for girls with travelling parents<sup>334</sup>.

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<sup>327</sup> Ibid

<sup>328</sup> Centre pour l'Égalité des Chances et la Lutte contre le Racisme (CECLR) (2008), *Demandeurs d'asile, réfugiés et apatrides en Belgique: un essai de démographie des populations demandeuses ou bénéficiaires d'une protection internationale*, Bruxelles

<sup>329</sup> Ramón Peña-Casas, Dalila Ghailani and Ides Nicaise (with the assistance of Eva Zemandl) *Promoting the Social Inclusion of Roma A Study of National Policies: Belgium*, July 2011

<sup>330</sup> European Union Agency for Fundamental Rights, 2012 UNDP, 2012 *The situation of Roma in 11 EU Member States Survey results at a glance*. Luxembourg: Publications Office of the European Union, 2012, p. 16

<sup>331</sup> Ibid

<sup>332</sup> Immigration and Refugee Board of Canada (2011) *Estonia/European Union: Migration of Roma throughout the European Union; whether Roma individuals can relocate to Estonia and seek employment; treatment of Roma individuals who relocate and then live in Estonia (2009-January 2011)*. Available from: <http://www.refworld.org/docid/4dd225842.html> [Accessed: 17/06/2013]

<sup>333</sup> Open Society Institute (2004) *Joint EU Monitoring and advocacy program/European Roma rights center shadow report*. Available from: [http://www.opensocietyfoundations.org/sites/default/files/roma\\_shadow\\_20040121.pdf](http://www.opensocietyfoundations.org/sites/default/files/roma_shadow_20040121.pdf)

<sup>334</sup> Open Society Institute (2004) *Joint EU Monitoring and advocacy program/European Roma rights center shadow report*. Available from: [http://www.opensocietyfoundations.org/sites/default/files/roma\\_shadow\\_20040121.pdf](http://www.opensocietyfoundations.org/sites/default/files/roma_shadow_20040121.pdf)

A qualitative study about the educational situation of German Roma and Sinti reported several interesting findings. There is a common understanding that German Roma and Sinti often have lower educational attainment than the majority population. The study gives some insight into the barriers faced by Roma and Sinti in attaining formal (higher) education. Firstly, it confirms the lack of ambition or incentive for formal education and secondly highlights intra-familial circumstances, as well as institutional and social conditions that act as barriers to the attainment of (higher) education. Low parental education and trauma caused by prosecution under National Socialism influence the relationship with school as an institution. There is little evidence of self-education<sup>335</sup>.

Girls are more likely to drop out than boys due to early marriage as discussed above. Girls with travelling parents in particular have problems in attaining an education (reported in Germany<sup>336</sup> and Latvia<sup>337</sup>).

Several reasons were reported for the low level of education amongst Roma. Language barriers are one reason cited for low school enrolment or attendance (Poland<sup>338</sup>, France<sup>339</sup>). In the Czech Republic, cultural values of Roma are reported to impact on engagement in education. Education is not seen as a priority, and therefore children might not be motivated by their parents to go to school (Czech Republic<sup>340</sup>). In Germany, research highlights the lack of trust among Roma in formal institutions as a barrier to engagement in education<sup>341</sup>. In France however, anecdotal evidence suggests that Roma children are refused at schools, on grounds that they lack vaccination records and could therefore pose a risk to the health of other children<sup>342</sup>. In Cyprus anecdotal evidence suggests that teachers have insufficient understanding of Roma cultural practices, beliefs and attitudes towards schooling, making the integration of Roma students more difficult<sup>343</sup>.

In all Member States that have statistics on Roma employment, unemployment rates of Roma are higher than non-Roma. For instance, in Bulgaria 40% of Roma are unemployed compared to 20% of non-Roma<sup>344</sup>. In Ireland up to 84% of Roma are

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<sup>335</sup> Daniel Strauss (Ed) (2012) Study of the current educational situation of German Sinti and Roma – Documentation and research report. Available from: [http://www.stiftung-evz.de/fileadmin/user\\_upload/EVZ\\_Uploads/Handlungsfelder/Handeln\\_fuer\\_Menschenrechte/Sinti\\_und\\_Roma/engl-studie.pdf](http://www.stiftung-evz.de/fileadmin/user_upload/EVZ_Uploads/Handlungsfelder/Handeln_fuer_Menschenrechte/Sinti_und_Roma/engl-studie.pdf)

<sup>336</sup> Ibid

<sup>337</sup> European Commission against Racism and Intolerance, report on Latvia - fourth monitoring cycle. (2012)

<sup>338</sup> Poland National Roma Integration Strategy, Annex 6.

<sup>339</sup> ASAV, AREAS, Médecins du Monde, Romeurope, (2012) Projet de Médiation santé en direction de femmes et jeunes enfants Roms, Rapport final, 59p

<sup>340</sup> Davidova E. a kol. Kvalita života a sociální determinanty zdraví u Romů v České a Slovenské republice( The Quality of Life from the Aspect of Health Determinants in the Roma in the Czech and Slovak Republics", TRITON, 2010

<sup>341</sup> Daniel Strauss (Ed) (2012) Study of the current educational situation of German Sinti and Roma – Documentation and research report. Available from: [http://www.stiftung-evz.de/fileadmin/user\\_upload/VZ\\_Uploads/Handlungsfelder/Handeln\\_fuer\\_Menschenrechte/Sinti\\_und\\_Roma/engl-studie.pdf](http://www.stiftung-evz.de/fileadmin/user_upload/VZ_Uploads/Handlungsfelder/Handeln_fuer_Menschenrechte/Sinti_und_Roma/engl-studie.pdf)

<sup>342</sup> Médecins du Monde (2007), Les Roms que l'Europe laisse à la porte, 30p.

<sup>343</sup> Theodorou, E. and Symeou, L. (2013): Experiencing the same but differently: indigenous minority and immigrant children's experiences in Cyprus, British Journal of Sociology of Education, 34:3, 354 -372

<sup>344</sup> UNDP UNDP-WB-European Commission regional Roma survey 2011



unemployed<sup>345</sup>. In Lithuania, 57% were unemployed<sup>346</sup>. In Croatia only 14% of Roma are employed, while 49% of non-Roma are employed<sup>347</sup>. In Hungary only 20% of Roma are employed, compared to 55% of non-Roma<sup>348</sup>.

In some Member States, research indicates that if Roma are employed, they are more often self-employed or employed part-time (Austria<sup>349</sup> and Portugal<sup>350</sup>). For example, in Portugal, almost half of Roma that are counted as actively employed are self-employed.<sup>351</sup>

As a consequence of these high unemployment rates, many Roma live in poverty<sup>352</sup>. Member States indicated that Roma have higher poverty rates than non-Roma. Reasons that were reported for these high unemployment rates are language difficulties, poor education levels and cultural differences.

Citizens from Bulgaria and Romania face similar challenges in Germany and France, as their access to the labour market is limited until the end of 2013<sup>353</sup>. They need a work permit to be hired which means that the majority are self-employed or work as 'day jobbers' in the clandestine labour market. They are by and large considered job seekers and thus excluded from ordinary healthcare services. Private insurance is an option but often unaffordable<sup>354</sup>.

#### **Table 29 FRA Report – Analysis of FRA Roma survey results by gender<sup>355</sup>**

This research, published in September 2013, provides an analysis of data collected through the FRA's Roma Survey (covering BG, CZ, FR, GR, HU, IT, PO, PT, RO, SK, and ES) broken down by gender and covering the core areas of employment, education, housing and health, as well as other gender-sensitive policy areas.

##### Education

Regarding education, the FRA reported lower levels of literacy and school attendance for Roma women compared to Roma men and the general population. Across the 11 countries 77% of Roma women (16+) declared the ability to read and write; significantly less than the 85% of Roma men and 99% of non-Roma.

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<sup>345</sup> Central Statistics Office, Information Section, Profile Central Statistics Office, Information Section (2011) Profile 7: Religion, Ethnicity and Irish Travellers.

<sup>346</sup> UNDP UNDP-WB-European Commission regional Roma survey 2011

<sup>347</sup> Ibid

<sup>348</sup> Ibid

<sup>349</sup> Austria, Riesenfelder, A., Schelepa, S. und Wetzels, P. (2011), Beschäftigungssituation von Personen mit Migrationshintergrund in Wien – Endbericht, Study commissioned by the Chamber of Labour, NGO/social: 99 telephone interviews with male and female Roma. Available at: [www.arbeiterkammer.at/bilder/d164/Studie\\_MigrantInnen\\_2012.pdf](http://www.arbeiterkammer.at/bilder/d164/Studie_MigrantInnen_2012.pdf)

<sup>350</sup> Health and the Roma Community: analysis of the situation in Europe

<sup>351</sup> ibid

<sup>352</sup> European Union Agency for Fundamental Rights, 2012 UNDP, 2012 The situation of Roma in 11 EU Member States Survey results at a glance. Luxembourg: Publications Office of the European Union, 2012, p.25

<sup>353</sup> Germany, Federal Ministry of Labour and Social Affairs (2013b), Halfen, S. (2012) Situation sanitaire et sociale des « Roms migrants » en Île-de-France, Rapport de l'Observatoire régional de santé d'Île-de-France p. 19

<sup>354</sup> Amnesty International (2013), « Facts of shame. Discrimination, forced evictions, segregation and violence against Roma in the European Union », Public Statement, 04.04.2013, AI Index: 01/008/2013,

<sup>355</sup> FRA for the European Parliament Analysis of FRA Roma survey results by gender, 2013. Available at: <http://fra.europa.eu/en/publication/2013/analysis-fra-roma-survey-results-gender>



This is most clearly demonstrated in Greece, where only 43% of Roma women can read and write compared to 55% of Roma men, and Portugal, where a 22% difference separates Roma women and men (55% compared to 77%). Inequalities are also seen in school attendance as 19% of Roma women have never attended school compared to 14% of Roma men and only 2% of non-Roma. The starkest responses are from Greece and Portugal where differences of 11% and 19% respectively separate Roma women and men. Results are, however, more promising in Roma aged 16-24 with 89% of women and men literate. Alongside this, more equal numbers are seen across Europe with 8 of 11 countries now declaring equal or more positive results regarding literacy in Roma women compared to men. These results are also reflected in school attendance as only 9% and 7% of Roma women and men respectively declared never attending school.

#### Employment

The FRA found that only 21% of Roma women (16+) were in paid work compared with 35% of Roma men. In this self-declared survey, 33% of Roma women registered as unemployed and 24% stated their main activity as taking care of the home. Roma women in France, Greece, Italy, Portugal, Romania and Spain take on a more traditional role with a higher likelihood of being full-time housekeepers than Roma men. In these countries the labour participation of Roma men is also markedly higher than that of Roma women. In central European countries (the Czech Republic, Hungary and Slovakia), however, Roma women have an equal or better rate of labour market participation than Roma men. A good example is in Hungary where 32% of Roma women are in paid work compared with 26% of Roma men.

#### Housing

The FRA report also surveyed the housing conditions of Roma across Europe. On the whole it found that many Roma households encounter severe deprivation with inadequate access to piped water, sewage or electricity. This is most aptly demonstrated by the fact that 42% of Roma respondents, compared with 12% of non-Roma respondents, declared no access to at least one of these fundamental amenities. More specifically, 84% of Roma households in Romania lived in deprived housing, the greatest difference being in France where a 70% gap exists between Roma and non-Roma respondents and 8 of the 11 represented countries demonstrated differences of more than 25% (Romania, France, Slovakia, Hungary, Bulgaria, Italy, Greece and Portugal).

#### Financial Situation

The financial situation has also been covered and disaggregated by gender in the FRA report. Roma households have are at a more substantial risk of poverty compared with their non-Roma equivalents. This survey states that 87% of Roma households have a disposable income lower than the national at-risk-of-poverty level compared to 46% of non-Roma households. It also demonstrates that larger households are more at risk with up to 100% of Roma in families with 4 or more children at-risk-of-poverty. Interestingly the employment status of women was shown to affect the at-risk-of-poverty with families containing an employed woman less at risk. There are also differences between Roma women, Roma men and non-Roma (45+) regarding entitlement to benefits. The data presented states that in both Roma and non-Roma there is a gender gap – 5% and 6% higher receipt or expectation of a pension for men respectively. This is at its greatest in Spain where 23% fewer Roma women are entitled to receive a pension than Roma men. The non-Roma population also state a higher expectation of receipt of a pension than the Roma population (13% less for Roma compared to non-Roma).

Perceptions of Discrimination and Rights Awareness

On average, more Roma men felt discriminated against while looking for a job compared with Roma women (27% vs. 22%) and there are notable differences between EU Member States; for example only 13% of Romanian women stated that they felt discriminated against while looking for work compared with over 30% of Czech, Greek and Italian Roma women. Concerning Roma rights on discrimination, 35% of Roma women and 45% of Roma men declared knowledge of anti-discrimination laws. Awareness within the non-Roma population is only slightly higher at 47% for women and 51% for men.

## Country Findings

The country summaries below outline the main findings for each of the 11 Member States which were the particular focus of this study, and a thematic analysis of the remaining 20 countries follows.

Two challenges exist when drawing conclusions from the available data. Firstly, the heterogeneity of Roma communities within and between Member States means that overarching conclusions can only be high level. Secondly, where data are collected from small sample studies, they frequently target the most marginalised of Roma communities, which may not be reflective of the health status of all Roma within a particular country. However, there are still clear themes, which are discussed in more detail in the analysis of specific indicators (see the above section).

EU wide efforts are already in place with the Health Programme and through the use of Structural Funds. These are initiatives with gravitas and which are large enough to operate efficiently and systematically. The study's country profiles report on data from such initiatives.

It also appears that national efforts on Roma inclusion have focused on actions on education and employment policies (social determinants of health) rather than health policies per se. Several country report findings including Latvia and Poland point to this fact. Again, this policy push may well stem from EU efforts as programmes have been identified around the time of the A8 and A2<sup>356</sup>.

The following paragraphs outline country specific findings in the 11 Member States and a thematic analysis of the remaining 20 country profiles.

### Bulgaria

#### Availability of health status data

There is no information on disaggregated official data. Health status data is most typically available from non-national government sources; particularly from international organisations. These sources provide much data on socio-economic determinants of health, healthy lifestyles and health-related behaviours. There are data available on prevalence of major diseases, self-assessment of health and access and barriers to healthcare. Specific data gaps include prevalence data for HIV, Hepatitis A, B and C, and estimates of life expectancy, antenatal care and cancer screening. Expert assessment indicates an underestimate of the Roma population in official census data<sup>357</sup>.

#### Health Status

The Roma population in Bulgaria is comparatively younger than the non-Roma population<sup>358</sup>. While life expectancy data are not available, the demographic profile indicates lower life expectancy for Roma compared to non Roma. Only 2.7% of Roma are aged 65 and over compared to 16.1% in the general population<sup>359</sup>. One study

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<sup>356</sup> Accession of the EU8 in 2004 and EU2 in 2007

<sup>357</sup> Ilona Tomova, "The Health Status of Roma in Europe. National Report on Bulgaria", 2009, Foundation "The health of romany people", Silven, Bulgaria

<sup>358</sup> National Statistics Institute, Census 2011, Final Results

<sup>359</sup> Ilona Tomova, "The Health Status of Roma in Europe"

(2003) estimated infant mortality to be three times higher in the Roma population than the general population<sup>360</sup>.

In a recent measles outbreak, Roma were overrepresented in the population affected<sup>361</sup>. Qualitative research indicates frequent outbreaks of Hepatitis A, B and C in geographically segregated Roma communities<sup>362</sup>. The severity of outbreaks is worse because of poor housing conditions and cultural norms which promote empathy visits to the sick. Vaccination rates are low, and 15% of Roma children are without mandatory vaccinations<sup>363</sup> compared to fewer than 10% of the general population<sup>364</sup>.

The Roma in Bulgaria are more likely than the general population to be at risk of poor nutrition; more likely to go to bed hungry<sup>365</sup> and their diet is typically of lower nutritional value<sup>366</sup>. Data on tobacco and alcohol consumption show purchase rates similar to the general population, Tobacco consumption is also similar to the non-Roma population<sup>367</sup>. Data indicate low physical activity levels and limited access to sports facilities and open spaces for recreation<sup>368</sup>. Cultural norms do not promote participation in sport or fitness activities<sup>369</sup>.

Roma in Bulgaria have low rates of health insurance (45-48% compared to 85% in the general population<sup>370</sup>). Roma typically live further from health facilities than the general population, perhaps due to the existence of segregated Roma neighbourhoods<sup>371</sup>. When using health and social services, approximately two in five experience discrimination from professionals<sup>372</sup>. Roma tend to participate in health check-ups less frequently than the general population but are more likely to undergo scans and X-rays<sup>373</sup>. The Roma population is three times more likely to not have access to essential drugs than the non-Roma population<sup>374</sup>, and is more likely to self-prescribe medication<sup>375</sup>. Young Roma women are more likely to access preventive gynaecological care than older Roma women<sup>376</sup>. Roma women living in rural

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<sup>360</sup> Council of Ministers of Republic of Bulgaria, "National Roma Integration Strategy of the Republic of Bulgaria (2012-2020)", 2012, Sofia, Bulgaria.

<sup>361</sup> Mira Kojouharova, NCIPD, Bulgaria, "Measles outbreak in Bulgaria, 2009-2010", 2010, National Center of Infectious and Parasitic Diseases, Bulgaria.

<sup>362</sup> Ilona Tomova, "The Health Status of Roma in Europe"

<sup>363</sup> Council of Ministers of Republic of Bulgaria, "National Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities", 2005, Sofia, Bulgaria

<sup>364</sup> Unicef, WHO, "Immunization Summary: A Statistical Reference containing data through 2010"

<sup>365</sup> FRA, UNDP, European Commission, The situation of Roma in 11 EU Member States – Survey results at a glance (2012), Luxembourg, Publications Office, p. 8. Available at [http://fra.europa.eu/sites/default/files/fra\\_uploads/2099-FRA-2012-Roma-at-a-glance\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/2099-FRA-2012-Roma-at-a-glance_EN.pdf)

<sup>366</sup> Ilona Tomova, "The Health Status of Roma in Europe"

<sup>367</sup> Prevalence surveys show 52% of Roma aged 30-44 smoking on a daily basis, equivalent to the non-Roma population as reported in Eurostat data. See Fundación Secretariado Gitano, "Health and the Roma Community, analysis of the situation in Europe- Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain 2009, FSG, Madrid, Spain. For general population data see Eurostat Daily smokers by number of cigarettes by sex, age and educational level (%) - collection round 2008

<sup>368</sup> Ilona Tomova, "The Health Status of Roma in Europe"

<sup>369</sup> Eurofound, Living Conditions of the Roma: Substandard housing and health, 2012, Dublin.

<sup>370</sup> UNDP/WB/EC, FRA, UNDP/WB/EC Regional Survey 2011 and FRA Pilot Survey 2011, 2011.

<sup>371</sup> Eurofound, Living Conditions of the Roma: Substandard housing and health, 2012, Dublin

<sup>372</sup> FRA, European Union Minorities and Discrimination Survey, 2009

<sup>373</sup> Ibid

<sup>374</sup> Ibid

<sup>375</sup> Fundación Secretariado Gitano, "Health and the Roma Community, analysis of the situation in Europe" (Ibid)

<sup>376</sup> Eurofound, Living Conditions of the Roma: Substandard Housing and Health, 2012, Dublin

communities are less likely to have mammography than those living in the capital.<sup>377</sup> Almost 60% of women do not use any contraceptives, though this is more likely due to cultural norms than problems with access to services<sup>378</sup>. Roma are more likely than the general population to make a positive self-assessment of their own health status<sup>379</sup>. This assessment could be due to a lack of awareness of health problems because of infrequent visits to health services, or cultural norms regarding perceptions of 'good' health<sup>380</sup>. 70% of Roma aged 65 and over experience one or more serious chronic disease or disability, although diagnoses of common conditions (e.g. high cholesterol, high blood pressure, asthma and chronic bronchitis) are lower than or similar to the general population<sup>381</sup>.

With regards to education, Roma have higher early dropout rates and lower rates of school attendance<sup>382</sup>. Poor educational attainment and functional illiteracy contribute to exclusion from the labour market. Unemployment rates amongst Roma are twice as high as the general population<sup>383</sup> and 1 in 3 report discrimination at job interviews<sup>384</sup>.

Roma populations are at greater risk of living in poverty and more than 4 in 5 (82%) live in households with severe material deprivation, compared to just under 2 in 5 (37%) of the non-Roma population<sup>385</sup>. On average the Roma population live in households with fewer square metres per household member and 25% of the Roma population lives in sub-standard housing. Forty per cent lack access to a water supply and 80% do not have an inside bathroom<sup>386</sup>.

## Croatia

### Availability of Health Status Data

The Croatian National Institute of Public Health and the Croatian Institute of Health Insurance are the two main institutions responsible for conducting statistical research on health. Neither body collects ethnically disaggregated data on health conditions or the accessibility of health services. There is limited scientific research in this area. Data in this report are drawn from articles focusing on a small sample and work done by UNDP and FRA. According to the Council of Europe, the official census data underestimates the total Roma population<sup>387</sup>.

### Health Status

The Roma population in Croatia is comparatively younger than the general population<sup>388</sup>. The average life expectancy of Roma is approximately 10 years less

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<sup>377</sup> Ibid

<sup>378</sup> Krumova, T., M. Ilieva, "The health status of Romani Women in Bulgaria", 2008, ASTARTA, Veliko Turnovo, Bulgaria, and Fundación Secretariado Gitano

<sup>379</sup> UNDP/WB/EC, FRA

<sup>380</sup> Eurofound, Living Conditions of the Roma

<sup>381</sup> Fundación Secretariado Gitano

<sup>382</sup> Council of Ministers of Republic of Bulgaria

<sup>383</sup> UNDP/WB/EC, FRA

<sup>384</sup> Tarnovschi, D.(ed.) "Roma from Romania, Bulgaria, Italy and Spain- A comparative Study", 2012, Soros Foundation, Romania

<sup>385</sup> UNDP/WB/EC, FRA

<sup>386</sup> Council of Ministers of Republic of Bulgaria

<sup>387</sup> UNDP, "At Risk: Roma and the Displaced in Southeast Europe" 2006

<sup>388</sup> 55% of the Roma population are under 19, compared to 18% of the general population aged under 14. Only 3% of the Roma population is over 60, compared to 20% of the general population. Roma population data sourced from: Office for Human Rights and Rights of National

than the general population (66.6 compared to 77)<sup>389</sup>. There are some estimates of a higher infant mortality rate amongst Roma than the general population<sup>390</sup>, with Roma infants more likely to die outside of medical institutions and without medical treatment<sup>391</sup>.

There is no data on prevalence of major infectious diseases, but a high perceived vaccination rate is reported, with 97% of Roma infants (0-6) vaccinated, compared to 99% in the general population<sup>392</sup>.

The Roma population in Croatia is more likely to smoke than the non-Roma population (64% Roma & 31% non-Roma). Roma are also more likely to be at risk of malnutrition (38% Roma & 5% non-Roma)<sup>393</sup>.

Various data sources indicate that Roma have lower levels of health insurance than the non-Roma population<sup>394</sup>. Roma are more likely to struggle to afford medicines and have less access to essential prescription drugs<sup>395</sup> and are more likely to express dissatisfaction with the health services they receive<sup>396</sup>. Roma are more likely than non-Roma to have visited a hospital<sup>397</sup>. Data indicate a lower incidence of specific medical check-ups (dental, x-ray, cholesterol tests and heart check-ups). Older Roma women are less likely than their non-Roma counterparts to undergo testing for cervical screening, while younger Roma women are more likely to use these services than non-Roma of a similar age<sup>398</sup>. Roma are more likely than the general population to have a positive self-assessment of their own health status<sup>399</sup>.

There is limited data on the prevalence of major diseases among Roma. One regional survey on prevalence of hypertension found lower prevalence than the general population<sup>400</sup>.

