

European
Commission

## Roma Health Report

Health status of the Roma population
Data collection in the Member States
of the European Union

## Appendices

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## Part 1

## Health Status of the Roma Population

## Appendices

## Appendix A Country Reports (Reports assessing the health status and health-related lifestyle attributes of the Roma population)

## Country Profile: Austria

| Main Characteristics of the Roma in Austria |
| :--- |
| Demography |

The presence of Sinti has been documented since the $15^{\text {th }}$ century; however a certain continuity in their residence on today's Austrian landmass can be proven only from the middle of the $18^{\text {th }}$ century.

Roma in Austria are mainly divided in two main categories:

- A group coming from different areas of the Austro-Hungarian Empire at the beginning of the last century. This group can be divided into several autochthonous subgroups: Burgeland-Roma, Sinti, Lovaraths and Vlax-Roma (Kalderas, Gubet);
- A group originating the Former Yugoslavia Republic from the 1960s onwards, with a common Muslim faith.

The Census carried out in 2001 reported a total of 6,237 members of the Roma community, of which 4,348 were of Austrian nationality and 1,925 of other nationalities. In reality the Census count underestimates total population. According to official estimation ${ }^{1}$ this is between 10,000 and 20,000; while Romany sources report the autochthonous community at 20,000-25,000. This figure is confirmed by an academic paper published in $2005^{2}$.

## Geographical distribution

Roma in Austria are both urbanised and rural and this does not depend on whether they are indigenous or migrants. They are distributed as such:

Lovara (horse traders), Kalderas (tinkers), Gurbet, Arlije and the Sinti are mainly city dwellers. The majority live in Vienna and eastern Austria. The Burgenland Roma are mainly rural. They settled in the eastern provinces Burgenland (especially in the area of the town Oberwart), Vienna and Lower Austria ${ }^{3 .}$

## Other Information (including highlights of data gaps)

[^0]Roma are the only minority to have been recognised in Austria since 1993.
However because of historic reasons linked to the issue of Nazism, data on ethnicity is not collected. ${ }^{45}$ Consequently, analysis of discrimination is not very easy. It should be noted that this site has only provided two examples of discrimination; one based on a small scale study conducted in the district of Oberwart and the second referring to the prejudice and discrimination in the relationship Roma have with law enforcement reported by the Council of Europe Anti-Racism Commission in 2005. ${ }^{6}$.

The National Roma Integration Strategy (NRIS) is included in more general mainstreamed actions for social policy. There are no positive actions targeting Roma explicitly, but the strategy for integration includes support in the fields of housing, health, education and employment ${ }^{7}$. The government has been focused on Burgenland Roma, because they are the most disadvantaged groups; however they are a small proportion of the total Roma population ${ }^{8}$. As illustrated in the next section, several health problems have been detected in parts of the country where the Roma community resides.

Mortality and Life Expectancy
As previously stated, there are no data broken down by ethnicity. However, by observing rates of mortality at territorial level the highest mortality rates are recorded in Burgenland district (Oberwart) where most of the autochthonous Roma population is resident. In this district mortality was $14 \%$ higher than the rest of the country. The rate of deaths due to chronic diseases was higher than the rest of the country (18\%) with obesity rates also representing a problem.

## Prevalence of Major Infectious Diseases

The research team have not found any qualifications for this indicator.

## Healthy Life Styles and Related Behaviours

The main source regarding Roma health status in Austria is: 'The Labour Market Development of Oberwart and the Socio-Economic Situation of the Roma'9. Although this is a study based on a specific local community, and does not specify the nationality and or legal status of the Roma participants, several points can be extracted from it.

The study has analysed the Roma community from Oberwart. According to the study's main findings Body Mass Index (BMI) is higher in both male and female Roma than in non-Roma (respectively 30.9 and 30.4 against 25.5. and 24.4 of non Roma).

[^1]Younger Roma have a healthier BMI. However, after the age of 40, obesity becomes an issue for a much larger share of the Roma population.

Less than 20 \% of Roma aged 15-40 have a BMI index over 30. For Roma aged 41-55, BMI is more than three times as high at 66.7 \%.

The Oberwart Roma population have a higher share of smokers; 40\% more than the general population. In fact, in the general population $30 \%$ of persons aged 16 and older smoke, but the corresponding figure for Roma is $72.7 \%$. Moreover, $64.7 \%$ of interviewed men, and $81.3 \%$ of women (i.e., almost four times as many as in Austria as a whole) have indicated that they are currently smokers.

Frequency of smoking is also high, with $80 \%$ of Roma men and $60 \%$ of Roma women smoking an average of one pack of 20 cigarettes per day ${ }^{10}$. No comparable data are available.

## Access and Use of Health Services and Prevention Programmes

Little information is available about access to health services and participation in prevention programmes.

The WIFO working paper reports the number of Roma who pay regular visits to the dentist is very low at just over 30\%. By comparison a Vienna Health Survey (from 2011) concludes that $54.3 \%$ of Viennese men and $62.1 \%$ of Viennese women had been at the dentist's at least five times over the past five years ${ }^{11}$.

Further, psychosomatic and mental illnesses pose a problem to the Roma population. Psychological issues are seen as a taboo within the community, hence Roma are more reluctant to seek medical assistance for mental health ailments. This problem is compounded by geographical issues. A large proportion of Roma reside in rural Burgenland where healthcare access is an issue. Those that live in urban areas may still be deterred from visiting a health centre due to the required paperwork that must be completed and the associated language barriers. ${ }^{12}$

This reluctance to utilise the health service was mentioned by the ambulance head for Styria, where about 50\% of their patients are uninsured. Although ethnic origin data has not been collected for this patient cohort, data relating to nationality does exist. According to the ambulance's annual report, in 2011 of the 767 uninsured patients, 353 had either a Romanian or Slovakian nationality - common within the Roma group. ${ }^{13}$

## Prevalence of Major Chronic Diseases

There is very little or precise data available. According to the research carried out by WIFO published in 2004, 41\% of the Roma population seems to show a prevalence of chronic illnesses ${ }^{14}$ but comparable data with the general population is not available.

[^2]
## Health Factors Related to the Role of Women in the Roma Community

The research team have not found specific qualifications for this indicator.
Anecdotal reports come from the NGO "Romano Centro" based in Vienna. According to their reports, the female population is less informed than the non-Roma population about necessity of health care services and the need for medical investigations in case of pregnancy and breastfeeding. This lack of awareness is more serious for Roma with a migratory background where many Roma women (especially) are reliant on coinsurance on their husbands' schemes. This situation is aggravated by the fact that when women do not have medical insurance, there are very few maternity wards available.

## Environmental and other Socio-Economic Factors

## - Housing

The RAXEN study clearly establishes that there is no quantitative information on the housing situation of Roma: "[...] there is no quantitative data - either official or unofficial - available that explicitly describes the housing situation of Roma. Nothing can be said about the housing situation of Roma women, children or seniors or Roma with disabilities" ${ }^{\prime 15}$.

Nevertheless evidence gathered in the field confirms that in general the housing situation of third country nationals (including Austrian Roma) is well below average ${ }^{16}$. Major problems are related to overcrowding, humidity/mould and noisy neighbourhoods. Even when naturalisation takes place the housing situation of Roma is still worse than the general population.

## - Education

According to the working paper 'Roma in Austria - A Historical Perspective' ${ }^{17}$ since 1995 several improvements have occurred in the education system for Roma, especially in primary schools. For instance, Roma children receive assistance to access schooling. However, the information provided covers less than a decade (1995-2002); therefore outside the scope of this country report.

## - Employment

The unemployment rate of members of the Roma community is reported to be much higher than that of the major population ${ }^{18}$, due to a variety of factors including low school education, migratory background and poor health status ${ }^{19}$. Male Roma are reported to be more likely to be unemployed than female Roma or non-Roma. Compared to non-Roma there is a higher percentage of Roma employed part time. There is a high share of multiple employment particularly among female Roma ${ }^{20}$.

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## Country Profile: Belgium

Main Characteristics of the Roma in Belgium

## Demography

The first mention of Roma (Gypsies) in Belgium was in $1421^{21}$.
There are two broad categories of Roma in Belgium:

- Travellers who have lived in Belgium or neighbouring countries for centuries;
- Roma, who are mainly recent migrants from Eastern and Central Europe, from either new EU member States or from third-countries.

The two groups have different histories, legal status and lifestyles, and they face separate challenges in terms of integration. Their common denominators are issues relating to stigmatisation and discrimination ${ }^{22}$.

With the fall of the communist regimes in central and eastern Europe in the 1990s and EU accessions in 2004 and $2007^{23}$, Belgium has seen an increase in Roma immigration.

Estimates on the size of the Roma population in Belgium vary between 10,000$15,000^{24}$ and $40,000^{25}$. The Council of Europe estimate stands at $30,000^{26}$. This is the most commonly quoted figure yet it does not distinguish travellers from Roma and the estimate dates back to the mid-2000s ${ }^{27}$. Liégeois (2007) estimates the population of Roma and Travellers at 20,000-40,000. One estimate from 2003 puts the number of Travellers at 10-20,000, while another from 2009 suggests $12-15,000{ }^{28}$. Nevertheless exact data on Roma or Traveller population size is lacking ${ }^{29}$. For the purpose of this study we will consider both groups.