Roma are less likely to be enrolled in school than non-Roma, less likely to have completed either primary or secondary education, and more likely to have no formal education<sup>401</sup>. Literacy rates are lower amongst Roma than non-Roma.<sup>402</sup> There are significant gender differences and male Roma are more likely than female Roma to have formal education and be literate<sup>403</sup>. Roma are more likely than non-Roma to be unemployed, and male Roma are more likely than female Roma to be in employment<sup>404</sup>.

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Minorities, Croatia, NACIONALNA STRATEGIJA ZA UKLJUČIVANJE ROMA, ZA RAZDOBLJE OD 2013. DO 2020.GODINE/ National Strategy for Roma Inclusion for 2013-2020, 2012. General population data sourced from World Population Ageing 1950-2050, Population Division, DESA, United Nations

<sup>389</sup> Office for Human Rights and Rights of National Minorities, Ibid

<sup>390</sup> Ibid

<sup>391</sup> Ibid

<sup>392</sup> UNDP/WB/EC, FRA (ibid)

<sup>393</sup> Ibid.

<sup>394</sup> Ibid.

<sup>395</sup> Ibid.

<sup>396</sup> Ibid

<sup>397</sup> Ibid

<sup>398</sup> Ibid

<sup>399</sup> Ibid

<sup>400</sup> H. Zeljko et al.: Traditional CVD Risk Factors and SES in Roma, Coll. Antropoi. 32 (2008) 3: 667-676

<sup>401</sup> UNDP/WB/EC, FRA (ibid)

<sup>402</sup> Ibid

<sup>403</sup> Ibid

<sup>404</sup> Ibid

Both absolute and relative poverty indicators show the Roma population are more likely to be living in poverty than non-Roma and be at much greater risk of severe material deprivation. The Roma population is less likely to have access to secure housing, water, sanitation, or electricity and have fewer rooms per household member than the non-Roma population.

## The Czech Republic

### Availability of Health Status Data

Official statistics and data on Roma are unavailable after 1990, apart from the Census, due to the removal of Roma-specific questions on the basis of human rights and personal data protection rules. Existing evidence on Roma is based on estimates on pre-1990 data, internal monitoring of Roma communities, government reports (produced since 2003), academic studies, NGO observations and regional studies and surveys conducted by international organisations. Health records generally do not form a part of collected information on Roma. Data gaps exist especially for mortality, life expectancy, disease prevalence, employment, comparative analyses and in understanding the determinants of differences between ethnic groups.

### Health Status

Data indicate that life expectancy for Roma is approximately 10-15 years less than for the non-Roma population, and this gap is greater for women than men<sup>405 406</sup>. The most recent data for infant mortality is from 1985.

There is no difference in disease occurrence between Roma and general population for diseases with mandatory vaccination (measles, mumps and pertussis). There is a much higher prevalence of hepatitis A in Roma than in the general population. Vaccination for nine diseases is mandatory and is free of charge for some people. However vaccination for Hepatitis A is neither obligatory nor free, although it is administered locally during outbreaks. There is no exact data about vaccination coverage of Roma, but it is probably comparable to the general population.<sup>407</sup> While Prevalence of TB amongst Roma is approximately ten times higher than the non-Roma population<sup>408</sup>, self-reported incidence/prevalence of headache, depression and other mental illness, stomach ulcer, CHD, respiratory problems and diabetes are higher than the general population. Self-reported rates of hypertension, arthritis, allergies and cancer are lower than the general population<sup>409 410 411</sup>. However, Roma and non-Roma data are from different time points.

The Roma population typically have a poor diet, with less than the recommended daily intake of vegetables, fruit and dairy products, and above recommended intake of

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<sup>405</sup> Czech Statistical Office

<sup>406</sup> Davidova E. a kol. Kvalita života a sociální determinanty zdraví u Romů v České a Slovenské republice (The Quality of Life from the Aspect of Health Determinants in the Roma in the Czech and Slovak Republics", TRITON, 2010

<sup>407</sup> Hana Orliková et al, Vaccine preventable infectious diseases in Roma population and in other ethnic minorities in the Czech Republic. Data from 2011/2012

<sup>408</sup> Nesvadbová, L., et al.: Romská populace a zdraví, Česká republika - Národní zpráva 2009 (Roma population and health, the Czech Republic, National report 2009

<sup>409</sup> Ibid.

<sup>410</sup> Nesvadbová a kol. Determinanty zdraví romské populace v České republice 1999-2001. (Health Determinants of the Romany Population in the Czech Republic 1999-2001). Praktický lékař, 8/3, 2003,3, 139-145

<sup>411</sup> EHIS, European Health Information Survey, 2008



meat, sweets and processed food<sup>412 413</sup>. Few Roma engage in regular physical activity or sport.<sup>414</sup> Roma are as likely as the non-Roma population to be overweight or obese.<sup>415</sup> Prevalence of smoking is higher in the Roma population than non-Roma but levels of alcohol consumption are lower, as is consumption of illicit drugs. However, the number of young Roma with addictions to illicit drugs is increasing<sup>416 417 418 419 420 421</sup>.

Roma report more obstacles accessing health care, although they use health services more frequently than the non-Roma population<sup>422 423</sup>. Visits to specialists and dentists are less frequent for Roma than non-Roma<sup>424</sup>. 42% of Roma women were invited to or received information about preventive screening for breast cancer, and 28% of Roma women were recommended cervical smear testing. One in ten Roma women report taking a form of contraception and 80% of women report visiting their doctor regularly from the beginning of pregnancy. 58% of women visit a gynaecologist every year<sup>425</sup>.

Education in the Czech Republic is mandatory to the age of 15. Only 15% of Roma women have completed more than lower secondary education. 27% of Roma men have completed upper secondary or higher education. 95% of the non-Roma population has finished upper secondary education<sup>426</sup>. Only 30% of Roma children aged 4-7 attend kindergarten or other pre-school facilities compared to 80% of the non-Roma population. There is no official data for levels of employment amongst the Roma population, but surveys estimate between 70-100% of Roma are unemployed in some excluded areas<sup>427</sup>. Social benefits, child benefits and disability benefits are often the main source of income<sup>428</sup>. Seventy per cent of Roma live in households with severe material deprivation compared to 21% of non-Roma<sup>429</sup>. 81% of the Roma population is at risk of poverty compared to 38% of the non-Roma population<sup>430</sup>. The

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<sup>412</sup> Brázdrová Z. a kol: jednotkové porce potravinových skupin jako nástroj hodnocení výživové spotřeby romských dětí. ( Serving Equivalents of Food Groups as a tool for Evaluation of Food consumption of Romany Children). *Hygiena*,43,1998, No4,p.195-206

<sup>413</sup> Lexová,P.a kol. Zdravotní stav skupiny romských dětí a možnosti intervence (Health Status of a Group of Gypsy Children and Possible Intervention), *Česko-slovenská hygiena*, 38,1993,4,210-213

<sup>414</sup> Davidova, E (Ibid)

<sup>415</sup> Ibid

<sup>416</sup> Nesvadbová, L.,et al 2009 (ibid)

<sup>417</sup> Davidova, E. (Ibid)

<sup>418</sup> Zurovcová, H. Romové v České Republice, občanské sdružení Vzájemné soužití, Ostrava, 2010, zpráva ( Roma in the Czech Republic, Report of NGO Vzájemné soužití, personal archive

<sup>419</sup> Nesvadbová a kol. Determinanty zdraví romské populace v České republice 1999-2001. (Health Determinants of the Romany Population in the Czech Republic 1999-2001). *Praktický lékař*, 8/3, 2003,3, 139-145

<sup>420</sup> EHIS, European Health Information Survey, 2008, USIS.

<sup>421</sup> DROM: Zdraví versus sociální vyloučení (Health versus social exclusion). Report from the website of NGO DROM, 2012 [www.drom.cz](http://www.drom.cz)

<sup>422</sup> Nesvadbová, L.,et al 2009 (ibid)

<sup>423</sup> Davidova, E. (Ibid)

<sup>424</sup> Devaux M. and M.de Looper: Income-Related Inequalities in Health Service Utilisation in 19 OECD Countries. 2008-2009, OECD Health Working Pápera No 58, OECD Publishing,

<sup>425</sup> Nesvadbová, L.,et al 2009 (ibid)

<sup>426</sup> Davidova, E. (Ibid)

<sup>427</sup> Zurovcová, H et al (Ibid)

<sup>428</sup> Úřad Vlády ČR: Zpráva o stavu Romské komunity, 2011 (The Governmental Office: Annual Report on Health situation of the Roma community,2011)

<sup>429</sup> FRA: The Situation of Roma in 11 Member States, Publication Office of the EU, 2012

<sup>430</sup> Ibid.

Roma population tends to live on the outskirts of towns and villages<sup>431</sup>. 15% of Roma live in households without at least one of the basic amenities; indoor kitchen, toilet, shower, bath or electricity. This compares to 3% of the non-Roma population.

## France

### Availability of Health Status Data

Data disaggregated by ethnicity is not collected in France. Data used in this study is largely based on the data of Médecins du Monde (MdM), findings from FRA research and a few other studies.

### Health Status

The research team was unable to find data on the demographic profile, life expectancy or infant mortality rates for the Roma population in France.

Data from MdM indicate 2,766 diagnoses of TB within medical visits to MdM Roma programmes in 2011<sup>432</sup>. Insecure housing situations (see below) make proper treatment of TB difficult. Measles was diagnosed in 35 cases resulting from visits to MdM clinics, and a 2010 vaccination survey found that only 51% of Roma below 30 years of age had been vaccinated against measles, mumps and rubella.<sup>433</sup> 90% of French infants are vaccinated against measles<sup>434</sup>. Outbreaks of Hepatitis A were reported in Traveller populations (Gens du Voyage) in 2008-2009<sup>435</sup>. Roma attending MdM clinics are commonly diagnosed with dermatitis and gastric complaints such as worms and parasites, gastroenteritis and other gastric infections<sup>436</sup>. 36% of Roma patients visiting MdM clinics reported chronic health problems or disease, including hypertension, obesity and diabetes<sup>437</sup>.

The research team was unable to find data on nutrition, consumption of alcohol, tobacco or illegal drugs or levels of physical activity for either the settled Roma population or Gens du Voyage.

Levels of insurance coverage are reported to be similar for the Roma population and general population<sup>438</sup>. However, MdM report that mass evictions implemented by the French authorities limit Roma access to essential health and social care services. Evictions make it difficult to organise health care and public health actions in a continuous manner, and forced resettlement impacts on healthcare follow up, improving settlement hygiene, maternal and infant care, immunisation, screening for diseases and the delivery of treatments for chronic diseases. In addition, evictions, and the rapid departure from settlements that they require mean that personal health

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<sup>431</sup> Zurovcová, H et al (Ibid)

<sup>432</sup> Médecins du Monde (2012), Actions mobiles auprès des Roms, 2011, non publié.

<sup>433</sup> Médecins du Monde (2011), Rapport d'enquête sur la couverture vaccinale des populations roms rencontrées par les équipes de Médecins du Monde en France, Rapport de la Direction des Missions France, 22p

<sup>434</sup> Unicef, WHO, "Immunization Summary: A Statistical Reference containing data through 2010"

<sup>435</sup> Lecocq, H. et al, Community outbreak of hepatitis A in the Nord department in 2008-2009. Saint-Maurice: Institute of Health, 2012. p28

<sup>436</sup> Médecins du Monde (2012), Actions mobiles auprès des Roms, 2011, non publié.

<sup>437</sup> Ibid

<sup>438</sup> FRA: The Situation of Roma in 11 Member States, Publication Office of the EU, 2012

records, prescriptions, medicines and the addresses of health care facilities are frequently misplaced.<sup>439 440 441 442 443</sup>

Access to free healthcare in France is granted under the Aide Médicale d'Etat (AME) to legal or illegal immigrants who can justify residence in France for an uninterrupted period of over three months. Registration is challenging for those who do not speak French to navigate the bureaucracy required to receive funds, and for those unable to prove their domicile, income or time spent in the country. Among patients of MdM clinics, 22.6% were not entitled to health coverage as they had been living in France for less than twelve months<sup>444 445</sup>. Of the 77% entitled to coverage, only 14% were in receipt.<sup>446</sup> Although all children under 6 are entitled to free Mother and Child Protection health facilities, only 14% of Roma children were engaged in the programme in 2011.<sup>447</sup> Some general practitioners and hospitals do not provide care to AME beneficiaries, and Roma are often not aware of their rights as AME beneficiaries<sup>448 449 450</sup>. An evaluation of a pilot programme administered by MdM has reported that health mediation services are a successful intervention to help Roma communities to access health services.<sup>451</sup>

Data from a 2008 survey showed that approximately 1 in 10 Roma women were using a birth control method of some kind<sup>452</sup>. In a 2011 survey, 27% of women aged 12-49 were using contraception, and 68% reported never having used contraception.<sup>453</sup> 36% of women attending MdM clinics reporting having had one or more abortions<sup>454</sup> and the average number of abortions per woman was 5.2<sup>455</sup>. 43% of women attending clinics who reported having had an abortion did not receive follow-up care<sup>456</sup>. Evictions from resettlements impact on the ability of Roma women to receive complete pre-natal care<sup>457</sup>. One MdM study reports that only one in two pregnancies result in a

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<sup>439</sup> Médecins du Monde (2011), Parias, les Roms en France, Dossier de Presse, 15p

<sup>439</sup> Médecins du Monde (2010), Synthèse - forum « La santé des Roms en France : une urgence sanitaire ? », Médecins du Monde - 25 février 2010, 10p.

<sup>440</sup> Médecins du Monde (2011), Rapport d'enquête sur la couverture vaccinale des populations roms rencontrées par les équipes de Médecins du Monde en France, Rapport de la Direction des Missions France, 22p

<sup>441</sup> Laurence, S., Chappuis, M., Rodier, P., Labaume, C., Corty, J-F. (2013), Campagne de vaccination hors centre contre la rougeole des populations précaires en période de pic épidémique, Marseille 2011, Revue d'Epidémiologie et de Santé Publique 61, pp.199-203

<sup>442</sup> Laurence S., Chappuis M, Lucas D, Duteutre M, Corty J-F, Campagne de vaccination rougeole des populations précaires : retour d'expérience, (submitted for publication)

<sup>443</sup> Médecins du Monde (2007), Les Roms que l'Europe laisse à la porte, 30p.

<sup>444</sup> Médecins du Monde (2011), Parias, les Roms en France, Dossier de Presse, 15p

<sup>445</sup> Médecins du Monde (2010), Synthèse - forum « La santé des Roms en France : une urgence sanitaire ? », Médecins du Monde - 25 février 2010, 10p.

<sup>446</sup> Médecins du Monde (2012), Actions mobiles auprès des Roms, 2011, non publié.

<sup>447</sup> Ibid

<sup>448</sup> ASAV, AREAS, Médecins du Monde, Romeurope, (2012) Projet de Médiation santé en direction de femmes et jeunes enfants Roms, Rapport final, 59p

<sup>449</sup> Médecins du Monde (2008), Médecins du Monde auprès des femmes Roms, 8p

<sup>450</sup> Médecins du Monde (2012), Rapport 2011 de l'Observatoire de l'Accès aux Soins de la Mission France, 215p

<sup>451</sup> ASAV, AREAS, Médecins du Monde, Romeurope, (2012) Projet de Médiation santé en direction de femmes et jeunes enfants Roms, Rapport final, 59p

<sup>452</sup> Médecins du Monde (2008), Médecins du Monde auprès des femmes Roms, 8p

<sup>453</sup> Médecins du Monde (2012), Actions mobiles auprès des Roms, 2011, non publié.

<sup>454</sup> Ibid

<sup>455</sup> Ibid

<sup>456</sup> Ibid

<sup>457</sup> Médecins du Monde (2008), Médecins du Monde auprès des femmes Roms, 8p

living infant among Roma women<sup>458</sup>. There is limited reported uptake of cervical or breast cancer screening among Roma women receiving care at MdM clinics<sup>459</sup>.

Providing every child in France with the chance of quality schooling is the main priority of France's National Roma Integration Strategy<sup>460</sup>. It is estimated that approximately 5,000-7,000 Roma children aged 16 are arriving in France without ever having attended school<sup>461</sup>. On average, only one in two Roma children attends kindergarten or pre-school. For children aged 7-15, fewer Roma than non-Roma are in school. Only 5% of Roma children complete any type of education<sup>462</sup>. Some children are denied enrolment to schools because they lack the relevant health and immunisation records or are late on an immunisation schedule<sup>463</sup>. Other barriers to enrolment include lack of fixed address. Enrolment is often temporary because of forced evictions and resettlement (see below). A FRA survey identified at least 10% of Roma children not attending school<sup>464</sup>. Approximately 6% of Roma children in France report working outside the home<sup>465</sup>.

Roma also experience barriers to employment. Workers from Bulgaria and Romania (many of whom are Roma) are not allowed to work in France without a work permit paid for by the employer. This obligation can make it expensive to hire Roma, discouraging employers from doing so, and contributing to Roma unemployment. Without access to regular jobs many do informal work for minimal wages without access to social security. The absence of visas and work permits for many Roma exclude them from the social benefits that legal immigrants and low-income French families are entitled to, and are denied permission to remain in France for more than three months.<sup>466</sup> The FRA survey reported only 1 out of 10 Roma aged 20 to 64 in paid employment. 20% said they were self-employed<sup>467</sup>. Over 90% of Roma live in households at risk of poverty, twice as high a risk as non-Roma<sup>468</sup>.

Roma communities usually settle in vacant plots or abandoned fields surrounding urban and industrial areas. For the past 10-15 years the main policy approach to these settlements has been to evict the inhabitants using police force. Although a recent government circular (August 2012) prohibits this approach, the policy is still frequently implemented. Roma communities therefore experience extremely poor and unhealthy living conditions. They live in shanty towns or squats, in dilapidated caravans or in sheds without water or electricity, lacking privacy, with overcrowding and a lack of appropriate heating and ventilation. The lack of drinking water, toilets, sewage systems and waste management in most vacant lands and squats they settle in create hygiene issues alongside potentially harmful dermatologic and digestive pathologies.

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<sup>458</sup> Médecins du Monde (2010), Synthèse - forum « La santé des Roms en France : une urgence sanitaire ? », Médecins du Monde - 25 février 2010, 10p.

<sup>459</sup> ASAV, AREAS, Médecins du Monde, Romeurope, (2012) Projet de Médiation santé en direction de femmes et jeunes enfants Roms, Rapport final, 59p

<sup>460</sup> An equal place in French society: French government strategy for Roma integration within the framework of the Communication from the Commission of 5 April 2011 and the Council conclusions of 19 May 2011

<sup>461</sup> CNDH Romeurope, "La non-scolarisation en France des enfants Roms migrants: Etude sur les obstacles des enfants Roms migrants en France, 2010.

<sup>462</sup> FRA: The Situation of Roma in 11 Member States, Publication Office of the EU, 2012

<sup>463</sup> Médecins du Monde (2007), Les Roms que l'Europe laisse à la porte, 30p.

<sup>464</sup> FRA: The Situation of Roma in 11 Member States, Publication Office of the EU, 2012

<sup>465</sup> Ibid

<sup>466</sup> Romeurope (2012), « Les Roms, boucs-émissaires d'une politique sécuritaire qui cible les migrants et les pauvres », Rapport 2010-2011 Collectif National Droits de l'Homme Romeurope, 30p

<sup>467</sup> FRA: The Situation of Roma in 11 Member States, Publication Office of the EU, 2012

<sup>468</sup> Ibid.

The squats and shanty towns also present numerous dangers for its inhabitants; fire and collapsing risks, respiratory intoxications, lead poisoning etc. These conditions also expose Roma populations to high epidemic risks of tuberculosis, whooping cough, measles, rats and other pests<sup>469</sup>.

In September 2012, France was condemned by the European Committee of Social Rights of the Council of Europe for violating the European Social Charter on the grounds that they denied Roma living in France their rights and access to their rights. Specifically, the Committee condemned the French government with not providing Roma with access to adequate housing, not ensuring access to shelter, for violating the right of Roma children to access the French education system, the non-access of Roma to health care and social health protection, and for lacking disease and accident prevention in Roma settlements<sup>470</sup>.

The Committee also found that evictions of Roma communities from their settlements have taken place without respecting the European Social Charter, thus violating the dignity of the evicted Roma. The Committee considered that the French policy towards Roma is insufficient, especially regarding their access to education and health care. Because of the lack of general resources invested by the French government to improve Roma's poor living conditions, the Committee declared that Roma living in France undergo discriminatory treatment and requested that France change its policies towards Roma to ensure their rights<sup>471</sup>. It was the fourth condemnation of the European Committee of Social Rights against France concerning its treatment of Roma, thus making it urgent that the French government change their policies towards Roma and to apply already existing laws and regulations ensuring their rights.

## Greece

### Availability of Health Status Data

Roma are not recognised as a national minority and are considered as Greeks without separate ethnic identity. Therefore, ethnically disaggregated national data is non-existent. There is a lack of data on regulated and unregulated encampments, social housing, private renting, ownership and household types, as there is no official or unofficial quantitative data available on the housing conditions for Roma and Travellers<sup>472</sup>.

### Health Status

Life expectancy estimates are lower for Roma in line with other European estimates. The data available on prevalence of infectious diseases are small-scale studies only, but indicate a markedly lower health status for the Roma population included in the surveys. For the same reasons it is difficult to assess Roma health status for the Healthy Life styles indicator, but there is evidence of barriers for Roma in accessing

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<sup>469</sup> Médecins du Monde (2011), *Parias, les Roms en France*, Dossier de Presse, 15p

<sup>470</sup> Council of Europe (2013), Committee of Ministers, Resolution CM/ResChs (2013)6, *Médecins du Monde – International v. France*, Complaint No. 67/2011, Adopted by the Committee of Ministers on 27 March 2013 at the 1.166th meeting of the Ministers' Deputies. (Consulted on May 23, 2013)

<sup>471</sup> Council of Europe (2013), Committee of Ministers, Resolution CM/ResChs (2013)6, *Médecins du Monde – International v. France*, Complaint No. 67/2011, Adopted by the Committee of Ministers on 27 March 2013 at the 1.166th meeting of the Ministers' Deputies. (Consulted on May 23, 2013)

[http://wcd.coe.int/ViewDoc.jsp?Ref=CM/ResChS\(2013\)6&Language=lanEnglish&Ver=original&Site=COE&BackColorInternet=C3C3C3&BackColorIntranet=EDB021&BackColorLogged=F5D383](http://wcd.coe.int/ViewDoc.jsp?Ref=CM/ResChS(2013)6&Language=lanEnglish&Ver=original&Site=COE&BackColorInternet=C3C3C3&BackColorIntranet=EDB021&BackColorLogged=F5D383)

<sup>472</sup> Ibid.

health services, in particular financial means<sup>473</sup>. Half of the Roma population visit a physician once a month, whereas the rest of the population visit a physician once a year. Five per cent have never visited a physician, which is significantly higher than the overall Roma population in Europe (2.4%). The most common reason for visiting a physician was for diagnosis and/or treatment<sup>474</sup>. Another interesting finding is the disproportionate use of emergency services amongst Roma. 31.5% had used the emergency services during the preceding 12 months. The main age group using the emergency services is 45 and older (39.5%) and 0-15 (32.0%). The disproportionate use of emergency services could be explained that these services are free in most countries. The data collected do not reveal if Roma women are worse off than non-Roma women. The data is somewhat unreliable because it comes from a small-scale survey. Moreover, the sample base for Roma women was too small to draw concrete conclusions. The general lack of data on Roma women in Greece indicates the need for more research into the health and general status of Roma women<sup>475</sup>. Data on the environmental and socio-economic indicator is more reliable and suggests that the Roma population are significantly poorer than the mainstream population. The data also indicates that Roma are more vulnerable to unforeseen economic events than the non-Roma population. The data, which stems from Eurofound as well as the FRA, can be considered reliable as the results find Roma residing in areas with population densities higher than national average<sup>476</sup>.

## Hungary

### Availability of Health Status Data

Data on Roma in Hungary are available from representative surveys from the early 2000s, some specific scientific research undertaken with small samples of specific populations, and a recent survey undertaken by UNDP/FRA. Data for many indicators come from sources that are unreferenced, have conflicting findings or categorise the indicator differently. Data was not available on maternal mortality, ante-natal care or measles.

### Health Status

Roma men have a life expectancy of approximately ten years fewer than non-Roma men. For women, the gap is greater; approximately 18 years<sup>477 478</sup>. There are no ethnically disaggregated statistics on infant mortality at national level, but regional surveys indicate an infant mortality rate of 8.1 per 1,000 for Roma in these regions compared to the national population average of 5.1 per 1,000.

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<sup>473</sup> EFXINI POLI et.al. (2009) Health and the Roma community, analysis of the situation in Europe. Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain

<sup>474</sup> Ibid.

<sup>475</sup> EFXINI POLI et.al. (2009) Health and the Roma community, analysis of the situation in Europe. Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain

<sup>476</sup> Pavlou, M. (2009) FRANET 'Housing Conditions of Roma and Travellers' Greece RAXEN National Focal Point. Available at: [http://fra.europa.eu/sites/default/files/fra\\_uploads/582-RAXEN-Roma%20Housing-Greece\\_en.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/582-RAXEN-Roma%20Housing-Greece_en.pdf)

<sup>477</sup> Gara I., (2011) "Betegebbek, előbb halnak és kiszolgáltatottak a romák" (Presentation at the meeting of the National Health Council by the vice-president of the National Health Council)

<sup>478</sup> Eduinvest (2009) The Roma population's state of health survey

There is some data on infectious diseases amongst the Roma population in Hungary, but they focus on specific and extremely vulnerable communities, so cannot be assumed to be indicative of the Roma population as a whole. One survey found that of a sample of injecting drug users in Budapest, Roma injecting drug users (IDUs) were more likely to have HIV than non-Roma IDUs. A rapid assessment survey of a neighbourhood (in 2004 and 2006) of Budapest with an extremely high concentration of poverty found higher rates of Hepatitis A and B in the Roma population than non-Roma<sup>479</sup>. A representative survey on data on TB infections (from 2000) found higher rates of TB infection amongst Roma than non-Roma<sup>480</sup>. Vaccination rates amongst Roma children are high and similar to the non-Roma population<sup>481</sup>.

Various vulnerable groups amongst the Roma population are more likely to smoke than their non-Roma equivalent. This includes those aged 30 years or over in the lowest income quartile<sup>482</sup>, adolescents aged 13-16<sup>483</sup> and pregnant women<sup>484</sup>. Roma tend to start smoking at a younger age than non-Roma<sup>485</sup>. Comparisons of Roma and non-Roma living in poverty indicate higher prevalence of smoking amongst Roma. Data on alcohol consumption amongst Roma populations indicate a higher prevalence of abstinence among men than the general population<sup>486</sup>. Roma women are slightly more likely to drink during pregnancy than non-Roma women<sup>487</sup>, and Roma adolescents are twice as likely to have been drunk as non-Roma adolescents.<sup>488</sup> Illicit drug use amongst Roma adolescents (13-16) is ten times as high amongst disadvantaged Roma compared to the non-Roma population (22% of Roma, 2% of non-Roma).<sup>489</sup> Male Roma are more likely to be obese than non-Roma, while the opposite is true for women.<sup>490</sup> Daily consumption of fruit and vegetables is less likely for Roma than the lowest income quartile of the general population.<sup>492</sup>

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<sup>479</sup> Gyarmathy V., Ujhelyi, A. E., A. Neaigus (2008) "HIV and selected blood-borne and sexually transmitted infections in a predominantly Roma (Gypsy) neighbourhood in Budapest, Hungary: a rapid assessment." *Central European Journal of Public Health*. September; 16(3): 124-127

<sup>480</sup> Babusik F. (2005) *Az esélyegyenlőség korlátai Magyarországon*, L'Harmattan, Budapest.

<sup>481</sup> Hungarian Central Statistical Office: 2001 census

<sup>482</sup> Szabóné Kármán J., (2008) "Roma/cigány népszerűség helyzete" In: Kopp Mária (ed): *Magyar lelkiállapot 2008*. Semmelweis Kiadó, Budapest

<sup>483</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>484</sup> Two sets of databases are merged: the National Health Survey 2003 (representative), and the Roma Health Survey 2004 (non-representative). The Roma Health Survey (2004) is a survey of the adult population living in Roma settlements in 3 counties of northeastern Hungary, part of the country with the highest Roma population. The survey is not representative of the overall Hungarian Roma population. By design, it excluded those Roma who have, to various degrees, assimilated with the majority population; it captured the characteristics of the most disadvantaged section of the Roma population. Data are disaggregated by age, ethnicity (People Living in Roma Settlements), gender, and status (Lowest Income Quartile).

<sup>485</sup> Gerevich J., Bácskai E., Czobor P., Szabó J. (2010) "Substance use in Roma and non-Roma adolescents." *The Journal of nervous and mental disease* Volume: 198, Issue: 6, Pages: 432-436

<sup>486</sup> Hungarian National Social Inclusion Strategy, and Presentation by the vice-president of the National Health Council.

<sup>487</sup> National Health Survey 2003 (representative), and the Roma Health Survey 2004 (ibid)

<sup>488</sup> Ibid

<sup>489</sup> Balázs P., Foley, K. L., Rákóczi I., Greczer A. (2010) A. "Koraszülő roma és nem roma nők összehasonlítása Szabolcs-Szatmár-Bereg megyei adatok alapján." *Nőgyógyászati és Szülészeti Továbbképző Szemle*, Vol 12. issue 4.

<sup>490</sup> National Health Survey 2003 (representative), and the Roma Health Survey 2004 (ibid)

<sup>491</sup> Ibid.

<sup>492</sup> Gara I., (2011) "Betegberek, előbb halnak és kiszolgáltatottak a romák" (Presentation at the meeting of the National Health Council by the vice-president of the National Health Council)

<sup>493</sup> National Health Survey 2003 (representative), and the Roma Health Survey 2004 (ibid)

<sup>494</sup> Ibid



Roma are over ten times more likely to suffer from iron deficiency (siderosis).<sup>493</sup> The Roma population is less likely than the lowest income quartile of the general population to engage in physical activity.<sup>494</sup>

Both Roma and non-Roma have almost complete access to medical insurance<sup>495</sup>, although one survey report cited in the National Roma Integration Strategy indicates that more than half of Roma never or rarely use healthcare services, including a family doctor<sup>496 497</sup>. Non-Roma are slightly more likely to be hospitalised than non-Roma<sup>498</sup>. Roma are less likely than non-Roma to have received an x-ray, ultrasound or other scan<sup>499</sup>. Around a third of Roma report having attended lung screening<sup>500</sup>. At least 18% of Roma report discrimination from healthcare personnel in the past 12 months<sup>501</sup>. Various data on self-assessment of health report conflicting results<sup>502</sup>. Estimates of the prevalence of cardiovascular disease amongst Roma vary greatly (16% and 70%) with similar issues for data on hypertension and diabetes. Data are either from 2000 or from an undated source<sup>503</sup>. Roma experience a greater prevalence of depression, asthma, stomachic ulcer and cancer than non-Roma<sup>504</sup>.

Roma are more likely than non-Roma to have only completed primary education<sup>505</sup>. Only 9% of Roma are likely to have completed secondary education and less than 1% are likely to have completed university<sup>506</sup>. Roma are at least twice as likely as non-Roma to be unemployed and nearly half report experiencing negative discrimination during efforts to find work<sup>507</sup>. 91% of Roma live in severe material deprivation, 4% live in absolute poverty and 71% live at the relative poverty rate<sup>508</sup>. Approximately a third of Roma do not have access to secure housing, an improved water source, or improved sanitation<sup>509</sup>.

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<sup>493</sup> Babusik F. (2005) *Az esélyegyenlőség korlátai Magyarországon*, L'Harmattan,

<sup>493</sup> Hungarian Central Statistical Office: 2001 census

<sup>493</sup> Szabóné Kármán J., (2008) "Roma/cigány népesség helyzete" In: Kopp Mária (ed): *Magyar lelkiállapot 2008*. Semmelweis Kiadó, Budapest

<sup>494</sup> National Health Survey 2003 (representative), and the Roma Health Survey 2004 (ibid)

<sup>495</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>496</sup> Health Survey, 2009 by the Central Statistical Office and the Roma population state of health survey, 2009. Eduinvest.

<sup>497</sup> Gara (2011) (Ibid)

<sup>498</sup> Hungarian Central Statistical Office: 2001 Census

<sup>499</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>500</sup> Gara (2011) (Ibid)

<sup>501</sup> European Union Agency for Fundamental Rights (2009) *European Union Minorities and Discrimination Survey. The data in Focus Report - The Roma*

<sup>502</sup> Gara I., (2011) "Betegebbek, előbb halnak és kiszolgáltatottak a romák" (Presentation at the meeting of the National Health Council by the vice-president of the National Health Council), UNDP-WB-European Commission, FRA regional Roma survey (2011), Hungarian Central Statistical Office: 2001 census.

<sup>503</sup> Babusik F. (2005) *Az esélyegyenlőség korlátai Magyarországon*, L'Harmattan and Gara (2011) (Ibid)

<sup>504</sup> Babusik F. (2005) *Az esélyegyenlőség korlátai Magyarországon*, L'Harmattan,

<sup>504</sup> Hungarian Central Statistical Office: 2001 census

<sup>504</sup> Szabóné Kármán J., (2008) "Roma/cigány népesség helyzete" In: Kopp Mária (ed): *Magyar lelkiállapot 2008*. Semmelweis Kiadó, Budapest

<sup>505</sup> Hungarian National Inclusion Strategy, UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>506</sup> Hungarian National Inclusion Strategy, UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>507</sup> Hungarian National Inclusion Strategy, UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>508</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>509</sup> Ibid.

## Italy

### Availability of Health Status Data

There is limited available data on the health status of Roma in Italy, and available data mainly derive from a FRA/UNDP study and small sample epidemiological surveys. In particular, the research team was unable to find available data for maternal mortality, tuberculosis, hepatitis, diabetes, cancer or cancer screening.

### Health status

Data on life expectancy is inconsistent. One 2009 study estimates life expectancy of approximately 40-45 years<sup>510</sup>. Another study from 2011 reports life expectancy for Roma as 20 years lower than the national average<sup>511</sup>. Neither study provides indication of how the data were obtained or calculated. A regional study of infant mortality from 2008 reports infant mortality at 6.5 per 1,000, compared to 3.5 per 1,000 for the non-Roma population<sup>512</sup>. An earlier study (2002) uses the same dataset but calculates an infant mortality rate of 9 per 1,000.

There is limited data regarding major infectious diseases for Roma, with no data on tuberculosis or hepatitis. There is some data on local measles outbreaks and the vulnerability of the Roma population due to low vaccination coverage. Studies also indicate the success of various local campaigns to increase vaccination rates in response to these outbreaks<sup>513</sup>.

Data collected between 2009 and 2010 on a small sample of Roma visiting a specific health clinic indicate smoking rates of over 50% among Roma, with men more likely to be heavy smokers<sup>514</sup>. However a small sample study from 2002 showed only 3.5% as smokers<sup>515</sup>. The same study showed 21.8% of this sample consumed alcohol. Data for illicit drug use is only available from a small sample survey of data collected between 1996 and 2002<sup>516</sup>.

A FRA study from 2011 reports similar rates of medical insurance amongst Roma and non-Roma populations<sup>517</sup>. Other local surveys report issues with registration to the National Health Service (SSN), access to the Tesserino STP (*Straniero Temporaneamente Presente*) which grants access to emergency treatments for

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<sup>510</sup> Osservazione, EU Values: The Roma Migration Challenge, 2009.

<sup>511</sup> CEPS, Promoting the Social Inclusion of Roma, 2011.

<sup>512</sup> Save the Children, Studio sulla Salute Materno Infantile nelle comunità Roma. Il caso di Roma, 2008

<sup>513</sup> Motta,F, Geraci,S, L'accesso di Rom e Sinti al diritto e alla tutela della salute, in La condizione giuridica di Rom e Sinti in Italia, Atti del Convegno Internazionale, Tomo II, pp1065-1080, Giuffré Editore, Milano, 2011, Filia,A, F.Curtale, P.Kreidl, G. Morosetti, F. Perrelli, J. Mantovani, D. Campus, G.Rossi, M.C.Sanna, A.Zanetti, F. Magurano, C. Fortuna, S. Iannazzo, MG. Pompa, M. Ciofi degli Atti, *Focolai di morbillo nella popolazione nomade in Italia/Cluster of measles cases in the Roma/Sinti population*, Medico e Bambino, 2007, Vierucci, F, T. Vanacore, R. De Tata, G. Palla, F. Massei, S. Stabilini, Giampiero I. Baroncelli, *Focolai di morbillo nell'area pisana/ Measles epidemic in Pisa territory*, Medico e Bambino, 2010,

<sup>514</sup> Colombo, Cinzia, A. Galli, M. Pero, R. Giani, S. Jucker, P. Oreste, C. Giommarini, E. Aiolfi, E. Judica, *Situazione sociodemografica e condizioni di salute della popolazione rom di Milano*, Epidemiol Prev 2011; 35 (5-6): 282-291.

<sup>515</sup> Gualdi-Russo , E , A. Zironi , G. V. Dallari ,S. Toselli, *Migration and Health in Italy: A Multiethnic Adult Sample*, Journal of Travel Medicine 2009;16(2):88-95.

<sup>516</sup> Nosotti, L, G.Franco, L. Toma, O. Latini, A. Morrone, *Gypsies' Health in Rome*, Department of Preventive Medicine for Migrations, Tourism and Tropical Dermatology, San Gallicano Dermatological Institute (IRCSS), Rome, 2004

<sup>517</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

irregular third-country migrants, the TEAM card (*Tessera Europea Assicurazione Malattia*) which provides evidence of medical insurance for other EU nationals or the ENI card (Europeo non iscritto); a regional equivalent<sup>518</sup>. There is no data on utilisation of health services. There is no data on the access of Roma women to preventive services such as screening for cervical or breast cancer. There is no data on prevalence of diabetes or cancer. A local study from 2004 reports a prevalence of respiratory difficulties in 23% of children aged 0-5<sup>519</sup>. A 2009 small sample study reports prevalence of hypertension in 1 in 3 men, and 1 in 4 women<sup>520</sup>. A 2008 study using a different small sample reports hypertension prevalence of 77% of people aged 35 or over<sup>521</sup>.

According to one study from 2009, 36% of Roma men and 28% of Roma women have no education at all. Roma women are more likely than Roma men to have education only at primary level<sup>522</sup>. A recent survey by FRA/UNDP found 15% of those aged 20-24 had completed general or vocational upper secondary education<sup>523</sup>. One study reports an illiteracy rate of 15.7%<sup>524</sup>. Roma are more than twice as likely to live in households at risk of poverty as non-Roma<sup>525</sup>. Approximately one third of Roma households are without at least one of the following basic amenities: indoor kitchen, indoor toilet, indoor shower/bath or electricity<sup>526</sup>. Roma households tend to have approximately 2.5 household members per room, compared to less than one person per room for the non-Roma population<sup>527</sup>.

## Romania

### Availability of health status data

In comparison with some countries, there is good availability of data on Roma, quantifiable and qualitative from national, international, regional and local sources. There are a few notable gaps in information on illicit drug use, infectious disease prevalence and antenatal care, attributable to a lack of research in the relevant area and inadequate data collection methodology as well as inadequately referenced source data.

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<sup>518</sup> Geraci, S, F. Motta, A. Ricordy, *Salute senza esclusione Sperimentazione di interventi per la promozione dell'accesso ai servizi sanitari e dell'educazione alla salute per la popolazione Rom e Sinta in Italia*, Caritas Roma, Rome, 2009, GrIS, Gruppo Immigrazione e Salute-Lazio, *Salute senza esclusione: campagna per l'accessibilità dei servizi socio-sanitari in favore della popolazione rom e sinta a Roma*, Rome, 2008, Colombo et al, 2011 (Ibid)

<sup>519</sup> Monasta, L, *Difficoltà respiratorie e prevalenza d'asma in bambini da zero a cinque anni in cinque insediamenti Rom*, Centro de Investigación de enfermedades tropicales (CIET), Universidad autónoma del Guerrero, Acapulco, México, 2004

<sup>520</sup> Gualdi-Russo, E, A. Zironi, G. V. Dallari, S. Toselli, *Migration and Health in Italy: A Multiethnic Adult Sample*, *Journal of Travel Medicine* 2009;16(2):88-95.

<sup>521</sup> GrIS, Gruppo Immigrazione e Salute-Lazio, *Salute senza esclusione: campagna per l'accessibilità dei servizi socio-sanitari in favore della popolazione rom e sinta a Roma*, Rome, 2008

<sup>522</sup> Gualdi-Russo, 2009 (ibid)

<sup>523</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>524</sup> Tarnovschi, D, A. M. Preoteasa, I. Vlase, A. Pamporov, P. Kabakchieva, P. Palvarini, and Fundación Secretariado Gitano, *Roma from Romania, Bulgaria, Italy and Spain between Social Inclusion and Migration*, 2012.

<sup>525</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>526</sup> Ibid

<sup>527</sup> Ibid.

## Health status

On average, the Roma population is likely to be of a younger age than the general population living in their close proximity<sup>528</sup>. For each Roma household member aged 30-59, there are likely to be 0.2 elderly members. For non-Roma, this is 0.5<sup>529</sup>. A 2011 study indicates a mortality rate 1.83% higher than non-Roma<sup>530</sup>. The maternal mortality rate is 0.62%, fifteen times higher than the non-Roma population<sup>531</sup>.

Data on TB infections report that Roma are ten times more vulnerable to TB than non-Roma<sup>532</sup>. A study on one specific community found that 60% of children had TB<sup>533</sup>. A WHO investigation of a measles outbreak in Romania reported that 90% of those affected were Roma<sup>534</sup>. Almost 46% of Roma children did not benefit from the mandatory and free of charge vaccines included in the National Immunisation Programme. More than 50% did not benefit from any vaccines<sup>535</sup>. Vaccination rates for the general population are above 95% for all vaccines<sup>536</sup>.

There is limited data on smoking in the Roma population. One study reports high rates of smoking during pregnancy (67%).<sup>537</sup> There is no data on alcohol consumption or the use of illicit drugs. The Roma diet is often calorically unbalanced, with relatively low consumption of fish, eggs and meat<sup>538</sup>. Roma are less likely to be overweight than non-Roma, and 61% reported going hungry in the last month<sup>539</sup>. Physical activity levels are low; only 9.8% report regularly taking exercise several times a month, and 61.5% report not taking any exercise during free time<sup>540</sup>.

Data from the Ministry of Health (2002) reported that only 34% of Roma had health insurance, compared to 75% of the national population<sup>541</sup>. A more recent FRA study

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<sup>528</sup> Masseria, C., P. Mladovsky, C. Hernandez-Quevedo (2010), 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.

<sup>529</sup> Fleck, G., Rughinis, C., (2008) *Vino mai aproape. Incluziunea si exclusiunea romilor în societatea românească de astăzi* (Come closer. Roma inclusion and exclusion in the Romanian society today), Soros, Human Dynamics, Bucharest

<sup>530</sup> Report "Roma Inclusion in Romania" from 2012, conducted by Children's Early Development Services (IRSDTC), sponsored by the Open Society, Roma Education Fund and UNICEF, and cited under <http://www.thediplomat.ro/articol.php?id=1703>

<sup>531</sup> Ibid.

<sup>532</sup> Berger, D., C. Butu, A. Dev, V. Olsavszky, A. Pana and V. Tripathi, 2010. Romania: controlling TB among the Roma – a community approach. In: *Poverty and social exclusion in the WHO European Region: health systems respond*, p. 147-155.

<sup>533</sup> Fleck, G., Rughinis, C., (2008) *Vino mai aproape. Incluziunea si exclusiunea romilor în societatea românească de astăzi* (Come closer. Roma inclusion and exclusion in the Romanian society today), Soros, Human Dynamics, Bucharest.

<sup>534</sup> Mankertz A, Mihneva Z, Gold H, Baumgarte S, Baillet A, Helble R, et al. Spread of measles virus D4-Hamburg, Europe, 2008-2011. *Emerg Infect Dis*

<sup>535</sup> Wamsiedel, M. & al., *Health and Roma community – analysis of the situation in Romania*, Fundacion Secretariado Gitano, Madrid, 2009.

<sup>536</sup> Unicef, WHO, "Immunization Summary: A Statistical Reference containing data through 2010"

<sup>537</sup> Meghea, C., D. Rus, I. Rus, J. Holtrop, L. Roman (2010), Smoking during pregnancy and associated risk factors in a sample of Romanian women, *European Journal of Public Health*, Vol. 22, No. 2, 229-233.

<sup>538</sup> Wamsiedel, 2009 (Ibid)

<sup>539</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>540</sup> Wamsiedel, 2009 (ibid)

<sup>541</sup> Report "Roma Inclusion in Romania" from 2012, conducted by Children's Early Development Services (IRSDTC), sponsored by the Open Society, Roma Education Fund and UNICEF

(2011) puts this figure at 50%, compared to 80% of the general population<sup>542</sup>. Forty-four per cent of Roma have never accessed dental services<sup>543</sup>. 20% of Roma who needed medical care were denied without reason<sup>544</sup>. In a comparative sample, 9% of Roma may not be registered with a family doctor, which is twice as many as the general population<sup>545</sup>. Eleven per cent report having been discriminated against in the past 12 months by healthcare personnel<sup>546</sup>. Over 84% of women have never had screening for cervical cancer, and nearly 90% have not had screening for breast cancer<sup>547</sup>. No data was available regarding antenatal care. One study reports 14.5% of Roma experiencing a disability or chronic disease. Of these, 13.7% of adults have CVD, 3.3% have asthma, 5.2% have stomachic ulcer, 6.9% have diabetes and 17.5% have hypertension<sup>548</sup>.

The Roma population is more likely to have no education or a low level of education than the non-Roma population<sup>549</sup>. Roma attendance at pre-school or kindergarten is 37%, compared to 77% of the non-Roma population<sup>550</sup>. Two out of ten Roma children of school age (6-16 years old) do not go to school because of a lack of financial resources. 25% of Roma aged 16 years or older report that they do not know how to read or write. Women are 10% more likely to be illiterate than men, and rates of illiteracy are higher in segregated communities<sup>551</sup>. A 2012 study reported 35% of Roma employed in comparison to 58% of non-Roma<sup>552</sup>. There is a high inequality of income amongst the Roma population in Romania<sup>553</sup>. A 2003 study showed 60% of Roma could not afford food at least once in the last month<sup>554</sup>. 90% live in households with severe material deprivation. Over 80% live in households without at least one of the following basic amenities: indoor kitchen, indoor toilet, indoor shower, bath or electricity, compared to approximately 55% of the general population<sup>555</sup>.

## Slovakia

### Availability of health status data

Because the state prohibits collection of data determined by ethnicity, there is limited data from official sources. There have been several surveys specifically targeting the Roma population, but they only collected data determined by socio-economic status or level of social exclusion/marginalisation. Data on the health status of the Roma population that has integrated into the general population is even less available. Available data is mainly gathered from international organisations such as the

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<sup>542</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>543</sup> Warnsiedel, 2009 (ibid).

<sup>544</sup> Ibid.

<sup>545</sup> Fleck et al, 2008 (ibid)

<sup>546</sup> EU-MIDIS. European Union Minorities and Discrimination Survey. Main results report, 2009.

EU-wide survey to ask immigrant and ethnic minority groups about their experiences of discrimination and criminal victimisation in everyday life; 500 Roma respondents were interviewed, Random route sampling in predominantly urban areas

<sup>547</sup> Warnsiedel, 2009 (ibid).

<sup>548</sup> Warnsiedel, 2009 (ibid).

<sup>549</sup> Masseria et al, 2010 (ibid)

<sup>550</sup> EU Structural Funds and Early Childhood Education and Care for Marginalised Roma Communities 2014–2020 (date of publication: 2012).

<sup>551</sup> EU-INCLUSIVE Project, 2012. Data transfer and exchange of good practices regarding the inclusion of Roma population between Romania, Bulgaria, Italy and Spain. Roma situation in Romania - Between social inclusion and migration (Country Report).

<sup>552</sup> Ibid.