## Geographical distribution

Roma and Traveller populations are distributed across the country. Roma tend to be more concentrated in urban areas ${ }^{30}$. Travellers are distributed more or less equally

[^4]across regions ${ }^{31}$. Travellers typically live in encampment sites, although some of them have a semi-itinerant lifestyle ${ }^{32}$.

The Flemish Minorities Centre (Kruispunt Migratie-Integratie) estimates that in Flanders alone, there are 850 families or 2,500 persons living permanently in trailers and 1,000 families travelling through the region in trailers. ${ }^{33}$

According to an assessment made for the Walloon region in 2005 by the Mediation Centre for Travellers in Wallonia, Travellers are travelling in relatively small groups (around 30 caravans), camping essentially along the major axes of circulation for short term duration (around three weeks) ${ }^{34}$.

For the Roma population, estimates in Flanders (including Brussels) stand at 15,000$20,000^{35}$. According to the Flemish Minorities Centre the Roma population in Flanders stem from:

- Romania and Bulgaria
- Ex-Yugoslavia
- the Slovak Republic and Bulgaria
- Kosovo ${ }^{36}$.


## Other Information (including highlights of data gaps)

Health data collection in Belgium is decentralised - the main data collectors are authorities on a regional level and data is thereafter aggregated nationally ${ }^{37}$. There are no ethnic statistics in Belgium. Indeed collecting data on the basis of ethnic origin is in principle prohibited in the country for constitutional reasons, Still, advice issued by the Commission for the Protection of the Privacy and existing legislation make it clear that the collection of ethnic data is possible, albeit under strict conditions ${ }^{38}$. However, policy makers and the administration are reluctant to collect ethnic data although progress has been made especially in the domain of socio-economic monitoring ${ }^{39}$. A number of studies rely on data on nationality and country of birth as a proxy indicator, as this type of data can more easily be collected by public registers and surveys.

[^5]As a result, quantitative information about Roma and travellers is fragmented and sparse ${ }^{40}$. Regional data collection also appears to have shortcomings in quality in terms of timeliness, methods and reporting. Thus data presented may be old or based on small scale studies only ${ }^{41}$.

Ultimately, this country report has derived data and estimations from either regional or international (EU) commissioned studies and from academic literature.

Data gaps are notable particularly for the following indicators:

- population figures (including population density in urban and rural areas)
- poverty and social exclusion indicators, particularly on income
- employment
- health (life expectancies, mortality and morbidity rates)
- housing


## Mortality and Life Expectancy

The study team has found no quantifications of this indicator pertaining specifically to the Roma population as ethnically disaggregated data is not collected.

Eurostat's latest data on life expectancy in Belgium is from 2010 at 79.6 years. Data from 2011 is estimated at 79.8 years ${ }^{42}$.

Anecdotal data and evidence obtained from EU funded initiatives (national peer review) find:

- According to the municipal social services Roma health status in Brussels is poor, even compared with refugees and undocumented migrants. The life expectancy of Roma is unclear with some suggestions that Roma lead lives 10 years shorter than the general population and anecdotal evidence that "few reach the age of $55^{\prime \prime 43}$. In Limburg between 2005 and 2009, the average life expectancy was just 65 for Roma and 80 years old for Belgians. ${ }^{44}$

Prevalence of Major Infectious Diseases
The study team has found no evidence of quantified health data relating to this disease group for Roma communities.

Anecdotal data and evidence cover:

- According to municipal health services "even young people (e.g. 30 years old) are already dealing with illnesses usually found among older persons (e.g. rheumatism)" ${ }^{45}$.

[^6]
## Healthy Life Styles and Related Behaviours

Although no national quantifications have been found, several national studies ${ }^{46}$ underline the poor health conditions of Roma in Belgium and the difficulties they experience in accessing health services.

The Belgian municipal services (CPAS) state that the Roma population's health is at least partly related to living conditions in their country of origin. It is suggested that Roma stemming from Central, Eastern and South-Eastern Europe who arrive in Belgium often already suffer from poor health, which further deteriorates in Belgium as a result of poor living conditions ${ }^{47}$.

According to the data shared by FRA, Roma tend to have illnesses associated with poor diet and stress ${ }^{48}$. Documentation compiled by FRA suggests that many Roma suffer from poor health. It is not uncommon for Roma families to have one or two persons with a severe illness or disability. It is thought that poor health of Roma may be attributed to excessive use of coffee, sugar, salt, fats and medicines. However, there have been no reports of problematic drug abuse. ${ }^{49}$ Most frequent diseases are diabetes, obesity, asthma and infections of the respiratory tract. Additionally, causes are attributed to poverty and culture as Roma tend to focus on short term rather than long term health concerns. The pressure of living with anxiety and traumatic warexperiences impacts on mental health; depression and psychosomatic complaints are common. There are also high frequencies of eye and dental problems ${ }^{50}$.