<sup>553</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>554</sup> Ibid

<sup>555</sup> Ibid

FRA/UNDP surveys, and NGOs. The Slovak Government Plenipotentiary for Roma communities does not collect any data on the health status of Roma communities.

### Health status

Life expectancy for the Roma population is estimated to be 10-15 years less than that of the general population<sup>556</sup>. Infant mortality in the Roma population is approximately 2%, compared to 0.8% in the general population<sup>557</sup>. The Roma population is younger than the general population. Young people comprise approximately 43% of the overall population, compared to 25% of the general population. Only 2% of the Roma population is over 65 years old, compared to 12.2% of the general population<sup>558</sup>. The life expectancy gap is more pronounced in segregated and secluded Roma settlements, where the mortality rate is estimated to be two or three times higher than the general population<sup>559</sup>.

There are reports of infectious diseases including Hepatitis B, dysentery, scabies and TB in marginalised Roma communities<sup>560</sup>. Vaccination rates amongst Roma are half that of the general population<sup>561</sup>.

Roma are twice as likely to smoke as the general population and Roma tend to start smoking at an earlier age<sup>562</sup>. The team found no data on alcohol consumption, but initiation starts at a similar age for Roma and non-Roma<sup>563</sup>. There is no data available on illicit drug use. Nearly one fifth of Roma adults are obese, and around one third do not exercise or undertake any physical activity. Nearly one third of Roma children are obese. Around 34% of Roma went to bed hungry at least once in the last month<sup>564</sup>. Around 80% of Roma infants are breast-fed, compared to 60% of the general population<sup>565</sup>.

Access to medical insurance is similar in Roma and non-Roma populations (coverage of approximately 90%). Self-prescription of medication is common, and 48% of Roma state that they do not have access to essential drugs, compared to 19% of the general population<sup>566</sup>. Fewer than 25% of women report having regular gynaecological check-ups, and only 12% attend consultations about planned parenthood and reproduction.<sup>567</sup> Preventive screening for breast cancer is good, with over 75% of women receiving this service. Two per cent of women report using contraceptives. Disparities between prevalence of chronic conditions amongst Roma and non-Roma populations widen with age, and are most marked between 60 and 69. Amongst this age bracket, 80% of Roma men report at least one chronic disease, compared to 44% of Slovak men<sup>568</sup>. Almost 9% of Roma men and 4% of Roma women have

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<sup>556</sup> Regional Office of Public Health Survey, 2008.

<sup>557</sup> Ibid

<sup>558</sup> Zdravotná starostlivosť v sociálne vylúčených rómskych komunitách, 2007, p. 28.

<sup>559</sup> Ibid

<sup>560</sup> Program of health support of disadvantaged communities in Slovakia for years 2009 – 2015 – Second phase

<sup>561</sup> Ibid.

<sup>562</sup> The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma survey

<sup>563</sup> Ibid

<sup>564</sup> Ibid

<sup>565</sup> M. Popper - P. Szeghy - Š. Šarkozy: Roma population and health: Analysis of situation in Slovakia, 2009, p. 70.

<sup>566</sup> Ibid

<sup>567</sup> Ibid

<sup>568</sup> Branislav Šprocha, Mortality and health status of the Roma population, 2. Part, Statistical Office of the Slovak Republic, 2012,

hypertension. 6.8% of all Roma adults and children have high cholesterol. Almost 3% of Roma adults and children have depression. 6% of the Roma population have heart disease and 8% have circulatory problems. Over 4% of adults have osteoporosis, and 7.3% have rheumatism/arthritis<sup>569</sup>. Approximately 29% of Roma perceive their health status positively, compared to 23% of the general population. Poor health was reported by 13.1% of the overall population and by only 8.1% of the Roma population<sup>570</sup>. Researchers conclude that this disparity in self-assessment arises because people living in Roma settlements assess their health status positively unless they have any health problems that require medical treatment or are diagnosed by a doctor<sup>571</sup>.

Approximately 30% of Roma children attend pre-school or kindergarten; one of the lowest rates of attendance in the survey conducted by FRA/UNDP<sup>572</sup>. 3% of Roma in Slovakia have no formal education. The majority of the Roma population have completed lower secondary education (62%). 20% of Roma have completed upper secondary education, and approximately 1% of Roma women have completed post-secondary education<sup>573</sup>. The unemployment rate for Roma of all ages is reported at 70%, compared to 33% of non-Roma. The number of Roma living in absolute poverty is similar to non-Roma. About 90% of Roma experience material deprivation, compared to 59% of non-Roma<sup>574</sup>. Approximately 32% do not have access to secure housing, compared to 3% of the general population. The majority of Roma live in households without at least one of the following basic amenities: indoor kitchen, indoor toilet, indoor shower/bath or electricity<sup>575</sup>.

## Spain

### Availability of health status data

The available data on Roma is comprehensive, encompassing social demographic studies, comparisons using the Spanish National Health Survey, database studies and a recent (2009) European survey of Health and the Roma community, providing both quantitative data and an analysis of determinants of behaviour. It is also emphasised by the national researcher that Roma in Spain are a heterogeneous group with different experiences; from those who are integrated and of medium socio-economic levels; to those who have made progress; to a minority who remain severely excluded. The data is limited in the same areas as other countries; namely the lack of mortality & life expectancy data, interesting but old data on HIV; and a lack of prevalence data for other infectious and chronic diseases.

### Health status

Life expectancy for Roma is approximately seven years less than the general population. The longevity rate for the Roma population is approximately 25.7% compared to 51% for the EU-27, and the old age rate is 4.5% for Roma compared to

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<sup>569</sup> M. Popper - P. Szeghy - Š. Šarkozy: Roma population and health: Analysis of situation in Slovakia, 2009, p. 70.

<sup>570</sup> Health and the Roma Community, analysis of the situation in Europe, Fundación Secretariado Gitano Health, 2009

<sup>571</sup> Branislav, 2012 (Ibid)

<sup>572</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>573</sup> Ibid

<sup>574</sup> Ibid

<sup>575</sup> Ibid



11.2% for the EU-27<sup>576</sup>. The Research Team found no data on infant or maternal mortality rates. The Roma population is comparatively younger than the general population<sup>577</sup>.

There is a comparatively high prevalence of Hepatitis A infection amongst Roma children<sup>578</sup>. A cohort study indicates that HIV infection for the Roma population is higher than for any other ethnic minority living in Spain<sup>579</sup>. HIV progresses more rapidly to Aids or death in Roma than non-Roma<sup>580</sup>.

Roma men smoke more than their non-Roma counterparts<sup>581</sup>. The gap is wider amongst younger cohorts. Fewer Roma women smoke than non-Roma<sup>582</sup>. Roma men start drinking at an earlier age than non-Roma men, but Roma women consume fewer alcohol beverages than non-Roma women<sup>583</sup>. The percentage of Roma children who do not eat breakfast is higher than non-Roma children<sup>584</sup>. There is no data on physical activity levels. 19% of Roma girls under-18 are obese, which is higher than the non-Roma population, and BMI for Roma women is higher than non-Roma<sup>585</sup>. There is no significant difference between BMI levels for Roma and non-Roma men<sup>586</sup>.

According to the FRA survey, there is no significant difference in access to medical insurance for Roma and non-Roma<sup>587</sup>. Similar numbers of Roma and non-Roma report incidents where they needed medical attention and did not receive it, but general medical check-ups are less frequent among the Roma population. Access to services not covered by the national health system (dental health, preventive practices for women, access to hearing aids and eye-glasses) is lower for Roma than non-Roma.<sup>588</sup> The Roma population consumes more medicines than the general population. One-quarter of Roma women aged over 16 have never gone to a gynaecologist compared with 18% of the non-Roma population, and are more likely to attend for a specific problem than a general check-up. 59% of Roma women recommended for mammography have received one, compared to 72% of non-Roma women. Roma children are less likely to have attended a dentist, and Roma adults are less likely to have had dental work such as fillings. Access to healthcare for Roma of Eastern Europe has been restricted since 2012. Restrictions to access include tightening the conditions for social assistance and restricted access to vaccinations.<sup>589</sup>

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<sup>576</sup> FSG Health Area (coord.) (2009). Health and the Roma Community, analysis of the situation in Europe. Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain. Madrid. Fundación Secretariado Gitano.

[http://ec.europa.eu/justice/discrimination/files/roma\\_health\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_health_en.pdf)

<sup>577</sup> Health and the Roma Community, analysis of the situation in Europe, Fundación Secretariado Gitano Health, 2009

<sup>578</sup> Prevalence of Hepatitis A antibody among disadvantaged Roma children in northern Spain.

<sup>579</sup> Characteristics and outcome of HIV infection in Roma in the Spanish VACH cohort.

<sup>580</sup> Ibid

<sup>581</sup> Hacia la equidad en salud. Estudio comparado de las Encuestas Nacionales de Salud a población gitana y a población general en España, 2006 (Towards equality on health. Comparative study of Health Nacional Survey to Roma and to Non Roma population in Spain 2006.

<sup>582</sup> Ibid

<sup>583</sup> Ibid

<sup>584</sup> Ibid

<sup>585</sup> Ibid

<sup>586</sup> Ibid

<sup>587</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>588</sup> FSG Health Area (coord.) (2009). Health and the Roma Community, analysis of the situation in Europe. Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain. Madrid. Fundación Secretariado Gitano

<sup>589</sup> The impact of the crisis on Roma communities, Fundación Secretariado Gitano, 2013

14% of Roma report problems with eyesight compared to 4% of the general population. 43% of Roma men aged 55 or over report hearing problems, compared to 24% of the general population<sup>590</sup>. Roma populations experience a higher prevalence of chronic diseases, including cholesterol, depression, stomach ulcers, migraines, headaches and depression<sup>591</sup>. Roma women have a lower self-assessment of their health than non-Roma women, are more likely to have had to curtail their main activity and to have used emergency rooms more frequently. Roma with a higher education status are more likely to have a better perception of their health status, and are less inclined to report hypertension, asthma, or eye problems<sup>592</sup>.

Just over 60% of Roma children attend pre-school or kindergarten, compared to over 90% of non-Roma children<sup>593</sup>. Just under 10% of Roma children aged 7-15 are not in school, compared to fewer than 5% of non-Roma children<sup>594</sup>. Approximately 5% of Roma aged 20-24 have completed general or vocational upper-secondary education, compared to over 30% of non-Roma<sup>595</sup>. Just fewer than 20% of Roma adults are in paid employment, compared to over 40% of non-Roma<sup>596</sup>. Over 30% of Roma report experiencing discrimination in the workplace<sup>597</sup>. Over 90% of Roma live in households at risk of poverty, compared to just over 70% of non-Roma<sup>598</sup>. The housing situation of Roma is not significantly different to that of non-Roma, in terms of access to basic amenities<sup>599</sup>.

## United Kingdom

### Availability of health status data

The UK is given as a good practice example by the Open Society Foundation as a country that collects ethnicity data. However UK Gypsies and Travellers were not counted as a separate category in the Census till 2011 and the accuracy and reliability of other collators of ethnicity data such as caravan park usage and local authority (including national health data) is debated. The NHS and Department of Health have committed to reducing inequalities through innovative practice and have made efforts recently to improve the quality of ethnicity data recording. However, much of the information currently available about the UK GRT and Roma from Central or Eastern Europe are based on small scale pre-2008 sources.

### Health status

Small scale, localised studies consistently state that the life expectancy of Gypsies and Travellers and Roma from Central and Eastern Europe is lower than the general

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<sup>590</sup> FSG Health Area (coord.) (2009). Health and the Roma Community, analysis of the situation in Europe. Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain. Madrid. Fundación Secretariado Gitano

<sup>591</sup> Hacia la equidad en salud. Estudio comparado de las Encuestas Nacionales de Salud a población gitana y a población general en España, 2006 (Towards equality on health. Comparative study of Health Nacional Survey to Roma and to Non Roma population in Spain 2006.

<sup>592</sup> Ibid.

<sup>593</sup> UNDP-WB-European Commission, FRA regional Roma survey (2011)

<sup>594</sup> Ibid

<sup>595</sup> Ibid

<sup>596</sup> Ibid

<sup>597</sup> Ibid

<sup>598</sup> Ibid

<sup>599</sup> Ibid.

population<sup>600</sup>. Irish Traveller women and men are expected to live 12 and 10 fewer years respectively<sup>601</sup>. Data on infant mortality show higher rates of infant mortality amongst UK Gypsies and Travellers compared with the general population. One local study (1988) reports infant mortality rates of 17.5 per 1,000, compared to 11.9 per 1,000 in the general population<sup>602</sup>. Traveller women from 'traditional' communities are at greater risk of maternal mortality than the general population<sup>603</sup>.

There is no data regarding the prevalence of major infectious diseases amongst UK Gypsies and Travellers or Roma from Central or Eastern Europe in the UK. Lower levels of childhood immunisation rates are reported in two older studies (1988 and 1993)<sup>604</sup>.

Data from 2007 show higher rates of smoking amongst UK Gypsies and Travellers than the general population<sup>605</sup>. The research team were unable to find data on smoking prevalence of Roma from Central and Eastern Europe. A local study of Central and Eastern European Roma reported increasing prevalence of illicit drug use amongst Roma men<sup>606</sup>. A regional 2010 study of Slovak Roma reported diets containing a particularly high fat content and low awareness of healthy eating<sup>607</sup>.

Barriers to access to healthcare exist for Central and Eastern European Roma, mainly relating to language and literacy<sup>608</sup>. Cultural norms may prevent Roma from accessing services for support with mental health, sexual health, and drug and alcohol misuse<sup>609</sup>. Cultural perceptions of ill-health may also limit uptake of services<sup>610</sup>. Some primary care services refuse to accept UK Gypsies and Travellers onto patient registration lists<sup>611</sup>.

Local studies indicate high prevalence of diabetes, cardiovascular disease, premature myocardial infarction, obesity and asthma amongst Central and Eastern European Roma<sup>612</sup>. More than one study points to higher incidences of mental health issues such as stress, anxiety and depression amongst both UK Gypsies and Travellers and

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<sup>600</sup> Clark, C., and Greenfields, M (2006) *Here to Stay. The Gypsies and Travellers of Great Britain*, University of Hertfordshire Press.

<sup>601</sup> Ibid.

<sup>602</sup> Jan Pahl and Michael Vaile (1988). *Health and Health Care among Travellers*. *Journal of Social Policy*, 17, pp 195-213

<sup>603</sup> Clark, C, 2006 (Ibid)

<sup>604</sup> Jan Pahl, 1988 (Ibid), Feder, G., & Hussey, R. (1990). *Traveller mothers and babies*. *BMJ: British Medical Journal*, 300(6739), 1536.

<sup>605</sup> Glenys Parry, Patrice Van Cleemput, Jean Peters, Stephen Walters, Kate Thomas, Cindy Cooper, (2007), *Health status of Gypsies and Travellers in England*, *Journal of Epidemiologic Community Health* 2007; 61:198-204

<sup>606</sup> Winyard and Felja 2010, *Children of Roma Druglink Vol 25 Issue 6 November/December 2010*

<sup>607</sup> Lizzie Moore (2010). *A Healthcare Needs Assessment of the Slovak Roma Community in Tinsley*, Sheffield, University of Sheffield

<sup>608</sup> Ibid.

<sup>609</sup> Tobi, P., and Sheridan, K., (2010) *Health and social care needs assessment of Eastern European Individuals (Including Roma) living in Barking and Dagenham*, Institute for Health and Human Development.

<sup>610</sup> Cleemput Van P., Bissel, D., Harriss, J. (2010) *Pacesetters Programme, Gypsy Roma and Traveller Core Strand*, Evaluation Report for the Department of Health, University of Sheffield

<sup>611</sup> Clark C, 2006 (Ibid).

<sup>612</sup> Moore 2010 (Ibid)

Central and Eastern European Roma<sup>613</sup>. Domestic violence is relatively common in UK Gypsy and Traveller Communities<sup>614</sup>. UK Gypsy and Traveller women in settled accommodation may experience isolation<sup>615</sup>. One local study reports that women may be unaware of their entitlement to maternity services and contraception.<sup>616</sup>

The 2004 Housing Act requires Local Authorities to carry out needs assessments for Gypsy and Traveller accommodation. However a lack of political will on the part of local government, substantial opposition to site development from the local population underpinned by racial prejudice and a perceived lack of land have all contributed to dwindling numbers of sites and inadequate provision for Gypsy and Traveller communities<sup>617</sup>. As a result, Gypsies and Travellers increasingly live in Local Authority or private housing as well as Local Authority and private sites, even when their preference is to maintain a more nomadic way of life<sup>618</sup>. A number of health issues connected to living on sites have also been raised. Insufficient site provision means that sites are often located in unhygienic and unsafe places. Many lack basic amenities such as running water and toilets and are often located near rubbish dumps, sewage works and busy roads.

Roma access to accommodation and employment in the UK is shaped by their status as EU migrants but is also mediated through their experiences as a socially excluded ethnic minority<sup>619</sup>. Since EU accession in 2004, Roma have entered the UK as economic migrants. Some local studies<sup>620 621 622</sup> show that housing for Roma is varied but that the majority live in privately rented, overcrowded accommodation which is often in very poor condition and is expensive to rent. There are two key reasons for this: first, Roma are often in low paid and insecure work, a situation which is exacerbated by poor English language skills and low levels of literacy, education and qualifications. They therefore rely on extended family networks to live together and contribute to the rent. Second, up until 2011 for A8 migrants, and January 2013 for A2 migrants, people could not access Local Authority housing or benefits unless they had registered with the Worker Registration Scheme (WRS), and had been in continuous employment for 12 months (SN/SP/5972, 2011). The WRS no longer applies, though migrants must still pass the Habitual Residency Test in order to access benefits.

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<sup>613</sup> Yin Har Lau and Ridge (2011) Addressing the impact of social exclusion on mental health in Gypsy, Roma and Traveller Communities, *Mental Health and Social Inclusion*, Vol. 15 No. 3 2011, pp. 129-137, Tobi 2010 (ibid)

<sup>614</sup> Yin Har Lau 2011 (Ibid)

<sup>615</sup> Staniewicz, T (2009), *Housing Conditions of Travellers and Roma*, FRA, UK.

<sup>616</sup> Cath Mahoney (2006), *Roma Families in Leeds. A social audit of their situation needs and services*, Travellers Health Partnership

<sup>617</sup> Niner, P. (2004) *Counting Gypsies and Travellers: A Review of the Gypsy Caravan Count System*. ODPM: London.

<sup>618</sup> Greenfields, M and Smith, D.M (2010), *Housed Gypsy Travellers, Social Segregation and the Reconstruction of Communities*, *Housing Studies*, 25,3.

<sup>619</sup> Poole, L., & Adamson, K. (2008). *Report on the situation of the Roma community in Govanhill, Glasgow*. Oxfam.

<sup>620</sup> Cath Mahoney (2006), *Roma Families in Leeds. A social audit of their situation needs and services*, Travellers Health Partnership

<sup>621</sup> Scullion, L and Morris, G (2010), *Central and Eastern European Migrants in Tameside*, Salford Housing and Urban Studies Unit, University of Salford

<sup>622</sup> Poole, L., & Adamson, K. (2008). *Report on the situation of the Roma community in Govanhill, Glasgow*. Oxfam.

Poverty and in some cases destitution is therefore a persistent problem for Central and Eastern European Roma. The evidence suggests that socio economic factors fundamentally impact on health<sup>623</sup>.

### **Other (20) Countries Summarised**

Three countries have reported that they have no Roma living in their countries: Iceland, Liechtenstein and Malta. Of the remaining 17 countries, data was collected across a range of indicators, from sources including international organisations such as FRA, national programmes, and local and regional studies and initiatives. The data collected is analysed in more detail in the Results section which explores each area of the assessment of health status in more detail. Additionally, a number of thematic areas of interest were identified and these are discussed below.

### **National Initiatives**

Firstly there is variation in how countries are addressing improving the situation of the Roma; Luxembourg and Germany have elected to pursue general policies of integration and promotion for all minorities rather than policies specifically aimed at Roma. Austria has a National Roma Integration Strategy that focuses on housing, health, education and employment but with no targets set specifically for Roma. Only three countries have created a department or organisation to specifically address the well-being of Roma (Finland, Portugal and Sweden) but the impact of these organisations is difficult to determine due to limited data collection, a focus on culture and history and lack of information on specific programmes. It is worth noting however that government plans to address a lack of information may not be successful. The Swedish experience is an example of this. An attempt to map the health situation of national minorities from 2008-2009 met opposition from the Roma population who were reluctant to be categorised due to fear of persecution, leading the quantitative aspect of the programme to be abandoned and replaced with qualitative interviews. Through the Swedish Institute for Public Health Sweden continues to work on assessing the health of Roma with a new project on Roma women and girls due to be completed in March 2014.

Some of the other countries have adopted specific projects aimed at Roma with varying success: Ireland has demonstrated a commitment to addressing Roma and Traveller health issues and Slovenia, while continuing to face data collection issues, has developed a data collection methodology in Pomurje which could be used as an example of good practice for the rest of the country. In addition, the 'Roma in Latvia' programme ran from 2007-2009 focusing on education and marginally on employment, but funds for this programme were diverted and there have been no subsequent initiatives. In 2003, Poland initiated a 'National Programme for the Roma Community' to run from 2004-2013 but there is no health data. This is attributed to a lack of provision for Roma in health services, the lack of a dedicated department or unit responsible for monitoring of minority health issues and the reforms in the health care system which had not yet responded to the needs of minorities.

### **Trends and Patterns in Migration and Integration**

Secondly, it is evident that Roma have entered countries in waves, primarily in the 1950s and 1960s and later following the fall of Communism in the 1990s, implying different degrees of assimilation and potentially varying experiences. In Denmark for instance, the following pattern was found: recent immigrants have less square metres per person in social housing than families who are of mixed immigration status. They

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<sup>623</sup> Cleemput, 2010 (Ibid),

in turn have less living space than older immigrants, and people who are ethnic Danish have the most living space of all.

### **Legal Systems**

Third, legal systems are not geared towards assisting Roma. Passport and ID requirements, immigration and administrative and financial support requirements act as barriers to entry and access, preventing Roma accessing health services, receiving financial assistance and entering into long-term and stable employment and can ultimately force them to give up a nomadic way of life in order to reside in the country.

In terms of legal recognition, Roma are not a recognised minority in all countries.

### **Ethnicity Data**

Finally, a recurrent theme throughout this study has been the lack of ethnically disaggregated data. In a detailed discussion of national approaches to the collection of ethnicity data in CoE countries, Simon (2007) makes reference to the obvious potential for stigmatisation using 'ethnic data', with risks including the use of ethnic data to confirm and reinforce negative stereotypes, strengthen ethnic or racial divisions between communities or that data will be used for persecutory purposes. However even where ethnicity data is collected (Estonia, Latvia, Poland and Slovenia), most data (including health) is still not disaggregated by ethnicity. Proxy measures such as country of birth, citizenship or nationality used by countries such as Luxembourg, Belgium and Ireland are of limited value. In Ireland for example, Irish Travellers are a recognised category in data collection but Roma are not distinguished from their national country and therefore data on their situation is limited. To successfully collect ethnically disaggregated the fear and pervasive discrimination evident in countries in health, housing, education, employment, police, media and by the public needs to be addressed first.

## Roma Health Status Conclusions and Recommendations

### Conclusions

In line with previous findings, the evidence currently available for the comprehensive indicators included in this project continue to demonstrate that, notwithstanding some variation between countries, Roma populations in Europe generally:

- Suffer greater exposure to wider risks of ill health (e.g. socio-economic and environmental).
- Live less healthy lifestyles.
- Have poorer access to and lower uptake of primary care and preventive health services.
- Suffer poorer health outcomes, in terms of morbidity from both infectious and chronic diseases and have shorter life expectancy.

Furthermore there are some indications that, as a result of the economic crisis and subsequent recessions in European countries, Roma health status and health access is deteriorating further in a number of places as a result of cutbacks.

The key conclusions per indicator are summarised below.