## Access and Use of Health Services and Prevention Programmes

There is anecdotal evidence that:

- Despite a right to emergency medical care regardless of migrant 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 ${ }^{51}$. In a study carried out by Dokters van de Wereld among Roma women in Brussels, 46\% did not have health insurance and $65 \%$ had experienced difficulties accessing the healthcare system. ${ }^{52}$
- Price and administrative requirements (complexities) of municipalities in order to receive care is another reported obstacle. For example, each municipality

[^7]has different social security procedures, which may be a disadvantage to vulnerable groups at risk of discrimination, including Roma. ${ }^{53}$

- Access to preventive services seems to pose a major problem. In a study carried out among Roma women and their children in Brussels it was found that only $39 \%$ of the children had received all recommended vaccines and only $13 \%$ at the recommended age. ${ }^{54}$
- Although issues of access persist with the Roma population, services provided by the National Office for the Child, and Child and Family; the Flemish public institution providing help and advice on the wellbeing of children, are frequently attended by Roma, especially the latter, which operates within Brussels. ${ }^{5}$


## Prevalence of Major Chronic Diseases

The study team has found no quantifications of this indicator.
Anecdotal data and evidence is very vague but finds:

- "Some illnesses that had been eradicated in Belgium are relatively common to the Roma, such as tuberculosis" ${ }^{56}$.

Health Factors Related to the Role of Women in the Roma Community
The health situation of Roma women has been described as 'worrying'57. Major issues affecting Roma women in Belgium include a low life expectancy (not quantified). Multiple pregnancies are frequent, as well as abortions which are used as a contraceptive method. Two studies state that health concerns with regard to Roma also include a lack of awareness and use of contraception, ${ }^{58}$ prenatal health and postnatal care. ${ }^{59}$

Psychosomatic diseases are also frequent and Roma women's access to healthcare is often limited due to language barriers, lack of information, low income or noneligibility, as well as the presence of cultural and religious barriers; Roma woman, for example, may not be allowed to visit a male doctor. ${ }^{60}$

## Environmental and other Socio-Economic Factors

## Housing

A main source of data for housing is the 2009 study commissioned by the Fundamental Rights Agency of the EU - the Raxen National Focal Point for Belgium ${ }^{61}$. This study undertook a thorough assessment of the housing situation of both Roma and Travellers.

[^8]Two main issues arose:

1. 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 $2007^{62}$. In the Walloon Region only one camp has been created. An alternative to public accommodation were 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. 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. According to the report, less than half of the Travelling families have access to the existing encampment facilities, leaving a significant proportion living on illegal sites ${ }^{63}$, yet many Travellers are Belgian citizens ${ }^{64}$.
2. Roma: Belgian Roma tend to live sedentary lifestyles in urban neighbourhoods. Housing conditions are generally poor, with physical and mental health implications. Moreover, Roma often live with other immigration communities and tensions between different communities can arise. Roma are often in a weaker position with respect to other groups, and the resulting relocations and displacements can make it difficult to maintain social links which are a lifeline for Roma ${ }^{65}$.

## Employment

Unemployment rates are extremely high for Roma in Bulgaria. 48\% of Roma women declared themselves unemployed with the male figure generally similar at $43 \% .{ }^{66}$ Self-employed Roma workers are often not formally registered with health insurance for small risks due to a lack of information on health insurance access. As a consequence, they are less eager to contact a doctor in order to avoid problems with the National Health Service ${ }^{67}$.

## Education

Most Roma stop education after primary school due to a combination of different cultures, historical rejection and difficult migration circumstances, including; Roma parents lacking experience with school visits; language barriers hindering good understanding of school personnel; material implications of children in school; itinerant lifestyles negatively affecting the child's track record in school; good practice of adult education (2009); falling behind on the school curriculum and extreme truancy and school absence (2010). However, it appears that educational attendance is increasing in the Roma population. 37\% of Roma women aged 16-24 have stayed

[^9]in school after the age of 16 compared to $23 \%$ for all ages above 16 . This trend is mirrored for men with $50 \%$ compared to $32 \% .{ }^{68}$ Another regional study in 2011 found youth caravan dwellers show a remarkably higher attendance rate of technical/parttime education than the Flemish average and a lower employment rate compared to Flemish average with a preference for jobs with high independence ${ }^{69}$.