#### Mortality and Life Expectancy

- The Roma population is demographically different from the majority European populations insofar as it is noticeably younger – and consistently so across Europe.
- Life expectancy data is very limited on a national and regional level. Most data is based upon estimates. The most widely cited data stems from the Council of Europe.
- Roma experience substantially lower (up to 20 years) life expectancy compared to non-Roma.
- Some evidence exists suggesting that shorter life expectancy for Roma occurs as a result of the broader environmental conditions they experience.
- Higher rates of infant mortality are reported in some Roma populations (those living in poor housing, with low educational levels and migrant Roma) compared to non-Roma in countries, including Bulgaria, the Czech Republic, Hungary, Italy and Slovakia.

#### Prevalence of major infectious disease and immunization uptake

- Recent comprehensive data regarding infectious diseases within Roma communities is not readily available, and the data obtainable are often old, small-scale or, in a few cases, collected during disease outbreaks.
- Some of the available studies show higher rates of infectious diseases or risk of infectious disease outbreaks amongst Roma (including Measles and Hepatitis A), particularly segregated Roma, compared to the majority population.
- Evidence relating to rates of HIV/Aids is more mixed, though some reports find faster disease progression.
- There is a lack of data on vaccination uptake in the Roma population.



- The available evidence suggests that with some exceptions (Croatia, Hungary, and the Czech Republic) the Roma population, particularly migrant Roma, have lower or much lower childhood vaccination rates.

#### Healthy lifestyles and behaviours

- Roma suffer disproportionately from illnesses that are associated with the social determinants of health.
- While limited data on health lifestyles and behaviours among Roma populations are generally limited, the available evidence from a large majority of countries included in the project suggests that Roma people have poorer health related lifestyles.
- Available data on diet and physical activity consistently suggest that healthy diet and physical activities to stay healthy are less common in the Roma population.
- Available data on smoking prevalence from Austria, Croatia, the Czech Republic, Slovakia, Bulgaria, Hungary, Ireland, Portugal and Romania consistently show smoking is more common in the Roma population.
- Available evidence on alcohol consumption and illicit drug use amongst Roma communities reports conflicting findings.
- Very few interventions were reported specifically targeting the health behaviours of Roma, although exceptions include drug rehabilitation programmes in Croatia, Finland, Ireland, Latvia and Lithuania.
- Small scale studies have identified a number of cultural factors which have a negative impact on the health lifestyles of Roma.

#### Access to and utilisation of health services and prevention programmes

- Patterns of access and use of health services are not homogenous across the Roma populations in the 31 countries, implying different impacts on Roma health and experience of health care. The level of marginalisation or integration of Roma populations appears to be a crucial factor.
- Where data is available it provides sufficient evidence that there are numerous barriers to health care across the majority of countries.
- Evidence consistently suggests that barriers to access are closely linked to social exclusion factors, and specifically include the following factors:
  - Language and literacy barriers
  - A lack of knowledge of available health care systems
  - Discrimination by health care professionals
  - A lack of trust in health professionals
  - Physical barriers – mobility and distance
  - A lack of identification and/or insurance.
- Evidence also shows that patterns of health care utilisation among Roma differ from the general population, including higher levels of use of acute hospital services, perhaps as a result of lower levels of engagement with or access to preventive primary care.
- There is evidence that the economic crisis is disproportionately impacting on Roma populations' access to health care.

### Prevalence of major chronic disease

- Once allowance is made for demographic differences to the general population, Roma communities appear to suffer higher rates of chronic disease (i.e. asthma, diabetes, cardiovascular disease, and hypertension) and the associated disability and limitations on daily activities.
- A range of small scale studies highlight dramatically higher and more complex cases of chronic disease amongst Roma across a range of European Countries: Germany, Finland, Poland, the UK (migrant Roma), Romania, Ireland, Italy, Spain and France.
- Some evidence reports links between higher rates of chronic disease and higher prevalence of risk factors (e.g. diet, exercise, stress), poor access to and uptake of primary care and preventive health programmes among Roma.
- A number of studies again highlight the disproportionate impact of the economic crisis on Roma populations and its relevance to chronic disease risk factors.

### Health factors related to the role of women in the Roma community

- Recent (2013) FRA data on Roma women's health is the most comprehensive European source and underlines that Roma women are generally in worse health and more disadvantaged than Roma men and non-Roma alike.
- Available evidence suggests a range of additional barriers to improved health amongst Roma women, including expectations to fulfil traditional gender roles, limited educational and employment opportunities, physical and social isolation and poor living conditions.
- Maternal health risks (i.e. early and late pregnancies, large families, poor access to and low uptake of antenatal care) and poor outcomes (i.e. miscarriage and still birth) are more common in Roma women.
- Evidence suggests that Roma women are at higher risk of domestic violence and associated mental health risks.
- A Spanish study reported that the position of Roma women had improved as a result in part due to lower birth rates, but also reported that they suffered more from obesity, depression, metabolic diseases, and sexual health problems; exercised less and had lower uptake of breast and cervical cancer screening.
- A French study suggests Mediation Programmes appear to offer a potentially effective means to engage with Roma women about health issues.

### Environmental and socio-economic determinants of health

- European institutions (the FRA and Eurofound) publish the most comprehensive data on environmental and other socio-economic factors.
- The housing situation of Roma families is generally worse than the housing situation of non-Roma citizens, though in a minority of countries some evidence suggested that access to social housing and standards were comparable to the general population (Germany, Lithuania, and Sweden).
- The Eurofound study reported that accommodation overcrowding is most severe in Slovakia and Hungary, and Roma suffer problems such as poor sanitation and segregation.
- Roma usually have a lower level of education than non-Roma. Comparatively low educational attendance (Bulgaria, Greece and Romania) and segregation remain challenges (Estonia and Germany).

- In all Member States that have statistics on Roma employment, unemployment rates of Roma are higher than those of non-Roma. Particularly stark differences in employment levels between Roma and non-Roma have been found in Bulgaria, Croatia, Ireland, Lithuania, and Hungary.

Although the main conclusions above show that sufficient data on Roma exists to evidence poor health and social and economic exclusion, there are still vast gaps in Roma health data which impedes our full understanding of the situation. Data that allows for comparisons between populations and that constitutes a baseline for measuring health improvements, are systematically collected predominantly on an international level and the data from national and regional level which are available is partly old, patchy and is not suitable for extrapolation. Member States that have implemented data collection systems should be encouraged to share and help spread best practice to ameliorate this situation.

Unfortunately little of the available evidence on Roma health adequately describes or categorises the precise ethnic group or lifestyle characteristics of the Roma communities concerned. Consequently it has not been possible to systematically review health across the actual heterogeneity of Roma groups, for instance whether they are settled, travelling, segregated or integrated, remotely located, living in urban or rural areas, migrant or non-documented.

There are also indications that not all data collected is fully utilised in the Member States nor used extensively as a basis for effective policymaking to improve the health situation of Roma. Past research efforts have largely focused on infectious diseases among Roma, yet not even here is there an identifiable comprehensive evidence base and baseline. There are gaps in largely every indicator covered by the study, with particularly acute gaps concerning Roma women's health, mental health issues, and migrant health. Methodologically, there is a dearth of longitudinal and in-depth studies to support and contextualise the findings uncovered by the international surveys.

The Roma population is the largest minority in Europe, living in principally all EU Member States. The poor health and data status of the Roma population is therefore a truly European issue which needs to be tackled through pan-European research and engagement.

The European Commission, the European Union Fundamental Rights Agency, the United Nations Development Programme and the World Bank are leading this work through their continued commitment to research, community engagement and in the development of the National Roma Integration Strategies. This work is vital and needs to be further supported by the Member States that, although improving, can step up their activities. As discussed in the accompanying Report on Roma health data, the Structural Funds make funds available to support socio-economic integration of marginalised communities such as Roma.

## Recommendations

The findings of this project suggest that comprehensive programmes of initiatives across the full range of potential public health interventions continue to be required across Europe to improve the health of Roma.

While variation exists between individual countries, in terms of the size, nature, and health of Roma populations and existing initiatives, it seems likely that all the actions above require consideration and review to varying degrees in all countries in order for proportionate responses to be made.

Key areas for potential action are summarised below.

### Wider determinants of health

- Access to and engagement with educational systems
- Improvement of employment opportunities
- Reductions in segregation and marginalisation
- Improvements in the provision of facilities with improved living conditions

### Healthy lifestyles and behaviour

- Provision of tailored health information materials
- Community initiatives to improve health engagement in Roma communities

### Disease prevention

- Improved information provision and marketing of disease prevention opportunities and services to Roma communities
- Adequate provision of tailored disease prevention programmes and services acceptable to Roma communities and meeting their particular needs (e.g. mobility and living circumstances)

### Accessibility to high quality services acceptable to Roma communities

- Adequate provision of tailored health services acceptable to Roma communities and meeting their particular needs in areas of large Roma communities
- Improvements in adherence to good practice standards (including discrimination) in the provision of health services to Roma by universal health care providers and professionals.

### Knowledge

Design of the above programmes and initiatives need to be informed by:

1. Improved generation of consistent information on the health risks and outcomes experienced by Roma communities to monitor progress, tailor action and target resources.
2. Monitoring and evaluation of interventions to improve Roma health.
3. Review and dissemination of knowledge on interventions effective in improving the health of Roma communities.
4. Translation of knowledge on effective interventions into best practice guides for policy makers and programme and service managers.
5. Primary research into key obstacles in improving Roma health, including:
  - i. Approaches to improve health knowledge in the Roma population.
  - ii. Tailoring of health knowledge, lifestyle and behaviour messages to recognise the perspective of Roma persons.
  - iii. Tailoring the delivery of health improvement, disease prevention and primary care services targeting or serving Roma communities.
  - iv. Empowerment of Roma girls and women.

### Investment

Investment in Roma health issues should be reviewed through systematic processes examining the size and needs of Roma communities, and knowledge on the effectiveness of alternative policies, programmes and services.

These recommendations should be read in parallel with the recommendations included in Report II regarding action to improve data collection and monitoring of Roma health status.

### **Limitations**

The data available on Roma health in Europe is overall limited, and is widely variable between the 31 included countries and associated regions. Consequently conclusions and recommendations are necessarily and appropriately high-level. Much of the available evidence has been collected largely through small surveys and studies of variable quality, with few providing clear information on the characteristics or immigration status of the groups studied, and limited sources of universal comprehensive data.

# **Part 2**

## **Data Collection**

### **in the Member States**

## Introduction

This report on Member States' current and future activities in data collection and development of specific surveys aiming to monitor the progress in the implementation of the NRIS in the area of health is the second of the two deliverables that constitute the Final Reports on the health status of the Roma population in the EU and the monitoring of the data collection in the area of Roma health in Member States.

The report is based on evidence and findings from the 28 EU Member States and the three EEA countries and presents draft conclusions on the following:

- How European countries collect data on Roma (especially health data)
- The extent to which such data are drivers in defining a national strategy for Roma in the health sector
- To what extent the existing or future actions in data collection can be aligned to the monitoring 'needs of the National Roma Integration Strategy (NRIS).

A report on Roma health in the EU, dovetailing this report, has assessed the health status and the health-related lifestyle attributes of the Roma population<sup>624</sup>. The findings of the report confirm what many supranational institutions and non-governmental organisations (FRA/UNDP, the World Bank, WHO, the EU) have already documented; compared to the non-Roma populations, Roma tend to be in poor social and economic circumstances and this is negatively affecting their health status. Members of Roma communities are subject to lower levels of life expectancy and exposed to a higher risk of serious illness. There is higher prevalence of respiratory and chronic diseases because of poor living conditions, and physiological discomforts related to the feeling of loneliness caused by segregation.

The next sections begin with an outline of the methodology, before moving on to illustrate the rationale of the study and provides a brief overview of the EU interventions for the inclusion of Roma in general, and for the health information system and policies in particular. This is followed by the main findings regarding the strengths and weaknesses of the data collection systems, and an exploration of which actions Member States are putting in place to monitor the progress and impact of the NRIS. The report ends with conclusions and recommendations.

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<sup>624</sup> Matrix Knowledge in collaboration with the Centre for the Study of Democracy, the European Public Health Alliance and individual national researchers on behalf of the Consumers, Health and Food Executive Agency and DG SANCO Reports on the health status of the Roma population in the EU and the monitoring of data collection in the area of Roma health in the Member States, 2013



## Background and Context

International and European institutions – the UNDP, World Bank and the FRA – are carrying out important work through their Roma survey exercises, which are providing the richest sets of comparable data across a significant number of countries. Although methodologically sound, surveys could usefully be complemented with other methods and tools. In particular by mapping micro regions and neighbourhood suffering of multiple disadvantages based on economic, infrastructural, employment and social indicators, Roma communities are likely to be reached given that they are highly overrepresented in most of these backward areas. Data gathered at regional and local levels, including by European project networks, Non-governmental Organisations (NGOs) and by Mediator programmes, also contribute to the overall understanding of the Roma conditions.

The EU has been supporting international network initiatives such as the First Roma Summit in 2008 and the Decade of Roma Inclusion (2005-2015). The Enlargement Countries have shaped their strategies to support the integration of Roma based on these foundations.

In February 2013, the International Organization for Migration launched the European Commission co-funded 'Equi-Health'; a three-year action with the objective to improve the access and quality of health care services, health promotion and prevention to meet the needs of migrants, Roma and other vulnerable minority groups, including irregular migrants. The action is prioritised within the EC 2012 Public Health Programme. The Equi-Health sub-action on Roma Health aims at supporting national authorities in monitoring, sharing and strengthening national approaches to Roma health. To this end, it will develop a coherent network and promote dialogue among key stakeholders on Roma health related issues and delineate strategies and interventions to support capacity building and cooperation within and between participating states. Progress country reports on the implementation of the Roma Integration Strategies and other national commitments to improve Roma health are planned to support EU Member States to better monitor, share and strengthen their national approaches<sup>625</sup>.

Notwithstanding the European guidance in implementing the non-discrimination package; the results for better inclusion of the Roma population have been limited<sup>626</sup>. In particular, issues related to health have been only partly addressed.

Despite Member States being committed to achieving common objectives – and related indicators – to reduce inequities in health (i.e. European Health Strategy 2008-2013), among and within countries, differences in health between the most advantaged and most disadvantaged social classes of the population remains substantial. The economic crisis has also exacerbated the situation because of the reduced possibility to access healthcare, preventive and social services, raising concern about the European solidarity model based on the universal right to health<sup>627</sup>.

Many sources confirm that the Roma population is suffering disproportionately from poor health in comparison with the general population. The Council has identified the

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<sup>625</sup> For further information and updates please visit <http://equi-health.eea.iom.int/>

<sup>626</sup> Council Conclusions 10658/11: 'An EU Framework for National Roma Integration Strategies up to 2020'. COM(2011) 173 'EU Framework for National Roma Integration Strategy'

COM(2013) 454 final: "Steps forward in implementing national Roma integration Strategy"

<sup>627</sup> COM (2009) 567 on Inequalities – Solidarity in Health

need for additional action on the health of Roma<sup>628</sup>, underpinned by the EU's overarching objectives to create economic growth with social inclusion as part of the Europe 2020 strategy.

Specifically, Member States were asked to include in their new National Roma Integration Strategy, presented to the European Commission in 2012, specific goals in the area of health, that, together with education, employment and housing, are seeking an integrated approach to inclusion.

Although the initial health conditions of Roma vary among countries, Member States have committed themselves to reducing the gap in the health status between Roma and the general population by:

- extending health and basic social security coverage and services (also via addressing registration with local authorities)
- improving the access of Roma, alongside other vulnerable groups, to basic, emergency and specialised services
- launching awareness raising campaigns on regular medical checks, pre- and postnatal care, family planning and immunisation
- ensuring that preventive health measures reach out to Roma, in particular women and children
- improving living conditions with a focus on segregated settlements.

Notwithstanding the Member States' engagement in the field of Roma inclusion, the first Commission assessment of the NRIS has reported some limitations regarding the possibility of measuring the potential impacts of the stated objectives<sup>629</sup>. There is a need to establish specific targets; attainable goals within the time frame set; and measurable deliverables through an effective system of monitoring and evaluation of the implementation of the national policies<sup>630</sup>.

The second Commission assessment in June 2013 reiterated that Member States need to make stronger efforts to set up sound monitoring and evaluation methods to assess the results and impacts of Roma inclusion measures, including health, in order to enable policy adjustments when necessary<sup>631</sup>.

The aim of the present study is therefore to assess the extent to which the existing research and data collection systems on Roma health might support the shaping of more relevant policies for Roma. The study explores the possible synergies between existing research and policy indicators and the NRIS monitoring system. In addition, this study analyses whether Member States are planning appropriate actions to systematically capture the overall impact of the strategy on Roma health as a whole, and suggest solutions in this context.

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<sup>628</sup> Council conclusion on inclusion of the Roma.

<http://ec.europa.eu/social/BlobServlet?docId=2808&langId=en>

<sup>629</sup> COM(2012) 226: 'National Roma Strategy Integration

COM(2013) 454: 'Steps forward in implementing national Roma integration Strategy'

<sup>630</sup> Impact Assessment Guidelines, European Commission (2009)

<sup>631</sup> COM(2013) 454: 'Steps forward in implementing national Roma integration Strategy'

## Methodology

The purpose of this study was to support the Consumers, Health and Food Executive Agency (Chafea) and DG SANCO to assess the progress of the Member States in the implementation of monitoring systems to gauge the outputs, outcomes and impacts of the National Roma Integration Strategy regarding health. This has been done through the collection of data on current capacities (and planned activities) and limitations or legal barriers to obtain and analyse information on Roma.

Our methodology entailed two steps of data collection that in turn developed our conclusions and recommendations:

- Desk Research (assessment of the National Roma Integration Strategies and related documentation including evaluations of the NRIS)
- Fieldwork research collecting primary data through a Delphi Survey.

### Desk Research activities

The first step of the research consisted of a comprehensive review of the existing institutional and academic literature on the methods and techniques to monitor Roma health status.

The National Roma Integration Strategies of each country were analysed. We assessed whether the national programming strategy: (i) identifies the specific objectives in the field of health, (ii) whether a monitoring system has been put in place or planned; and (iii) to what extent such the monitoring system is able to assess the impact of the proposed strategy's health interventions.

Such assessment of the NRIS was carried out against the SMART Objectives approach, an acronym built around the five leading measures of a strong strategy<sup>632</sup>:

**Specific** – The strategy has a precise objective to be accomplished. The outcome is stated in numbers, percentages, frequency, reach, scientific outcome, etc. The objective is clearly defined.

**Measurable** – The objective can be measured and the measurement source is identified.

**Achievable** – The objective or expectation of what will be accomplished must be realistic given the initial conditions, time period, resources allocated, etc.

**Relevant** – The outcome or results of the strategy should be relevant for the targeted beneficiaries

**Timely** – This means stating clearly when the objective will be achieved

### Field work activities (Delphi survey)

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<sup>632</sup> Impact Assessment Guidelines, European Commission, 2009

The second step of our research was the launch of a Delphi survey. This targeted stakeholders at EU / International and national levels. The list of the persons contacted can be found in the Appendices.

A Delphi survey is a useful tool in building consensus among diverse or dispersed stakeholders. It is also useful in areas of limited research, since ideas are generated from a knowledgeable participant pool. It was originally developed as a means of forecasting future scenarios, although the method can equally be used to determine the range of opinions on particular matters, to test questions of policy, and to explore consensus on disputed topics<sup>633</sup>.

Although the detail of implementation can vary, broadly speaking, a Delphi survey poses questions to a group of participants who have been selected based on their knowledge of a specific topic. Delphi surveys tend to be constructed on two rounds:

1. The first round is designed to generate ideas and respondents are asked to identify a range of important issues.

During the first round the Delphi survey explored which types of data, studies and research (including methodologies and tools) are used but equally what data and research would facilitate the understanding and monitoring of Roma health. The questions also explored which types of data and research is used successfully and might be shared across countries or stakeholder groups. We will equally look at the issue of transferability i.e. gathering broader lessons that would help inform the development of a future Roma Health Data Strategy.

One open question was included to allow respondents to articulate additional ideas freely or provide other feedback.

2. The second round collates ideas gathered from the initial round to construct policy responses.

For the second round our Delphi survey focused on presenting and inviting validation of a number of specific policy initiatives which could support the process of gathering data and monitoring Roma health in the context of the National Roma Integration Strategy. This included local regional and national actions.

One open question was included to allow respondents to articulate additional ideas freely or provide other feedback.

3. Delphi surveys can also include a third round in which respondents would be provided with the results of the first two rounds and invited to re-evaluate their original responses<sup>634</sup>.

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<sup>633</sup> S Iqbal and L Pison-Young, the Delphi method: a step-by-step guide. Available at: [http://www.thepsychologist.org.uk/archive/archive\\_home.cfm/volumeID\\_22-editionID\\_177-ArticleID\\_1536-getfile\\_getPDF/thepsychologist/0709meth.pdf](http://www.thepsychologist.org.uk/archive/archive_home.cfm/volumeID_22-editionID_177-ArticleID_1536-getfile_getPDF/thepsychologist/0709meth.pdf)

<sup>634</sup> Ibid

Potential strengths and weaknesses of Delphi surveys are listed below.

Strengths	Weaknesses
Draws together existing knowledge and pinpoints areas of agreement/disagreement	High levels of commitment required from panellists; drop-out levels may be high
Enables group communication that otherwise might have been impossible due to geography or time constraints	Generalisations are limited: another panel may reach different conclusions, and it cannot be concluded that the only or correct issues have been identified
Conformity to the dominant view less likely <sup>635</sup>	

The Delphi survey was created using an online survey tool. The drafts of both Delphi surveys were submitted to the client for comments before finalising the tools. The list of respondents to the surveys, the questionnaires and the NRIS country fiches are appended to this report. The Research Team also received logistical support from Chafea in reaching out to the selected respondents.

The Research Team requested the input of a range of stakeholders:

1. National Public Health Officials across the 31 countries
2. Roma experts of European or international institutions
3. National Roma Experts/NGOs across most of the countries (we did not envisage locating Roma experts in all 31)
4. National Contact Points (NCPs) for the implementation of the National Roma Integration Strategy (second round survey)

Since FRA had recently completed a survey of NCPs on the subject of the NRIS, it was agreed with EAHC to first focus on different survey respondents. We involved the NCPs through the second round of the Delphi survey once the first round and conclusions on the current status of Roma health monitoring were complete.

We were able to reach 38 individuals through the first round of the Delphi survey.

The first round of the survey was launched in the third week of July 2013 (commencing 15 July) and kept open for participation until 8 September 2013. A reminder was sent out to those who had not responded on 2 September. In parallel we launched a semi-structured interview programme involving a select (sub-) group within the three groups above.

The second round of the survey targeting the NCPs was launched 31 October 2013 and left open one month, and we received responses from 12 individuals. Due to the medium level of response, we contacted the remaining NCPs via mail and phone (receiving three more respondents). The results of the analysis of the national strategies were synthesised in NRIS country fiches.

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<sup>635</sup> S Iqbal and L Pison-Young, the Delphi method a step-by-step guide. Available at: [http://www.thepsychologist.org.uk/archive/archive\\_home.cfm/volumeID\\_22-editionID\\_177-ArticleID\\_1536-getfile\\_getPDF/thepsychologist%5C0709meth.pdf](http://www.thepsychologist.org.uk/archive/archive_home.cfm/volumeID_22-editionID_177-ArticleID_1536-getfile_getPDF/thepsychologist%5C0709meth.pdf)

## Results (Findings)

This section presents our findings of the desk research, surveys and interviews undertaken.

### Mapping practices in data collection on Roma health status

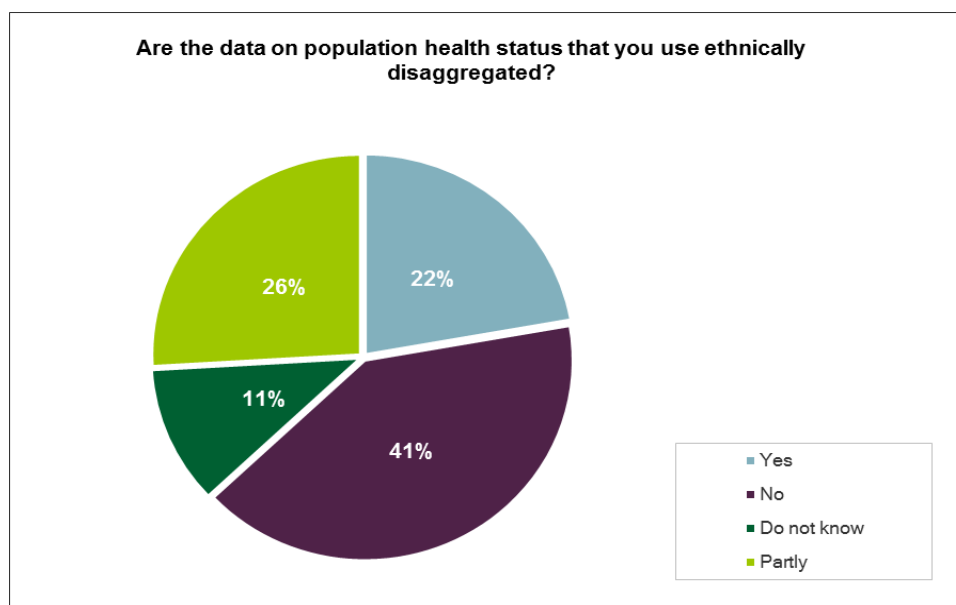
#### Country actions

Our findings reveal a rather fragmented picture across Member States in the data collection system to monitor Roma health.

Reporting on the health status of Roma poses some practical data obstacles. One of the main – and most discussed – obstacles is the lack of ethnically disaggregated data on health status. Many of the censuses in the European Union do not gather data on ethnicity<sup>636</sup>.

Our survey<sup>637</sup> reflected this, with 40.7% of the respondents reporting the lack of disaggregated data and 25.5% relying mainly on administrative registers or existing international surveys able to provide partly disaggregated data.

**Table 30 Level of availability of disaggregated data by ethnicity**



Source: Roma Health Report First Round Survey, Question n.12

<sup>636</sup> CoE (2007): "Ethnic" statistics and data protection in the Council of Europe countries, 2007 [http://www.coe.int/t/dghl/monitoring/ecri/activities/themes/Ethnic\\_statistics\\_and\\_data\\_protection.pdf](http://www.coe.int/t/dghl/monitoring/ecri/activities/themes/Ethnic_statistics_and_data_protection.pdf)

<sup>637</sup> The survey was carried out in the period between 15 July and the 8 September. It was directed to a sample of 150 respondents selected between national and regional health institutions, policy maker and representatives of civil society (i.e. NGOs advocacy for Roma). Survey respondents rate 38 persons.

Research carried out by academic experts within the framework of the FP7 project on Promoting Comparative Quantitative Research in the Field of Migration and Integration in Europe (PROMINSTAT) reveals that of the 25 EU Member States surveyed prior to EU enlargement in 2007 only Estonia, Ireland, Lithuania, Slovenia and the United Kingdom collect data on 'ethnicity' in their national censuses<sup>638</sup>. Bulgaria and Romania, who joined the EU in 2007, also collect data on ethnicity. The Member States often refer to the EU legislation on data protection as an explanation for not collecting ethnic data. The legitimacy of this as the primary reason is discussed in Simon (2007)<sup>639</sup>. This report, summarising the European Commission against Racism and Intolerance's position, is "that the collection of ethnic data is a beneficial instrument for shaping sound policies against racism and racial discrimination" and helps monitor improvements<sup>640</sup>.

The Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data, prohibits the processing of data revealing racial or ethnic origin, unless such data is used to prove discrimination. Moreover, the Directive permits the use of ethnic data for legitimate activities and with appropriate guarantees, if the actual consent of the persons has been secured<sup>641</sup>. Some countries, such as France, have specific provisions in their national legislation that explicitly prohibit the gathering of ethnic data.

In general when looking at Member States, collection of data is normally organised through a bottom-up system with regional and local authorities gathering data that is then aggregated nationally. However since national legislation normally prevents countries from taking information on the basis of ethnicity, quantitative information about Roma is fragmented at a local level. Data is also sparse and data collection appears to have shortcomings in terms of quality, timeliness, collection methods and reporting.

The low level of satisfaction among the respondents taking part in the first round of the survey (Table 3) supports emerging findings from the review of the existing sources and literature. In particular the system of collection and the techniques available is judged to be 'very poor' or 'poor' with specific concerns on the possibility of comparing data on Roma health with the general population. The timeliness of the data it is also a major issue, with half of the respondents unable to state how frequently the data that they have access to is collected<sup>642</sup>. In an email response to the survey, one respondent commented on the challenge of undertaking systematic data collection for a very mobile population.

A medium level of satisfaction has been registered, instead, regarding the level of cooperation among the different tiers of jurisdictions and actors involved in the collection of Roma health data.

### **Table 31 Level of satisfaction with data collection of Roma Health**

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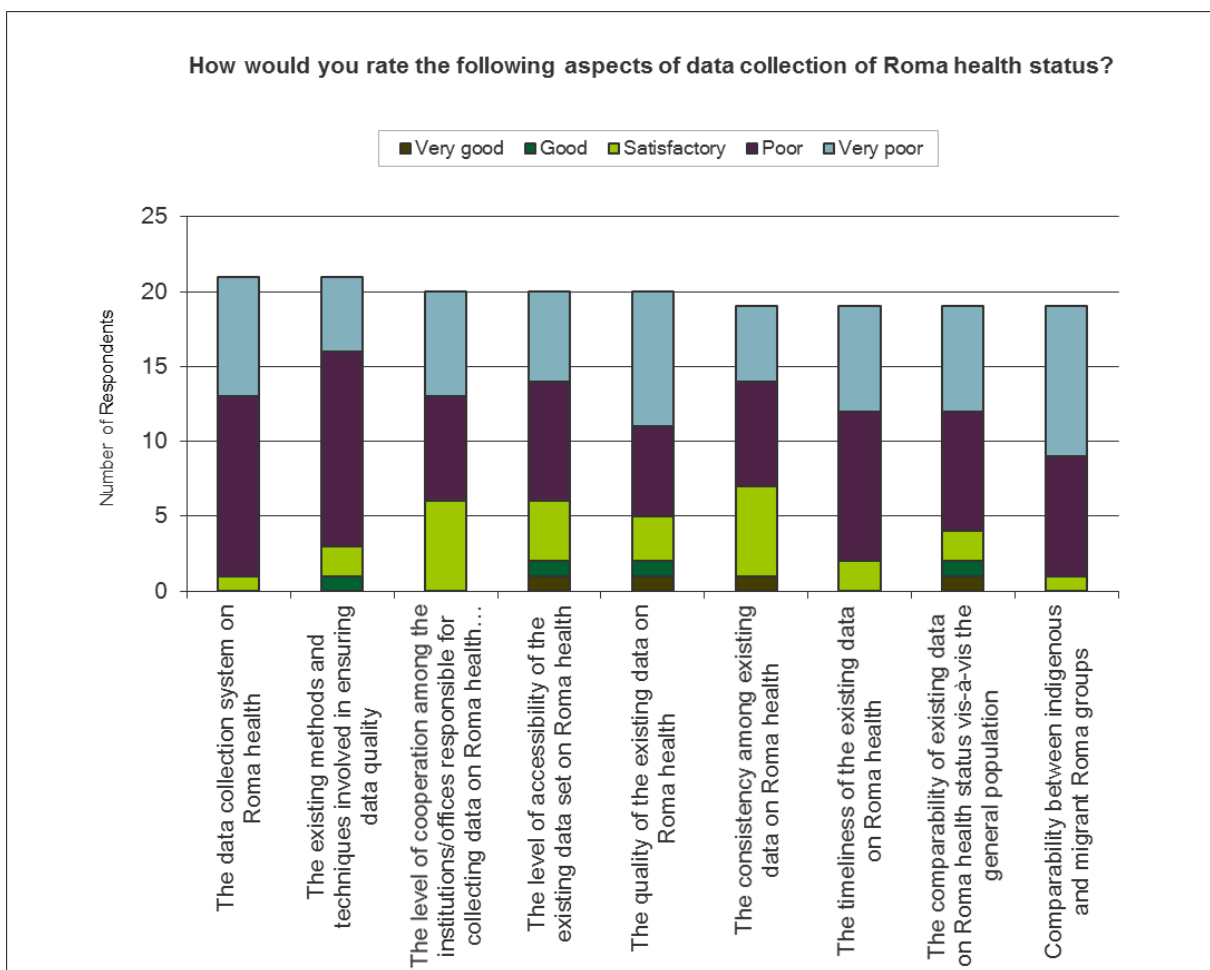
<sup>638</sup> Fonseca, M.L., McGarrigle, J. and Esteves, A. Possibilities and limitations of comparative quantitative research on immigrant's housing conditions, PROMINSTAT, Thematic Study on Housing. 2010

<sup>639</sup> Simon P. Institut National d'Etudes Demographiques European Commission against Racism and Intolerance "Ethnic" statistics and data protection in the Council of Europe countries, 2007

<sup>640</sup> Simon P. Institut National d'Etudes Demographiques European Commission against Racism and Intolerance "Ethnic" statistics and data protection in the Council of Europe countries, 2007

<sup>641</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:31995L0046:en:HTML>

<sup>642</sup> Survey Question n.16.



Source: Roma Health Report First Round Survey, Question n.22

The table in the next page illustrates which actors have been involved in the collection of data in the health sector and which quantitative surveys have been carried out based on primary data.



**Table 32 Overview of actors involved and of the studies carried out as a regard as Roma health data collection<sup>643</sup>**

AT	BE	BG	HR	CY	CZ	DK	EE	FI	FR	DE	EL	HU	IS	IE	IT
Academic studies  FRA Raxen Study	ESF Study  FRA Raxen Study	Academic studies NGOs  FRA UNDP survey  Bulgarian census (unconfirmed)	Academic studies  FRA UNDP Survey	Academic studies  FRA Raxen Study	Academic/ Government  NGOs  FRA UNDP survey  Statistical office European Health information Survey	Danish National Health Board	Central Statistics Office (housing)  Ministry of Culture  FRA Raxen Study	FRA Raxen Study  Religious institutions	NGOs  FRA UNDP Survey	NGOs  FRA Raxen Study	Ministry for Labour and Social Affair and the EU  FRA UNDP Survey  MULTI ROMA ACTION HELLAS  NGOs	Central Statistics Office  Academic Studies  FRA UNDP survey	No Research	Central Statistics Office  Academic Studies  NGOs  FRA Raxen Study	Academic Studies  NGOs  Research Centres  FRA UNDP Survey  FRA Raxen Study
LV	LI	LT	LU	MT	NL	NO	PL	PT	RO	SK	SI	ES	SE	UK	
Register on Drug and Substance Users  FRA Raxen Study	No Research	Academic Studies  NGOs  Research Centres  FRA Raxen Study	No Research	No Research	FRA Raxen Study	No Research	Central Statistics Office  Academic Studies  EP Study  FRA UNDP Survey  FRA Raxen Study	Health and Roma Community  FRA UNDP Survey	Academic Studies  FRA UNDP Survey  NGOs	Regional Office for Public Health (Programme of health support of disadvantage community in Slovakia)  Academic Studies  FRA UNDP Survey	Academic Studies  FRA Raxen Study	Spanish ministry of Health NGOs and EU  Academic Studies  FRA UNDP Survey	Swedish National Institute of Public Health  Ministry of Justice Ministry of Social Inclusion FRA Raxen Study	Central Statistics Office  Academic Studies	

Source: Country profile (please see Appendix B)

<sup>643</sup> References for each of the study mentioned are detailed in the paragraph below.

This study's country-level examination suggests that, in practice limited feasibility to collect data on the basis of ethnicity has contributed to a problem of a 'lack of ownership' regarding minorities and the collection of data.

However, as illustrated in the paragraphs below, in 12 countries (DK, EE, ES, GR, HU, IE, LV, PL, PT, SK, SE and the UK) institutions at domestic central level have carried out quantitative studies to monitor Roma health that might constitute a starting point to evaluate and monitor the national strategy for Roma in the future.

In Denmark, the Danish National Health Board has produced a rich literature on the health of ethnic minorities. This includes indicators for sickness and the use of healthcare services<sup>644</sup>, social risk groups<sup>645</sup>, prevention, and health promotion<sup>646</sup>. The majority of these studies draw on register data, in which Denmark offers a wide range of individual data records associated with the social security number (CPR). Through these public registers it is generally possible to distinguish between ethnic minorities using birthplace and parents' citizenship as proxies<sup>647</sup>. Neither of these indicators directly reveals the ethnicity of the individual in question, respecting Danish law regarding data protection.

In Estonia the census collects data on ethnicity, but it is unclear whether the Roma population will be included as a minority in the on-going publication: 'Households and families' based on the population and housing census in 2013. In addition, a survey of subcultures, including Roma, from the Estonian Ministry of Culture was conducted in 2012-2013. The results from this survey should subsequently illustrate how the Roma target group cope in society as well as map the need of Roma.

In Poland and Hungary censuses collect data on ethnicity, but in both cases information is not up-to-date and only basic demographic information is provided, and do not relate to health. However the Hungarian academic community have produced a significant amount of information based on comparison between the general population and the Roma communities. For example a study has been undertaken which merged two sets of databases – the National Health Survey 2003 (representative), and the Roma Health Survey 2004 (non-representative). The Roma Health Survey (2004) is a survey of the adult population living in Roma settlements in three counties of north-eastern Hungary, part of the country with the highest Roma population. The limitations of the survey are that it was not representative of the overall Hungarian Roma population. By design, it excluded Roma who have, to various degrees, assimilated with the majority population; it captured the characteristics of the most disadvantaged section of the Roma population. However, the needs of this group are the most important to understand from a policy perspective. Data are disaggregated by age, ethnicity (People Living in Roma Settlements), gender, and status (Lowest Income Quartile)<sup>648</sup>.

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<sup>644</sup> Vinther-Jensen and Primdahl (2010) *Etniske minoriteter i det danske sundhedsvæsen – en antologi*. Sundhedsstyrelsen, Copenhagen Folman and Jørgensen (2006) *Etniske minoriteter – sygdom og brug af sundhedsvæsenet – et registerstudie*. Sundhedsstyrelsen, Copenhagen.

<sup>645</sup> Sundhedsstyrelsen (2006) *Social udsathed og viden hos etniske minoriteter – rådgivning fra Sundhedsstyrelsen*. Sundhedsstyrelsen, Copenhagen

<sup>646</sup> Kristiansen et al. (2006) *Forebyggelse og sundhedsfremme for etniske minoriteter – målgruppeinddragelse og organisatorisk forankring*. Sundhedsstyrelsen, Copenhagen

<sup>647</sup> <http://www.dst.dk/da/informationsservice/oss/valg/regvalg.aspx>

<sup>648</sup> Kósa, Zs., Széles, Gy., Kardos, L., Kósa, K., Németh, R., Országh, S., Fésüs, G., McKee, M., Ádány, R., Vokó, Z. (2007) "A Comparative Health Survey of the Inhabitants of Roma Settlements in Hungary." *American Journal of Public Health*. May; 97(5): 853-859.

In Greece and Portugal synergies between the national level policies and EU institutions have produced a large quantity of data regarding Roma health lifestyle, based on direct and indirect interviews. In Greece as a result of research under the Operational Programme 'Multi Roma Action Hellas' (2000) the health lifestyle of 698 Roma families were scrutinised for a total of 4,086 individuals.

In Latvia and Slovakia, data collected at a local level has been the basis for research. In Latvia the Register on Drug and Substance Users allows for the collection of data on the basis of ethnicity and the comparison between minorities and the general population. In Slovakia in 2003-2004 NGOs together with the government carried out a mapping exercise of Roma settlements and communities that have then become the target of resources of Structural Funds<sup>649</sup>. Likewise in Spain and Sweden there have been synergies among health institutions, academic researchers and NGOs. In Spain this collaboration has resulted in the collection of a body of data mapping the health situation of Roma in the country. The data allowed for analysis of the health status of Roma in Spain in comparison to national health indicators, which informed specific measures to address health inequalities of Roma<sup>650</sup>.

In Sweden the most important recent study mapping the health situation of national minorities in the country (2010) was carried out by the Swedish National Institute of Public Health in collaboration with representatives of national minorities and the Swedish National Board of Health and Welfare together with the National Commission of Roma Issues<sup>651</sup>. The research for this study (carried out in 2008-2009), however, met strong resistance from Roma groups and organisations who feared a systematic registration of the Roma population, even if the existing national legislation on data protection would have mitigated this risk. The quantitative survey approach was then abandoned in favour of individual qualitative interviews combined with focus groups meetings<sup>652</sup> reaching a total 334 individual Roma<sup>653</sup>. In France, data is collected through the use of intervention programmes, such as providing access or supporting relocation<sup>654</sup>.

Ireland and the United Kingdom systematically collect data on ethnicity through their censuses. In Ireland a study was launched in July 2007 with the aim of mapping the Traveller population and examining their health status to assess the impact of the health services currently being provided and to identify the factors that influence morbidity, mortality and health status<sup>655</sup>. According to the Irish study coordinator, the key success of these initiatives was the involvement of Roma who when explained that

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<sup>649</sup> <http://www.errc.org/cms/upload/file/improving-the-tools-for-the-social-inclusion-and-non-discrimination-of-roma-in-the-eu-2010.pdf>

<sup>650</sup> Towards Health Equality, available at: <http://www.msc.es/profesionales/saludPublica/prevPromocion/promocion/desigualdadSalud/jornadaEquidadSalud.htm>

<sup>651</sup> Statens Folkhälsoinstitut (2010) Hur mår Sveriges nationella minoriteter? Kartläggning av hälsosituationen bland de nationella minoriteterna samt förslag till förebyggande och hälsofråamjande åtgärder. Available at: <http://folkhalsomyndigheten.se/documents/livsvillkor-levnadsvanor/nationella-minoriteter/redovisade-uppdrag/aterrapportering-hur-mar-sveriges-nationella-minoriteter.pdf>

<sup>652</sup> Statens Folkhälsoinstitut (2010) Hur mår Sveriges nationella minoriteter? Kartläggning av hälsosituationen bland de nationella minoriteterna samt förslag till förebyggande och hälsofråamjande åtgärder. Available at: <http://folkhalsomyndigheten.se/documents/livsvillkor-levnadsvanor/nationella-minoriteter/redovisade-uppdrag/aterrapportering-hur-mar-sveriges-nationella-minoriteter.pdf>

<sup>653</sup> Presentation to EU-Expert group on social determinants and health (2013) Sweden's Strategy for Roma Inclusion 2012-2032. Luxembourg. Available at: [http://ec.europa.eu/health/social\\_determinants/docs/ev\\_20130121\\_co05\\_en.pdf](http://ec.europa.eu/health/social_determinants/docs/ev_20130121_co05_en.pdf)

<sup>654</sup> Email communication 10<sup>th</sup> September, Mission Prospective et Recherche, Direction Générale de la Santé

<sup>655</sup> Our Geels-All Ireland Travellers Health Study, available at:

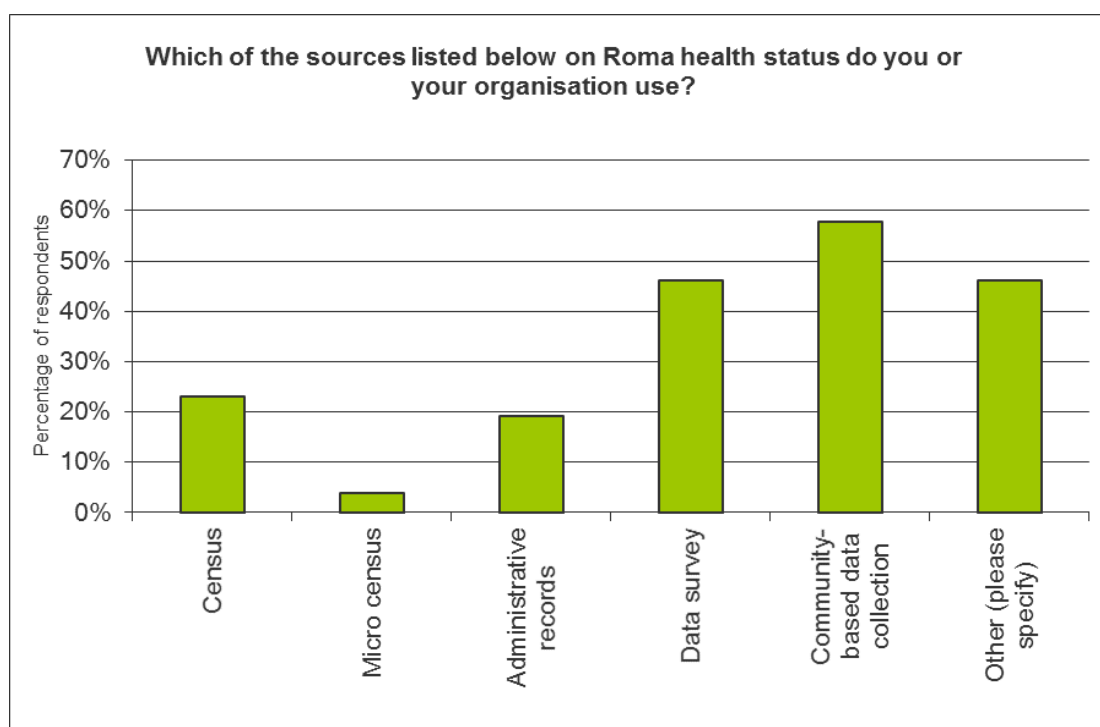
<http://pavepoint.ie/travellers-and-issues/traveller-health/our-geels-health-study/>

investigations on the basis of ethnicity might lead to policies that are beneficial to their communities, became less reluctant to identify themselves as Roma<sup>656</sup>.

Consequently, judging by the above-mentioned examples, the surveys have to some extent overcome the deficiencies in disaggregated data by providing data on ethnic minorities. Surveys are also a solution to the fact that aside from lacking data on ethnicity, national censuses do not provide a good reference point on Roma health as they are generally conducted every ten years, which does not allow for the development of a dynamic assessment of changes in Roma health status. Surveys by comparison can be repeated, updated and eventually provide longitudinal analyses.

Survey responses also highlight the essential role of local institutions and NGOs in implementing actions to collect data. The results of our first round survey<sup>657</sup> illustrate that the most frequently used sources of information available with regard to Roma Health have been produced as a result of the collaboration of local actors. Community based data collection is the most preferred source (57.7%), followed by data specific survey (46.2%)<sup>658</sup>. Within the group of alternative options, ad hoc surveys (46.2%) are most commonly used.

**Table 33 Most used sources on Roma health**



Source: Roma Health Report First Round Survey, Question n.11

The crucial role exercised by the local actors also holds true when looking at the other 14 countries (AT, BE, BG, HR, CY, CZ, DE, FI, FR, IT, NL, SI, LT and RO), where the actions of the domestic central level of government have been more limited in comparison to the initiatives of local and supranational organisations in collecting

<sup>656</sup> Interview with Ronnie Fray director of the Pavee-Point, Ireland.

<sup>657</sup> The survey was carried out in the period between the 15 July and the 8 September 2013. It was directed to a sample of 300 respondents selected between national and regional health institutions, policy maker and representatives of civil society. Level of feedback 38 respondents.

<sup>658</sup> Survey Question n.11

data. In fact, among those individuals who responded that there are examples of good practice in data collection, surveys supported by the EU and UNDP survey are mentioned most frequently<sup>659</sup>.

It can be concluded that in the 31 countries included in the study, where recent data and research are available they have usually been generated because of civil and academic society initiatives or under the aegis of a supranational institution commissioning ad hoc studies.

Especially after the dissolution of the communist regimes, supranational organisations such as the European Union and its agencies, the World Health Organization, the UN Development Programme, and the World Bank have taken responsibility in carrying out studies and research in those countries where the Roma population is relatively large compared to the general population. In recent years, there has been a tendency towards a constant and enhanced collaboration among supranational and territorial/local actors regarding Roma issues.

Coordinated actions at a supranational level have also helped to fund large-scale surveys that overcome one of the main limitations of the existing studies on Roma health; the small sample size of the ethnic group. This limitation leads to doubts about data reliability at domestic and local level. This is especially true for migrant Roma communities whose small size and mobility makes them very difficult to capture in surveys.