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## Country Profile: Bulgaria

| Main Characteristics of the Roma in Bulgaria |
| :--- |
| Demography |
| Roma are Bulgaria's second largest ethnic minority, numbering 352,343 or $4.9 \%$ of the |
| total population according to census results in 201170. However, expert assessment |
| places the number of Roma between 640,000 and 800,00071. |
| The Roma population is characterised by an inverted age pyramid and a youthful |
| population; Roma aged 19 and below constitute 39\% of the total Roma populace, while |
| among ethnic Bulgarians, only $15 \%$ are aged under 19. Conversely, $15 \%$ of ethnic |
| Bulgarians are aged 70 and over, while for Roma, the share of this age group is just |
| under $2 \% \%^{72}$. |

Age pyramid Roma


[^11]Age pyramid majority population


## Geographical distribution

The Roma community is present in all territorial units of Bulgaria. The highest concentration of Roma is in the towns of Montana, where Roma represent $12.7 \%$ of the local population, the town of Sliven, where Roma constitute $11.8 \%$ of the overall population, and in Dobrich and Yambol, where Roma constitute $8.8 \%$ and $8.5 \%$ of the population respectively ${ }^{73}$.

## Other Information (including highlights of data gaps)

International attention toward the disadvantaged position of the Roma minority in Southeast Europe and the relatively large presence of the minority in Bulgaria have prompted numerous surveys and studies by international agencies (notably the World Bank, UNDP, FRA) and NGOs (notably, Open Society Institute, the Health of the Roma Foundation, Amalipe Foundation). The studies provide a plethora of information on socio-economic determinants of health and, to some extent, healthy lifestyles and health related behaviours. Comparative and local studies focusing specifically on the health status of the minority also provide information for most parametre data, such as prevalence of major diseases, self-assessment of health and access and barriers to healthcare. A shortcoming of the representative surveys, however, is that they conceal important regional and sub-group differences in the health and socio-economic status of the Roma communities.

A data gap in research concerns quantitative data on several important indicators such as HIV spread, Hepatitis A, B and C, ante-natal care and cancer screening as well as obesity. Nevertheless, qualitative data from interviews and focus group discussions quoted in reports reveals that there are frequent outbreaks of hepatitis in geographically segregated Roma communities. In addition, health practitioners have

[^12]indicated that there is a high level of HIV spread among vulnerable Roma, such as prisoners and drug users. The UNGASS ${ }^{74}$ report identifies young Roma with risk behaviours as a group that is highly at risk of HIV infection.

Mortality and Life Expectancy
One of the most alarming health status differences between the Roma communities and the majority population concerns infant mortality rates. Infant mortality rates among Roma are $28 / 1000$ compared to $9.9 / 1000$ for the general population (almost three times higher for Roma than for non-Roma). The data on infant mortality rates is quoted in national policy documents and is somewhat outdated, as it refers to statistics from $2003^{75}$. Nevertheless, there is little reason to believe that the rates have changed significantly over the past decade and infant mortality remains one of the most serious health concerns among the Roma community. An NGO report cites an infant mortality rate that is insignificantly lower (24/1000), though as the source quoted is again a public policy document the difference may be derived from earlier national statistics ${ }^{76}$.

According to the National Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities, the life expectancy of Roma is at least 10 years less than the general population. The mortality rate among Roma is highest in the 40-49 age group, with the biggest cause of death being cardiovascular and cerebrovascular diseases. The strategy refers to data from "survey", although the survey sample or agency in charge is unclear. Publicly available life expectancy data provided by the National Statistics Institute is not disaggregated by ethnicity.

The demographic profile of the Roma community confirms that the average life expectancy of the population is significantly lower than the majority population. For instance, only $2.7 \%$ of Roma are aged 65 and over compared to $16.1 \%$ of the general population (according to census results in 2001) ${ }^{77}$.

Prevalence of Major Infectious Diseases
Although significant data gaps exist with regards to prevalence of major infectious diseases, both quantitative and qualitative data reveals that Roma are especially vulnerable to outbreaks of measles and hepatitis $A, B$ \& $C$, while high rates of HIV spread have been witnessed among the most socially excluded, such as prisoners, drug addicts and prostitutes. An outbreak of measles registered in 2009 revealed that $89.3 \%$ of the 24,047 people affected were of Roma origin and 22 out of the 24 deaths were Roma patients ${ }^{78}$. Qualitative information from interviews with health practitioners working with Roma reveals that there are frequent outbreaks of hepatitis $A, B \& C$ in geographically segregated Roma communities.

Field work among 12 towns and villages with a segregated Roma neighbourhood reveals significantly higher rates of infection of tuberculosis among Roma than the general population in this specific region. For instance, in the village of Sevar the rate

[^13]of tuberculosis among Roma is $1587.3 / 100,000$ compared to an average rate of 78/100,000 for the region of Razgrad. Similarly, the rate of tuberculosis among Roma in the village of Kotel is $1454.5 / 100,000$ compared to $73.4 / 100,000$ for the region of Sliven.

Recent outbreaks of measles cases in Bulgaria have been registered almost entirely among the Roma community. In 2009-2010, $90 \%$ of 21,470 cases were Roma. Measles cases often evolve with complications such as pneumonia, encephalitis and diarrhoea. A study of 206 measles cases in Burgas, found that there is a correlation between the cases with complications ( $88 \%$ of the caseload had complications) and educational attainment of the mother. Poorer education increased the chance for complications when controlling for other variables such as immunisation status and number of family members in the household (ECDC 2012).

Overpopulation of Roma settlements and households (discussed in a later section of this report) makes it more difficult to isolate virus carriers, and disease outbreaks frequently turn into epidemics. In addition, scholars have also identified cultural norms such as frequent empathy visits to the sick as contributors to the spread of infectious diseases ${ }^{79}$.

Another important factor increasing the vulnerability of the community towards infectious diseases is the low coverage of vaccination of preventable diseases among Roma children. According to the National Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities, 15\% of Roma children are without complete mandatory vaccinations ${ }^{80}$. It is likely that in some segregated communities the rates of Roma children with incomplete vaccinations are much higher. In the case of the measels outbreak in 2009, the vaccination status was known in 482 cases of whom 142 (29\%) were not vaccinated, 248 (52\%) had received one dose, and 91 (19\%) had received two doses of the vaccine (ECDC 2013).

Healthy Life Styles and Related Behaviours
There are several key indicators that reveal that the typical lifestyle and health related behaviours among the Roma community are not conducive to a good health status. Some of the key differences in the life styles of the minority and the majority population could be explained by higher rates of poverty and lower levels of income of Roma compared to the general population (poverty rates are discussed in a later section of this report). One of the most striking differences between the Roma minority and the majority population is evidenced in food consumption, and particularly the inability to afford basic foods which is 6 times more common among Roma. Notably, $42 \%$ of Roma live in households in which someone went to bed hungry at least once in the past month compared to just $7 \%$ of the general population ${ }^{81}$. Unsurprisingly, Roma consume only $13.6 \%$ of the daily recommendations of meats and $25 \% \%^{82}$ of cheeses; basic foods that are relatively more expensive. Other healthy life style indicators that could be explained by the typically low income of Roma households is the access to essential drugs; 70\% of Roma do not have access to

[^14]essential drugs, a difference that is more than threefold compared to the majority population $(21 \%)^{83}$.

Available data on dependencies does not allow for comparison between Roma and the general population. Nevertheless, the rates of dependencies on drugs and alcohol among Roma are evidently high; according to one source, $17 \%$ of Roma live in households with at least one member who has problems with alcohol or drugs ${ }^{84}$. Tobacco consumption is also typically high among Roma; according to a representative survey $52 \%$ of Roma aged $30-44$ are heavy smokers, smoking on a daily basis ${ }^{85}$. Interestingly, the only comparable data on alcohol and cigarette purchases reveals that the share of Roma who purchase alcohol and cigarettes regularly is almost the same as that of the general population; 29.78\% for Roma and $30.45 \%{ }^{86}$ for the general population. However, these rates need to be considered when accounting for lower income levels and less purchasing power of Roma, and also bearing in mind that cigarette and alcohol purchases may in fact replace purchase and consumption of other necessities such as foods and medicines.

Another alarming indicator revealing behaviour that is not conducive to good health is the sedentary lifestyle of the Roma community. $83.7 \%$ of the adult Roma and $40.5 \%$ of the children do not perform any kind of physical activity, while rates for weekly practice of physical activities are extremely low for both groups; $0.7 \%$ and $1.5 \%$ respectively ${ }^{87}$. This is partially due to a lack of sport facilities and open spaces for recreation purposes in Roma neighbourhoods. However, sporting activities and keeping in shape are also not a priority among the Roma community ${ }^{88}$.

## Access and Use of Health Services and Prevention Programmes

The most significant barrier to accessing health services beyond emergency care for the Roma minority is low rates of health insurance. Two sources reveal similiar rates of health insurance among Roma at $48 \%{ }^{89}$ and $45 \%{ }^{90}$ compared to $85 \%$ for the general population ${ }^{91}$. However, the rates of health insurance, as well as other health determinants and health status, need to be considered on a micro level as substantial variation is evident between different Roma settlements. For instance, 91.4\% of the members of 76 interviewed households ( 402 people) in the village of Veselinovo (Yambol region) stated that they had health insurance. This rate is significantly higher than for the 43.5\% of interviewed Roma in the village of Kitanchevo (Razgrad region) who had health insurance, and is significantly higher than the average values of 45$48 \%$ registered by the general studies cited above ${ }^{92}$.

In general, doctors and health facilities tend to be further away from Roma communities than the general population. This difference could be explained by the

[^15]existence of segregated Roma neighbourhoods, which are isolated from infrastructure, public services and health facilities. Around 59\% of the general population and 43\% of Roma live within a kilometre of a medical centre, but 41\% of Roma compared to 30\% of the general population live between 1 km and 3 km of a medical centre ${ }^{93}$.