The next paragraph illustrates the main actions carried out by supranational organisations monitoring progress in Roma health.

### **Supranational organisations actions**

Education, employment and social policies (including health) that fall within the competence of the Member States are in general regulated at EU level through the Open Method Coordination (OMC)<sup>660</sup>. The OMC provides a framework for cooperation between the Member States, whose national policies can thus be directed towards certain common objectives. Under this intergovernmental method, the Member States are evaluated by one another (peer review), with the Commission's role being limited to surveillance. Even if not legally bound to monitor the progress of such objectives, EU countries jointly establish measuring instruments (statistics, indicators, guidelines).

Nevertheless monitoring health outcomes remains a significant challenge at EU level. The current EU health information system does not always provide consistently high-quality and fully comparable information. Recognising this challenge, the European Commission, together with Eurostat, has put forward several initiatives for widening access to and improving quality and comparability of health data at EU level. The Commission has produced a list of EU health indicators, based on common definitions, collections and use. The European Community Health Indicators (ECHI)<sup>661</sup> is a core set of over 40 relatively comparable indicators for which country information should be readily available. Nevertheless, problems with lack of national data for many indicators and inadequate comparability between and within countries still exist.

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<sup>659</sup> First Round Survey Question n.32

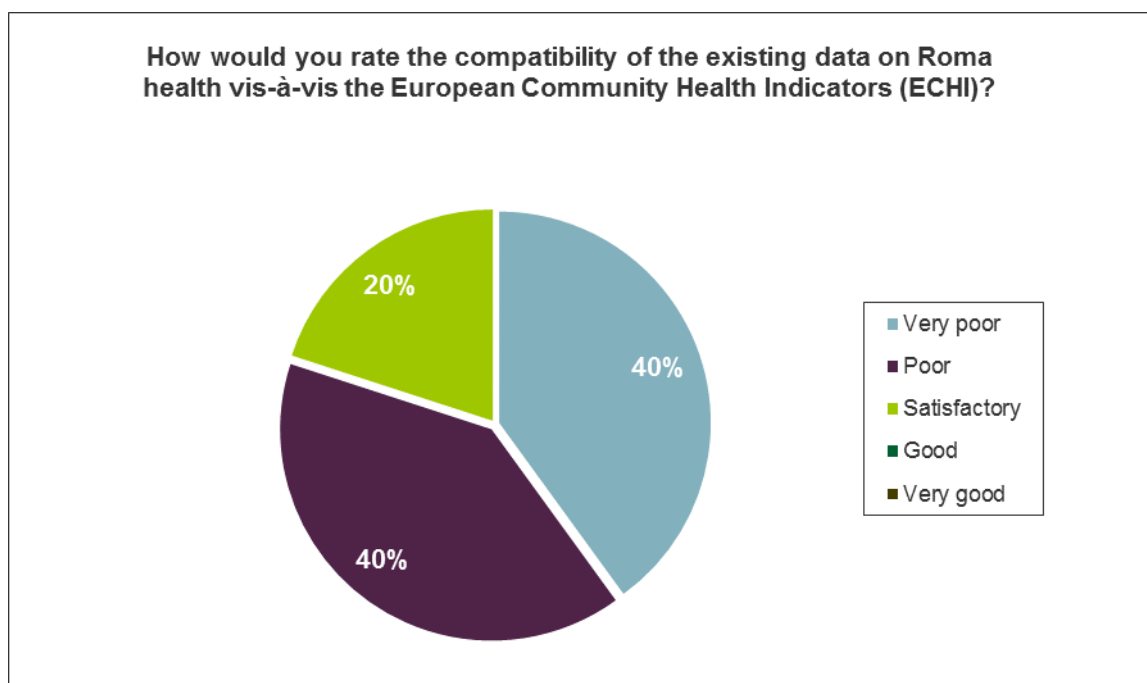
<sup>660</sup> [http://europa.eu/legislation\\_summaries/glossary/open\\_method\\_coordination\\_en.htm](http://europa.eu/legislation_summaries/glossary/open_method_coordination_en.htm)

<sup>661</sup> [http://ec.europa.eu/health/indicators/echi/index\\_en.htm](http://ec.europa.eu/health/indicators/echi/index_en.htm)

To the end of improving health reporting mechanisms, the EU has established the European Health Survey System (EHSS), the European Health Interview Survey (EHIS) and the European Health Examination Survey (EHES). The EHIS is managed by Eurostat under the Community Statistical Programme and is to be held every five years with the first round of the EHIS having taken place between 2006 and 2009. EHIS aims to measure the health status, health determinants and health care service use by EU citizens on a harmonised basis and with a high degree of comparability among Member States. The survey contains around 130 questions with background variables on demography and socioeconomic status. The EHES is a survey that collects health information from both face-to-face interviews and medical examinations. In addition, the European Health Surveys Information Database (EUHSID) was developed to maintain an updated database of the characteristics of major Health Interview Surveys (HIS) and Health Examination Surveys (HES) in Europe. The goal of EUHSID is to gather information on health survey design, questions and examination protocols and to enhance comparability of health surveys.

Although the tools developed at European level have made substantial progress in standardising health monitoring and reporting across the EU, challenges still remain in the coverage of and access to data as well as its comparability. For instance, an overview of the methods and contents of the EHIS concludes that there is a lack of comparability of the questions across countries and some countries have not yet conducted health interview surveys<sup>662</sup>. It is of note that 80% of the respondents to the first round survey rate the level of the compatibility between existing data on Roma health and the ECHI indicators as 'poor' or 'very poor'.

**Table 34 Level of compatibility between existing data and ECHI indicators**



Source: Roma Health Report First Round Survey, Question n.23

<sup>662</sup> Swinkels, H. and Hupkens, C. (1998): Health Interview Surveys in the European Union. Overview Methods and Contents [http://ec.europa.eu/health/ph\\_projects/1998/monitoring/fp\\_monitoring\\_1998\\_annexe3\\_02\\_en.pdf](http://ec.europa.eu/health/ph_projects/1998/monitoring/fp_monitoring_1998_annexe3_02_en.pdf)

In addition, the 'Study to measure the implementation of EU health policies at national, regional and local levels, assessing the utility of existing indicators for this task and developing new indicators as necessary'<sup>663</sup> did not specifically carry out an assessment of the indicators regarding their capability of capturing the health conditions of Roma. However, the study does provide an overall picture of the extent to which existing indicators are able to measure the impact of EU soft law intervention in the field of health. The report concluded that there is a need to streamline the objectives of the EU Health Strategy in order to make them measurable and achievable.

The EU has also set up a monitoring system to report the progress of the goals of the EU 2020, the global strategy of the European Union for the next decade. This global strategy has also set goals to be reached in the area of social inclusion<sup>664</sup>, which are monitored through Eurostat support. The existing European Platform for Roma Inclusion should take marginalised communities as the basis for disaggregating EU2020 targets on education, employment and poverty (including health), but mechanisms for 'explicitly but not exclusively' targeting Roma within these categories have not been set yet<sup>665</sup>.

The Fundamental Rights Agency and the UNDP, funded by the European Commission, have also undertaken a survey and pilot study regarding 'The situation of Roma in 11 EU Member States'<sup>666</sup>. One aim of this survey was to overcome the issue of ethnically sensitive data collection when measuring progress of Roma inclusion.

The survey investigated the condition of Roma in Bulgaria, the Czech Republic, France, Greece, Hungary, Italy, Poland, Portugal, Romania, Slovakia and Spain. 22,203 Roma and non-Roma individuals were interviewed providing information on 84,287 household members. Non-Roma in this context refers to the general population living in close proximity to Roma interviewed in the surveys.

The methodological approach was developed to consider vulnerable people's needs in general and as a part of the assessment of the progress of the Millennium Development Goals<sup>667</sup>. In other words, verifying whether there is anything specific about Roma communities' contributing to health inequalities requires comparisons with neighbouring populations.

As an expert<sup>668</sup> from the UNDP observed, however, in order to make such a survey sustainable and the results comparable across time, major engagement of Member States' central statistical offices, supported by Eurostat, is needed. The reluctance of countries in assuming a stronger role stems from a lack of resources, both financial and intellectual, and the lack of a clear methodology to overcome the ethnicity issue regarding data collection. Census results, which should provide the official number of Roma in each country, have been challenged by significantly higher expert estimates. The reason for this discrepancy is that many of Roma prefer not declare themselves as

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<sup>663</sup> [http://ec.europa.eu/health/strategy/evaluation/index\\_en.htm](http://ec.europa.eu/health/strategy/evaluation/index_en.htm)

<sup>664</sup> In the field of Employment the objective is 75% of the 20-64 year-olds to be employed. In the field of Education, the objective is: reducing the rates of early school leaving below 10%: at least 40% of 30-34-year-olds completing third level education. In the field of Fighting poverty and social exclusion: at least 20 million fewer people in or at risk of poverty and social

<sup>665</sup> Open Society Foundation: Making the most of EU funds for Roma common standards for national Roma integration strategies.

<sup>666</sup> FRA, (2012), "The situation of Roma in 11 EU Member States", UNDP, Publications Office of the European Union: Luxembourg

<sup>667</sup> <http://www.undp.org/content/undp/en/home/mdgoverview/>

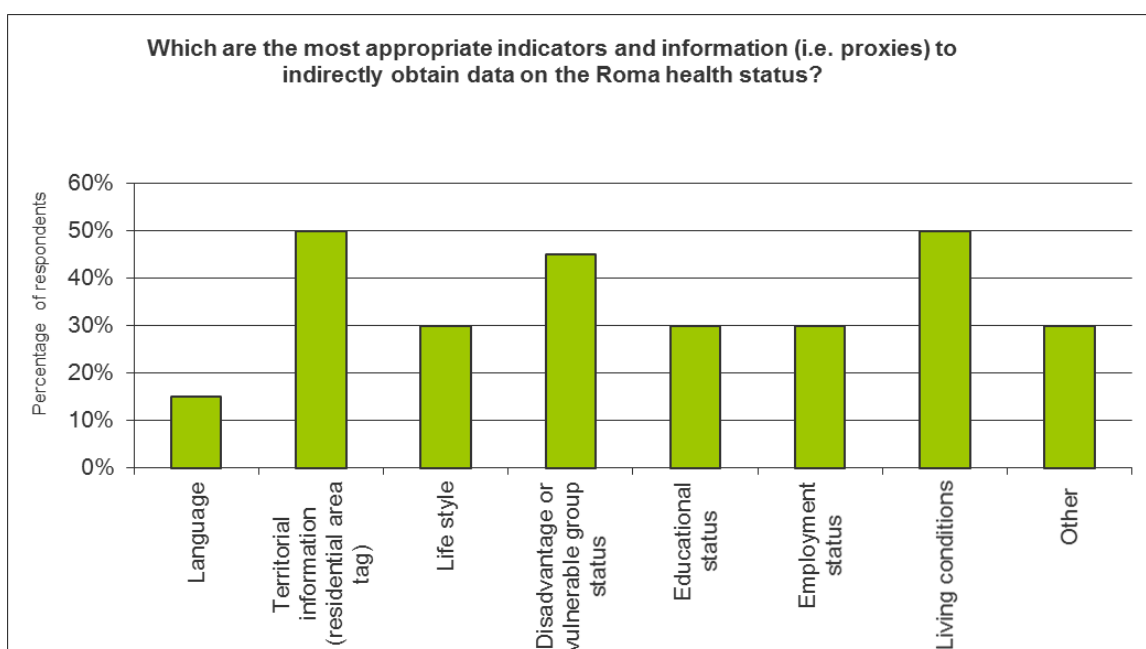
<sup>668</sup> Interview as part of this study with the UNDP 18 June 2013. Unpublished.



such in census surveys for fear of discrimination. In fact official and unofficial population estimates of Roma tend to differ significantly across the EU<sup>669</sup>.

The responses to the first round of our survey confirm that the possibility of developing datasets based on ethnicity within national censuses is limited<sup>670</sup>. Stakeholders were then asked to provide alternative solutions to identify minorities and the potential impact of targeted policy interventions. Territorial and living condition information gathered through local actors are judged to be the most appropriate proxies to indirectly obtain data on Roma health status. Other options suggested are: i) observing the status of vulnerable groups within which Roma are very often present; and ii) gathering data from health bodies that operate close to Roma settlements. In practice, this is geographical data that can be used to obtain information on mortality and life expectancy and to plan health initiatives at local level.

**Table 35 Preferred proxies to obtain information on Roma health**



Source: Roma Health Report First Round Survey, Question n. 37

The solutions provided encompass a territorial dimension in line with the 2011 UNDP pilot project approach<sup>671</sup>. Such an approach is based on the fact that many vulnerable Roma live in communities territorially separated from the general population. Territorial mapping of excluded communities is thus possible through this approach. The following step requires attaching an 'ethnic tag' to the community: i.e. defining the persons living in that area as predominately Roma. These tags can be used by local registries such as social housing and primary care databases. Several indicators can then be calculated on the basis of this approach. Such indicators are nevertheless

<sup>669</sup> Figures provided by the World Bank of Roma in southeastern Europe reveal a total gap between high and low estimates of more than 3.5 million people, Eurofound, Living conditions of the Roma: Substandard housing and health, 2012.

<sup>670</sup> Survey Question n.33

<sup>671</sup> UNDP (2011) 'Quantitative indicators for the measuring progress in the area of Roma Inclusion. Possible approaches to the issues of ethnic sensitive data collection'. Draft Report on the initial findings and ideas.



referring to individuals that live in a certain area and they are not indicators for a specific ethnic group. However given that Roma are normally highly concentrated in a specific territory there is a match.

In line with this approach the European Commission (DG Regio – in close collaboration with the World Bank) – has launched the preparation of the poverty maps in the new EU Member States (except Malta and Cyprus)<sup>672</sup>. The poverty maps present the pockets of extreme poverty on NUTS2 and NUTS3<sup>673</sup> level, and it should help to formulate the social inclusion policies, in order to mobilise people most in need and focusing on the integration of marginalised groups, such as Roma communities.

The geographical approach therefore provides opportunities for observing the progress/impacts of efforts to improve the conditions of the Roma population in specific areas subject to inclusion policies such as the Roma National Integration Strategy.

The next section provides an assessment of the monitoring systems of the Roma National Integration Strategy (NRIS). When possible, specific observations regarding achievements in monitoring health are made.

## Monitoring the National Roma Integration Strategies

In several policy documents the EU institutions and especially the European Commission have underlined the importance of monitoring Roma integration and inclusion efforts by Member States. The following section describes these monitoring obligations, especially with regard to the implementation of the National Roma Integration Strategies (NRIS), and the progress made to date by Member States in putting in place such monitoring systems.

The EU Framework for National Roma Integration Strategies up to 2020<sup>674</sup> foresaw the need for the inclusion of strong monitoring methods in Member States' NRIS (to evaluate the impact of Roma integration actions) and a review mechanism for the adaptation of the strategy. This requirement on the part of the Member States was reiterated in the Commission's progress report of the implementation of the NRIS in 2012:

*Member States should develop or make use of existing robust monitoring systems by setting a baseline, appropriate indicators and measurable targets in collaboration (where possible) with the National Statistical Office<sup>675</sup>.*

Moreover, the Commission observed a greater need to regularly compare data in order to rigorously evaluate the impact of the measures on the ground against the

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<sup>672</sup> Discussion Paper on the Territorial Aspects of Extreme Poverty Drawing up a European Extreme Poverty Map prepared by the Hungarian Presidency in 2011  
[http://ec.europa.eu/justice/discrimination/files/romaplatform\\_discussion\\_paper\\_poverty\\_2011\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/romaplatform_discussion_paper_poverty_2011_en.pdf)

<sup>673</sup> The NUTS classification (Nomenclature of territorial units for statistics) is a hierarchical system for dividing up the economic territory of the EU for the purpose of Socio-economic analyses of the regions. NUTS1: major socio-economic regions. NUT2: BASIC Regions for the application of regional policy. NUT3 identifies small regions for specific diagnoses.

<sup>674</sup> COM (2011) 173, Commission communication on an EU Framework for National Roma Integration Strategies up to 2020, p. 8.

<sup>675</sup> COM(2012) 226 Commission Communication, National Roma Integration Strategies: a first step in the implementation of the EU Framework, p.12.

baseline<sup>676</sup>. Additionally the Commission pointed towards the monitoring of the implementation of the Racial Equality Directive (Directive 2000/43/EC) as a useful instrument for measuring integration of Roma<sup>677</sup>.

A year after the EU Framework for NRIS was set up, only four Member States had robust monitoring in place to evaluate impact (IE, LV, PT, SK) and eight Member States had a review mechanism in place for adapting the NRIS (BG, IE, ES, GR, LV, SK, FI, SE)<sup>678</sup>. According to a report by the European Roma Policy Coalition of 2012, there were indications of how the national strategies will be monitored in a further three Member States (FI, PL, SI) and a reporting system for the NRIS was in place in a further seven Member States (FI, HU, PL, SK, SI, ES)<sup>679</sup>.

To help Member States measure progress on Roma integration, the European Union Agency for Fundamental Rights (FRA) set up an ad hoc working group on Roma integration and monitoring to help participating Member States set up effective monitoring mechanisms to obtain reliable and comparable results<sup>680</sup>. The FRA working group has highlighted that the monitoring system should be able to provide accurate feedback to governments at various levels. Firstly, on progress towards the goals in the national strategy and in the local action plans, and secondly on improvements in the socio-economic situation of Roma and in their fundamental rights compared to the majority population (monitoring 'the gap'). The working party feeds its results to the Commission's network of National Roma Contact Points. Fourteen Member States (BE, BG, CZ, ES, FI, FR, GR, IT, HU, HR, NL, RO, SK, UK)<sup>681</sup> participate in this working group, which also includes representatives of the European Commission and experts from the European Foundation for the Improvement of Living and Working Conditions (Eurofound) and the United Nations Development Programme (UNDP)<sup>682</sup>.

However, the Commission's second progress report in June 2013 on implementation of the NRIS established that despite clear efforts made by Member States to put in place a robust monitoring and evaluation framework in order to systematically and consistently produce data on the impact of Roma integration measures, this remains a challenge in most Member States<sup>683</sup>.

The following table shows the current situation regarding monitoring systems in place in the Member States since the establishment of the EU Framework for NRIS, as observed in the 2013 progress report.

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<sup>676</sup> COM(2013) 454 final, Commission Communication, Steps forward in implementing Roma integration strategies, p. 8.

<sup>677</sup> COM (2011) 173, Commission communication on an EU Framework for National Roma Integration Strategies up to 2020, p. 3 and COM(2013) 454 final, Commission Communication, Steps forward in implementing Roma integration strategies, p. 12.

<sup>678</sup> COM(2012) 226 Commission Communication, National Roma Integration Strategies: a first step in the implementation of the EU Framework, p.12.

<sup>679</sup> ERPC, Analysis of the National Roma Integration Strategies: March 2012, p. 53. Deed [http://www.ergonetwork.org/media/userfiles/media/Final%20ERPC%20Analysis%2021%2003%2012\\_FINAL.pdf](http://www.ergonetwork.org/media/userfiles/media/Final%20ERPC%20Analysis%2021%2003%2012_FINAL.pdf)

<sup>680</sup> COM(2013) 454 final, Commission Communication, Steps forward in implementing Roma integration strategies, p. 3.

<sup>681</sup> FRA, (2012), "Assisting Member States to measure the progress of Roma integration", [Online], Available: <http://fra.europa.eu/en/node/5992>

<sup>682</sup> COM(2013) 454 final, Commission Communication, Steps forward in implementing Roma integration strategies, p. 3 (footnote 9)

<sup>683</sup> COM(2013) 454 final, Commission Communication, Steps forward in implementing Roma integration strategies, p. 8.

**Table 36 Monitoring transformation in Member States as assessed by EC (June 2013)**

Monitoring transformation and enabling policy adjustment	Member States that have taken such measures
Mapping of the situation of Roma ('baseline') undertaken or under way	CZ, EE, EL, ES, FI, FR, HU, LT, LV, NL, PT, RO, SI, SK
A monitoring system to measure the results and impacts of the national strategy	Initial steps: BG Under development: BE, ES, FI, HU, IT, SE
Identification of areas with extremely poor Roma communities	CZ, EE, EL, FR, HU, PL, RO, SK
Involvement of all major stakeholders in the monitoring and evaluation process	AT, CZ (planned), FI, HU, IT (planned), LT (planned), SE (partially), SI, SK (planned)
Cooperation with National Statistical Offices	BG, CZ, EL, ES, FI, HU, IT, LV, RO, SK, UK
Planned regular reporting and evaluation	BE, BG, CZ, EL, FI, HU, LT, PL, RO, SE, SI, SK

Source: COM (2013) 454, p. 7.

As can be concluded from the table above, half of the Member States were not yet able to map the a baseline for Roma which is necessary in order to evaluate the impact of the measures on the ground (as this is compared to baseline). Moreover one can infer from the table that the majority of Member States do not have a monitoring system in place to measure the results and impacts of their NRIS. In this regard the Commission observed a general lack of impact indicators and recommended Member States explore possible synergies with existing EU policy indicators<sup>684</sup>. In more than half of the Member States no plans exist to regularly report on or evaluate the NRIS at a national level.

This assessment is in line with the evaluation conducted by Open Society Foundations (OSF) of the NRIS submitted by the governments of five Member States (CZ<sup>685</sup>, BG, HU, RO & SK) which pointed to weak monitoring practices and a lack of data to monitor the Member States reviewed<sup>686</sup>.

According to the 2013 progress report, examples of countries with robust monitoring systems are Hungary and Estonia<sup>687</sup>. The Hungarian monitoring system includes (i) a set of indicators measuring societal changes, aligned to the targets set in the national strategy; (ii) a regular reporting system set up in cooperation with an external international consultant to monitor whether the measures in the action plan have been implemented; and (iii) finally a social inclusion information system enabling data collection in various policy areas. In Estonia a survey assessing the situation of Roma is being carried out from 2012 to 2013 in order to plan the next steps of the NRIS.

<sup>684</sup> COM(2013) 454 final, Commission Communication, Steps forward in implementing Roma integration strategies, p. 8.

<sup>685</sup> the 2010–2013 Roma Integration Concept submitted by the Czech Government

<sup>686</sup> OSF review of NRIS Foundation, Review of EU Framework National Roma Integration Strategies (NRIS) submitted by Bulgaria, the Czech Republic, Hungary, Romania and Slovakia (February 2012), p. 3

<sup>687</sup> COM(2013) 454 final, Commission Communication, Steps forward in implementing Roma integration strategies, p. 15.

The Commission expressed its concerns regarding the extent of stakeholder involvement in monitoring, evaluation and policy review, as recommended in the Ten Common Basic Principles for Roma Inclusion<sup>688</sup>. As illustrated in the table above, only nine Member States involve (or are planning to involve) all major stakeholders in the monitoring and evaluation process. More specifically, the Commission stated that the legitimate representation of Roma and the involvement of all the relevant civil society organisations had remained insufficient, including the monitoring process of the Roma integration policies<sup>689</sup>. This finding is in conformity with our review of the NRIS and our survey findings: survey respondents were most likely (8/20) to not agree with the statement that the existing data collection system ensured that civil society organisations working with Roma, Roma NGOs and Roma community representatives are involved in the design, implementation and assessment of data collection. Many respondents stated that they were “not sure” of the extent to which they agree or disagree with the four statements regarding data collection and monitoring provided. This lack of knowledge could be further evidence that stakeholders are kept out of the loop on these issues.

A best practice example of stakeholder engagement is France where a national monitoring group has been set up which brings together associations, representatives from the various Ministries involved and local actors. The monitoring group can propose measures to the inter-ministerial steering committee in charge of coordinating the implementation of the French NRIS<sup>690</sup>.

It may be that monitoring challenges are the result of constraints arising from a lack of funds allocated by Member States to develop and improve data collection systems. The EU Framework invited Member States to allocate sufficient funding for Roma inclusion measures from national budgets, to be complemented by international and EU funding (such as the ESF and ERDF). However, according to our survey, more than a third of the respondents did not believe that the funds allocated for the data collection system are enough to monitor NRIS progress on Roma integration (totally disagreed). These findings are supported by the EU 2013 progress report, which observed that the financing of national strategies was not yet adequate<sup>691</sup>.