Another barrier to access of healthcare is discrimination by health personnel toward Roma. In a survey examining different types of discrimination, the most frequently cited discrimination by Roma respondents was discrimination by staff of health centres and hospitals experienced by $43.10 \%$ compared to $34.70 \%$ by social services and $32.30 \%$ at job interviews ${ }^{94}$. Again, there are significant differences at a micro level, and surveys, representative of Roma populations in 12 villages with higher concentration of Roma that there are various degrees of trust and content/discontent with the general practitioners, treating the community. In addition, the study reveals that health mediators have in many cases positively influenced the patient-doctor relation ${ }^{95}$.

Having in mind the above mentioned barriers to access to health, it is not surprising that Roma tend to perform different types of medical check less frequently than the general population. For instance, only $14 \%$ of the Roma in household surveys had performed cholesterol test, as compared to $33 \%$ of the general population, $24 \%$ had performed a heart check-up as compared to $44 \%$ of the non-Roma population. The exception to the rule is the incidence of performance of x-rays or other types of scans, where $11 \%$ of the Roma had performed such a test, as compared to $6 \%$ of the nonRoma population ${ }^{96}$.

A clear tendency in the treatment of illnesses among the Roma is the self-prescribed use of medicines. A quarter of the Roma respondents of a survey declared that they had consumed blood pressure medicines without prescription in the past two weeks, another $18 \%$ stated that they had consumed painkillers in the preceding two weeks without a medical prescription ${ }^{97}$.

Members of the minority group have generally more positive health self-assessment than the general population. $71 \%$ of the Roma people perceive themselves to be in good health, compared to $62 \%$ of the majority population. Respectively, the percentage of those who perceive themselves to be in bad health is lower in the minority (12\%) than in the majority (15\%) population ${ }^{98}$. This positive perception among the Roma, however, does not necessarily correspond to a more positive health status, but could be explained by lack of awareness of health problems due to infrequent visits to doctors and hence lack of diagnosis of health conditions. Another explanation is provided by the perception of good health among the Roma as the absence of biological disease ${ }^{99}$.

An important initiative with regards to improving the access to health is the establishing of the profession and network of health mediators. The profession started as a pilot model in 2001 in Kjustendil with the employment of the first five health mediators. In 2007 the profession was institutionalized and the state started to

[^16]allocate a budget for health mediators to the municipalities. In 2007 there were 55 health mediators. In 2013, 130 health mediators work in more than 70 municipalities in Bulgaria (and 17 others are trained and hired under a project). The health mediators played a key role in coping with the measles epidemic outbreak in 2010 when 24,000 people were infected and 24 children died. Health mediators cooperate with general practitioners and subdivisions of the Ministry of Health (Regional Health Inspectorates) to obtain better vaccination coverage among children, to prevent epidemic outbreaks and to increase the health culture and awareness of Roma communities.

## Prevalence of Major Chronic Diseases

Particular concerns regarding health status of Roma in Bulgaria are high rates of disabilities and serious chronic diseases among the Roma population - $12 \%$ of all Roma, including children. The share of persons with disabilities and serious chronic diseases reaches $70 \%$ for Roma aged 65 and over. Other frequently diagnosed maladies among the community include high blood pressure ( $12 \%$ by diagnosis for Roma, $23 \%$ for the general population), high cholesterol ( $7.4 \%$ for Roma, $7.5 \%$ for the general population), asthma and chronic bronchitis ( $8 \%$ for Roma and $14 \%$ for the general population $)^{100}$. It must be noted however, that the occurrence of these health problems is by diagnosis. Having in mind the less frequent use of health services and medical checks by the Roma, it could be expected that the actual occurrence of these chronic diseases are higher that the diagnosed rates.

## Health Factors Related to the Role of Women in the Roma Community

Although on the whole, the Roma population perceive their health as better than the average, a disproportionately high number of Roma women over 50 report a 'bad' or 'very bad' health status - $48 \%$ compared to the Bulgarian average of $31 \%$. ${ }^{101}$ This trend could be strongly related to the low number of Roma women who are not covered under a health insurance plan, almost 3 times more Roma women are uninsured in comparison to the general population. ${ }^{102}$

One of the most notable indicators related to the role of women in the Roma community is related to the infrequent use of contraceptives. According to a report on the health status of the Roma women in Bulgaria, almost 60\% of the women do not use any contraceptives ${ }^{103}$. Other sources confirm the low use of contraceptives according to a survey, only $9 \%$ of the respondents had consumed birth control pills in the preceding two weeks ${ }^{104}$. Different authors have pointed out that the use of contraceptives is unacceptable in many Roma communities, and is especially denounced by male Roma.