Another issue that was raised by the OSF review of the NRIS, is that few governments are drawing on official national level, international organisation (UNDP, Council of Europe, UNICEF, etc.), or academic sources and NGO publications and materials that draw upon these official datasets, to monitor their compliance with the NRIS<sup>692</sup>. Doing so could potentially alleviate the data-gap problem.

The general concerns expressed by the European Commission about the lack of monitoring of Roma integration are in line with our study findings which specifically address Roma health monitoring issues. One of the first round survey questions asked respondents to rate the extent to which they agreed or disagreed with four statements about data collection related to monitoring Roma health status in their Member State.

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<sup>688</sup> COM(2013) 454 final, Commission Communication, Steps forward in implementing Roma integration strategies, p. 8.

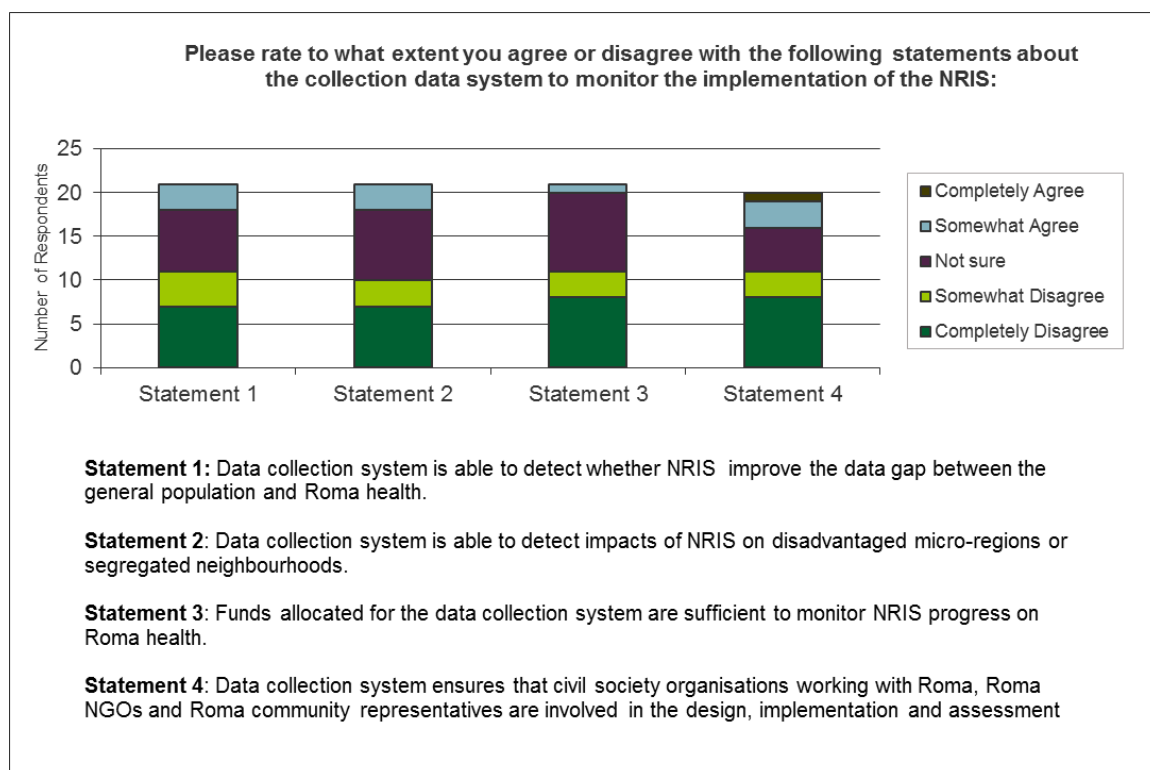
<sup>689</sup> COM(2013) 454 final, Commission Communication, Steps forward in implementing Roma integration strategies, p. 5.

<sup>690</sup> COM(2013) 454 final, Commission Communication, Steps forward in implementing Roma integration strategies, p. 14.

<sup>691</sup> COM(2013) 454 final, Commission Communication, Steps forward in implementing Roma integration strategies, p. 6.

<sup>692</sup> OSF review of NRIS Foundation, Review of EU Framework National Roma Integration Strategies (NRIS) submitted by Bulgaria, the Czech Republic, Hungary, Romania and Slovakia (February 2012), p. 3.

**Table 37 Survey results on data collection enabling monitoring of implementation NRIS**



Source: Roma Health Report First Round Survey, Question n.31

As can be seen in the figure above, one third (7/21) of the respondents to the first round of the survey did not find that the existing data collection system was able to detect whether the NRIS is improving the data gap between the general population and Roma health, nor that the data collection system is able to detect the impacts of the NRIS on disadvantaged micro-regions or segregated neighbourhoods (completely disagreed).

Our in-depth investigation on a country-by-country basis (see Appendix A) regarding planned monitoring activities and studies on Roma health suggests that some initiatives within the NRIS framework will be put in place to improve the current situation. Member States have not presented precise sustainable data collection strategies with a long term perspective. Our analysis is based on the review of the national strategies documents and on comments provided by National Contact Points in the second round of our survey<sup>693</sup>.

<sup>693</sup> Insert numbers 12 respondents, plus 2 reached via phone interviews.

**Table 38 Overview of National Roma Integration Strategies**

Member State	Roma health issues targeted through mainstreamed actions in the general domestic welfare and social inclusion policy	Roma health issues subject to specific positive actions	NRIS priorities for Roma health	NRIS Specific Indicators/benchmarks to evaluate NRIS outcomes/impacts on Roma Health	NRIS (current or future) specific projects on monitoring Roma health	NRIS (current or future) project on Roma that might produce data on health	Allocation of NRIS funds for project to monitor or to improve Roma health	Use of structural funds for projects to monitor or to improve Roma health
Austria	✓	x	✓	x	✓	✓	✓	✓
Belgium	✓	x	x	x	x	✓	x	✓
Bulgaria	✓	x	✓	Unconfirmed	Unconfirmed	Unconfirmed	✓	✓
Croatia	✓	x	✓	✓	✓	✓	✓	✓
Cyprus	✓	x	x	x	x	x	x	x
Czech Republic	x	✓	✓	x	✓	✓	x	✓
Denmark	✓	x	x	x	x	x	✓	✓
Estonia	x	✓	x	✓	✓	✓	✓	✓
Finland	x	✓	✓	x	✓	✓	✓	x
France	✓	x	✓	x	x	✓	✓	✓
Germany	✓	x	x	x	x	✓	✓	✓
Greece	x	✓	✓	✓	x	✓	✓	✓
Hungary	✓	x	✓	✓	x	x	x	✓
Ireland	✓	x	✓	x	✓	✓	✓	x
Italy	✓	x	✓	✓	✓	✓	✓	✓

Member State	Roma health issues targeted through mainstreamed actions in the general domestic welfare and social inclusion policy	Roma health issues subject to specific positive actions	NRIS priorities for Roma health	NRIS Specific Indicators/benchmarks to evaluate NRIS outcomes/impacts on Roma Health	NRIS (current or future) specific projects on monitoring Roma health	NRIS (current or future) project on Roma that might produce data on health	Allocation of NRIS funds for project to monitor or to improve Roma health	Use of structural funds for projects to monitor or to improve Roma health
Latvia	✓	x	✓	x	✓	✓	✓	✓
Lithuania	✓	x	x	x	x	x	x	x
Luxembourg	✓	x	x	x	x	x	x	x
Malta <sup>694</sup>	✓	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Netherlands	✓	x	x	x	x	x	x	x
Portugal	✓	x	✓	✓	✓	✓	✓	✓
Poland	x	✓	✓	x	x	✓	✓	✓
Romania	x	✓	✓	✓	x	✓	✓	✓
Slovakia	✓	x	✓	✓	✓	✓	✓	✓
Slovenia	✓	x	✓	✓	x	x	✓	x
Spain	✓	x	✓	✓	x	x	x	✓
Sweden	✓	x	✓	x	✓	✓	✓	✓
United Kingdom	✓	x	✓	x	✓	x	✓	x

Source: Roma Health Report Country Reports

<sup>694</sup> Malta has no Roma population.

The table above summarises the findings of our research regarding the current and future activities in the national context that might support the monitoring of the NRIS progress related to health. As illustrated above, the existing studies already express a limited level of satisfaction with the monitoring system used to assess the NRIS as a whole. Subsequently, aside from analysing NRIS indicators used to verify the achievements of the strategy with respect to Roma health, we enlarged the scope of our analysis by looking for projects targeting Roma health and social inclusion that might directly and indirectly produce additional information and data on Roma well-being. As a proxy for this investigation we also considered the funds allocated to these projects, including European Structural Funds and Technical assistance to support and enhance the monitoring and evaluation capacities of the Member States<sup>695</sup> (Table 39). Finally in the context of our investigation we assessed whether Member States address Roma health issues via mainstream or specific targeted welfare and social policies.

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<sup>695</sup> COM(2013) 460 final, Proposal for Council Recommendation on effective Roma Integration measures in the Member States.



**Table 39 The European Structural Funds and Technical Assistance**

The EU Cohesion Policy, managed by DG Regio and DG Employment, is the EU's regional policy to support (mainly) the less developed regions of the Union. The EU's cohesion policy complements the broader European policy agenda of non-discrimination and social inclusion, by co-financing a range of projects to support Roma inclusion<sup>696</sup>. The primary financial tools of the policy are the European Structural and Investment Funds: the European Social Funds (ESF) and the European Regional Development Fund (ERDF)<sup>697</sup>. Both funds may contribute to the social inclusion of Roma communities: ESF primarily supports employment, social inclusion and training measures. ERDF supports education, health, housing and social infrastructure investments. The range of programmes and projects co-financed are accompanied by resources for technical assistance. Technical assistance is needed to foster the administrative capacity and enhance capacity building of funds beneficiaries by:

- ensuring the necessary human resources;
- providing training of staff;
- ensuring stable and lasting employment of the staff responsible for supporting the evaluation and monitoring system;
- ensuring on-going improvement of the qualifications of persons involved in the implementation of the project's structural instruments – taking particular account of the skills necessary for monitoring Roma health
- putting in place well-functioning monitoring and evaluation systems;
- creating an efficient informatics system for the management, implementation, monitoring, evaluation and control of the National Strategic Reference Framework (NSRF), and;
- enhancing information, communication and promotional exchange activities

Member States could make increased use of Cohesion Policy and apply for technical assistance funds to design, promote and manage Roma inclusion policies on the ground.

In practice, 22 of the countries analysed (AT, BE, BG, HR, CY, DK, FR, DE, HU, IE, IT, LV, LT, LU, MT, NL, PT, SK, SI, ES, SE, UK) have a strategy that mainstreams actions for Roma health in the more general framework of social inclusion policy for vulnerable groups. In this way countries have developed an approach that explicitly but not exclusively targets Roma<sup>698</sup>. In several cases however this has been translated into a lack of specific health priorities/objectives and related indicators and benchmarks to assess them. Only Croatia, Estonia, Greece, Hungary, Italy, Portugal, Romania, Slovakia, Slovenia and Spain set indicators to verify the results of the NRIS in the field of health (*NRIS Specific Indicators/benchmarks to evaluate NRIS outcomes/impacts on Roma Health*).

These countries set baseline scenario indicators and minimum thresholds to be achieved for:

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<sup>696</sup> [http://ec.europa.eu/regional\\_policy/activity/roma/index\\_en.cfm](http://ec.europa.eu/regional_policy/activity/roma/index_en.cfm)

<sup>697</sup> A Third fund is the Cohesion Fund targeting in particular infrastructure.

<sup>698</sup> The 10 Common Basic Principles on Roma Inclusion: [http://www.coe.int/t/dg4/youth/Source/Resources/Documents/2011\\_10\\_Common\\_Basic\\_Principles\\_Roma\\_Inclusion.pdf](http://www.coe.int/t/dg4/youth/Source/Resources/Documents/2011_10_Common_Basic_Principles_Roma_Inclusion.pdf)

- accessing health care services by increasing the percentage of health insurance access to the Roma population (Croatia), household visiting doctors and the number of community workers (Slovakia) and visits to dentists and gynaecologists (Spain)
- improving health by increasing drinking water and decreasing infectious disease (Slovakia) and increasing the level of vaccination from 30% to 50% (Italy)
- encouraging changes in lifestyle by reducing smoking by 30% and obesity by 10% (Spain) or involving 30,000 Roma persons in sport activities (Hungary)
- promoting disease prevention by providing screening tests for 150,000 Roma persons (Hungary), 20 awareness campaigns and evaluation of their impact (Portugal) and increasing the number of conferences and meetings held regarding Roma (Slovenia)

Within the countries that have instead adopted a 'positive actions' approach (the Czech Republic, Estonia, Finland, Greece, Poland and Romania) Greece and Romania have established detailed systems of measurement of the NRIS outcomes. In Greece there is a specific focus on the number of primary health programmes that will be carried out in Roma settlements. Similarly in Romania there is an emphasis on the improvement of services provided to backward communities quantified by the 25% increase in health mediators.

Regarding studies and research to investigate Roma health (launched or planned to be launched), all the countries acknowledged the necessity of carrying out studies on Roma health conditions, but only a few concrete examples were made available to the research team.

Hungary and Slovakia have both elaborated on the Atlas of Roma Communities. This entailed a public initiative, undertaken with government and NGO cooperation to gather complex data about the living conditions and general situation of Roma living in scattered communities, including their needs and the authorities' approach. It was the basis for elaborating local development plans and strategies by regional and local administrations, and for identifying communities for targeted investment of resources from EU Structural Funds. This is a good practice that both governments are planning to repeat, however it is not exclusively focused on health.

The territorial dimension is also relevant in Italy where the strategy makes reference to a feasibility study to promote experimentation through a local programme for the inclusion of Roma and Sinti persons. The respondent to our survey confirms that in this case, the collaboration among regions is relevant to collect data on the socio-economic conditions of Roma.

Similarly in Portugal and Latvia, the national respondents to the second round of our survey refer to the implementation of national studies about the social and economic situation of Roma communities. While in Belgium a survey on the push and pull factors for migration will be carried out, but according to the national respondents no plans to fund activities to collect data on Roma health are known.

Studies explicitly focusing on Roma health are currently ongoing in five countries (AT, CZ, EL, FI, IE, HR and SE). The respondent for Austria declares that there is a proposed research project which will use expert interviews, focus groups and database analysis as part of a mixed-methods approach to better understand Roma health. In the Czech Republic some activities to collect data on Roma health are planned, but according to our respondent they are still under scrutiny from the national anti-discrimination law. In Greece, the Strategy for 2020 aimed at integration of the Roma

community set out three measures for the health sector, and within the first measure field research to gather data on epidemiology, vaccinations, primary health care and mental health should be undertaken (i.e. *access to primary health care (women and children) health education and field research for epidemiological data*). In Ireland a project to measure the improvement in access to health services (Health Key performance indicators (KPI)) will be launched.

In Finland, Croatia and Sweden the public authorities in the field of health will play a relevant role in the collection of data on Roma health. In Croatia annual surveys are to be carried out through the Ministry of Health, Central Statistics Bureau and research institutions (e.g. Social Work Study Centre, Ivo Pilar Social Science Institute and UNDP). Further epidemiological data are suggested to be extracted from forms provided by the Central Health Information. In Finland the Ministry of Social Affairs and Health has commissioned a pilot study to the National Institute for Health and Welfare to investigate the health and welfare of Roma in Finland. The Finnish respondent to the second round of our survey stated that the study contains an extensive interview programme and health checks. Methods are currently being tested and the study will be carried out in 2014 if sufficient resources are available. Meanwhile in Sweden the National Institute of Public Health and National Board of Health and Welfare are to produce health status reports (particularly on Roma women). In these three cases however the repetition of these studies over time is limited by the future allocation of funds. In general the documents mention the total amount of financial resources allocated to the strategy, but there is no specific financial information regarding resources devoted solely to study and research of Roma health.

When analysing projects to improve Roma health conditions, there are common factors in many Member States that suggests an existing exchange of good practice; specifically the use of cultural mediators and mobile health clinics.

Cultural mediators<sup>699</sup> have the objective of facilitating relationships between citizens in order to promote reciprocal knowledge and comprehension in the case of different cultural backgrounds. The main skills of cultural mediators are communicative competence, empathy, active listening and good knowledge of both the hosting country and country of origin (culture, laws, traditions, etc.)<sup>700</sup>. Cultural mediators had a significant role during the late 1990s in supporting the activities of different medical professionals by translating health material, but also carrying out research and studies. Mobile health clinics have instead been able to reach more remote Roma communities who do not normally access GP services in great numbers<sup>701</sup>. Both types of projects could be used to collect data on Roma health. Unfortunately because of recent budget constraints, the continuation of such projects is not always guaranteed. Moreover the new Member States are currently undergoing welfare reforms that do not always include the support and protection of disadvantaged groups<sup>702</sup>.

The use of the European Structural Funds might represent a solution to this resource shortage, in fact with the exception of Cyprus, Finland, Ireland, Lithuania, Luxembourg, Slovenia and the United Kingdom, all the other Member States mention ERDF and ESF as a source to fund projects for the inclusion of Roma communities. Nevertheless, there is no system in place making ring fenced allocation of European Structural Funds towards Roma health projects or studies compulsory.

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<sup>699</sup> See for example <http://romed.coe-romact.org/content/roma-mediators>

<sup>700</sup> <http://www.inmp.it/index.php/eng/Social-and-Health-Care-Services/How-to-Accede/Cultural-Mediation>

<sup>701</sup> <http://www.irishhealth.com/article.html?id=21793>

<sup>702</sup> [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0018/163053/e96443.pdf](http://www.euro.who.int/__data/assets/pdf_file/0018/163053/e96443.pdf)

From the above examinations it can be concluded that very few countries make use of indicators to evaluate their strategy in the field of Roma health. Also the indicators set are very often related to immediate outcomes of the projects encompassed in the strategy and the timeframes for the objectives to be achieved are not always clearly defined.

Only a few countries have a detailed plan for studies and research in the Roma health field, while almost all the countries make use of cultural mediators and mobile clinic units to reach isolated Roma communities. The main limitation in both cases is the lack of consistency in the allocation of financial resources. However the European Member States that have also been countries of the Decade of Roma Inclusion (Croatia, Hungary, Slovakia, Czech Republic and Romania) do seem to have developed the appropriate administrative capacity to monitor the socio-economic situations of Roma.

## Conclusions and Recommendations

The Roma populations in Europe are in poorer health than the non-Roma populations. But while sufficient data on Roma exists to evidence social and economic exclusion, and poor health, there are still vast gaps in Roma health status data which impede any full understanding of the situation. Responses from the study survey indicate that stakeholders are generally dissatisfied with the quality of data and data collection systems available to support efforts to improve Roma health. Some respondents feel strongly that a lack of funds available to support monitoring of NRIS is one of the main barriers to improving the quality of data collected.

Roma health related data collection is normally organised and collected through a bottom-up system with a reliance on community-based data and surveys. But there are significant obstacles to data collection, including Member State statutes that prevent the collection of data that identifies specific ethnic groups and the practical challenges of collecting data relating to a sometimes highly mobile Roma population.

The National Roma Integration Strategies are moving forward, but there is a recognised need for stronger monitoring methods to support data collection specifically, as well as the overall evaluation of the aggregate impact of actions.

The findings from the survey of Member States of this study, when taken in conjunction with the reports from National Researchers, provide support for the policy recommendations set out by the Commission earlier in 2013<sup>703</sup>.

The study provides additional detail as to how each of the Council recommendations could be most purposively focused. The need to establish a robust and consistent European baseline has been reinforced by this study and the means to do this illustrated through the examples provided by countries such as Hungary and Estonia. Setting core indicators alongside the establishment of a common evaluative framework remains a challenge for many Member States and the study findings suggest that further concentrated and coordinated effort will be required to support the NRIS programme. It is good that the groundwork for this next developmental stage has been undertaken. However, the concern remains that without a further concentrated effort to support Member States, the limited progress that has been made to date will not be built upon and that delivery of the NRIS could be fundamentally undermined.

International and European institutions – the FRA, the UNDP and the World Bank – are carrying out important work through their Roma survey exercises and are providing the richest sets of comparable data across a significant number of countries. Although methodologically sound, the surveys could usefully be complemented with other methods and tools. Data collection is also undertaken at regional and local levels, such as NGOs and Mediator programmes, whose continued important contributions can improve overall understanding. Data collection at national level is not comprehensive.

As the report on Member States' current and future activities in data collection and development of specific surveys aiming to monitor the progress the implementation of the National Roma Integration Strategies in the area of health, the NRIS can further strengthen their data collection and monitoring aspects to complement international and regional activities.

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<sup>703</sup> Recommendation on effective Roma Integration measures in the Member States.

Recommendations for the European Commission are listed below.

### **Recommendations for the European Commission**

- The European Commission should provide leadership in setting standards and establishing protocols for data collection. To this end it should continue to facilitate cooperation between relevant international agencies, so as to minimise the risk of duplication and to maximise the potential to develop a common platform for data collection and reporting.
- Research commissioned by the European institutions should strongly encourage the use of comparable indicators and comparable research to allow for a baseline from which research can develop across Europe. The Commission could support the Member States in developing suitable and sustainable data collection and monitoring approaches. Where possible, the European institutions should encourage data collection which is *ethnically disaggregated* and collected in agreement with Roma communities in the EU.
- Where *barriers to collect ethnically disaggregated data are encountered*, the study recommends that the European Commission go beyond the debate about the collection of data on ethnicity and the respect of anti-discrimination by considering experimental methods such as poverty mapping by the World Bank based on socio-economic indicators. The European Commission could clearly lead the work in the use of appropriate proxy indicators to ensure the highest level of compatibility across Europe.
- The Commission should support the Member States in exchanging best practice and ensure compatibility and comparability of data collection and of monitoring and evaluation of the NRIS. For example, some regional vaccination programmes have proved very successful, and lessons from these interventions could potentially be applied to other programmes within the country, or other vaccination programmes implemented by other Member States.

### **Recommendations for the Member States**

- Data collection and monitoring measures should be designed with SMART targets in mind and have sufficient financial resources allocated. Research methods should be tried and tested and best practice should be shared among stakeholders. If ethnically disaggregated data are not available, consideration should be given to begin collection of this. If such data is not available appropriate proxy indicators should be used as a substitute, when agreed upon by civil society actors and government agencies at a European level and endorsed by the Commission.
- This study recommends that Member States are encouraged to collaborate on data collection concerning migrant and undocumented Roma. This is an area in urgent need for more data and is particularly challenging considering the highly mobile nature of the population subset. The IOM's Roma EQUINET may be able to provide guidance.

- The NRIS should ensure the participation of a range of civil society and governmental organisations, including local government research bodies to provide methodological support to grassroots monitoring efforts. Data collection is often a bottom-up exercise. Monitoring and evaluation capacities could be enhanced by using the European Structural Funds Technical Assistance.
- The NRIS should ensure the active participation and engagement of the Roma and civil society organisations representing Roma. The strategies should moreover focus on Roma real needs as and when they are identified by the evidence base from European projects. Regions, local authorities and local civil society can contribute to reviewing and monitoring their national strategies.
- This study recommends that the focus of data monitoring should be on indicators measuring Roma access to health care (including immunisation) as a lack of health care access hampers improvements in Roma health at large and contributes to social exclusion experienced by Roma. A focus on administrative data rather than health outcomes data may prove easier to collect in a format that is comparable and can be aggregated into national and international data sets. Indicators of health access are useful proxy indicators for inequalities in health status.

## **Limitations**

This study was completed in a short time frame, and undertaken very soon after a similar piece of work undertaken by the Fundamental Rights Agency. Therefore the sample of respondents was limited (38+12) and we did not contact representatives from each of the Member States. However, by developing the survey after FRA had developed and administered their own research, the research team was able to tailor the questions very specifically to the research questions required within this project.

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Appendices are available upon request to the contracting authority at the following address: [chafea@ec.europa.eu](mailto:chafea@ec.europa.eu)