Roma women visit the gynaecologist quite frequently. One fourth of the Roma visited this specialist during the last year for reasons other than pregnancy. Young Roma women go for gynaecological check-ups for reasons other than pregnancy three times more often than those over 45. Breast and uterine cancer prevention in the Roma community is insufficient. Women between the ages of 30 and 44 submit to pap smear tests more frequently than younger women - almost half of this age group had this test. Only one fourth of Roma women examine themselves for breast cancer.

[^17]Mammographies are especially uncommon for rural population: women from the villages had mammographies 2.8 times less frequently than those living in the capital ${ }^{105}$.

## Environmental and other Socio-Economic Factors

Plenty of studies have provided ample evidence that the Roma community is socially excluded. The social exclusion in key areas such as education, labour market, housing translates into an environment that brings about health inequalities between the Roma and non-Roma population. A history of school segregation and discrimination brings about early drop-out rates among the Roma or overall non-attendance of school and high rates of illiteracy among the Roma (21.80\% among Roma, 0.9\% among the general population $)^{106}$. The poor educational attainments and functional illiteracy lead to exclusion from the labour market - unemployment rates among the Roma aged 1564 reach $40 \%$ as opposed to $20 \%$ of the general population ${ }^{107}$. All socio-economic indicators, unemployment and employment included, display high macro and regional varieties. For instance, data on socio-economic and health status of Roma in 16 villages/towns reveals the relative share of the employed in the two years is highest in Damianitsa - 39.4\% (2006) and 40.4\% (2008), lowest in 2006 in Straldzha $0.9 \%$, and in 2008 - in Vazovo - 4\%; biggest share of registered unemployed in the two years in Straldzha - 45.8\% (2006) and 37.2\% (2008), lowest in 2006 in Satovcha - $2.7 \%$, in 2008 - in Damianitsa - 1.8\%; biggest share of not registered unemployed in 2006 in Rakovski - 25.9\%, and in 2008 - in Vazovo - 45.9\%, lowest in 2006 in Straldzha - 1\%, and in 2008 - in Veselinovo - 0.3\%.

The high levels of unemployment and low incomes of Roma households explain the high at risk of poverty rates ( $88 \%$ among Roma, $51 \%$ among general population) and high share of households with severe material deprivation ( $82 \%$ of Roma, $37 \%$ among the general population). The severe material deprivation limits the possibility to lead a healthy lifestyle, to buy basic foods and medicines (discussed earlier in this report), but also negatively affects the housing situation of the Roma. The problem of high unemployment presents future issues relating to pensions. Approximately 79\% of non-Roma Bulgarian residents over 45 will be eligible for a future pension compared to the lower Roma figure of $66 \%$. ${ }^{108}$

The poor housing conditions of the Roma minority in Bulgaria have been widely documented. Studies reveal that one quarter of the Roma population lives in substandard housing and $4 \%$ live in shanty towns ${ }^{109}$. According to the FRA, 51\% of Roma in Bulgaria live in deprived housing conditions (either no piped water, sewage and/or electricity) in contrast to $17 \%$ of the general population. ${ }^{110}$ Overcrowding (Roma typically have 14 square metres per household member, as compared to 26 for the majority of the population) leads to the fast spread of any disease. The lack of access to water supply (affecting $40 \%$ of Roma households) and lack of indoor bathroom facilities ( $80 \%$ of the Roma do not have an inside bathroom), together with infrequent waste disposal leads to the poor hygiene both in Roma neighbourhoods and Roma households, which is conducive to the breed and spread of disease ${ }^{111}$.

[^18]
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## Country Profile: Croatia

## Main Characteristics of the Roma in Croatia <br> Demography

The 2011 census: number of Roma in Croatia increased to 16.975 ( $0.40 \%$ ) compared to the census data 20019.463 ( $0.21 \%$ ). However, it is important to note that according to the estimates of the Council of Europe there are about 30,000 or 40,000 Roma living in Croatia.

According to the National strategy ${ }^{112} 55 \%$ of the population belong to the age group $0-19,40 \%$ to the age group 20-59 and only $3 \%$ is older than 60.

Roma live in the whole territory of Croatia but are most numerous in the Međumurje county, the City of Zagreb, Osjek Baranja county, Sisak Moslavina County, Istria county and Primorje county. In the majority of cases Roma live in marginalised and segregated communities which are to be found both in urban and rural areas.

When looking at the unemployment rate, the difference between Roma and non-Roma is as follows - 65\% unemployed Roma compared to $24 \%$ unemployed non-Roma.

According to the UNDP report Faces of Poverty ${ }^{113}$ the poverty rate is two and a half times higher for Roma compared to non-Roma - thus $76 \%$ of Roma and $20 \%$ of nonRoma living nearby Roma settlements live in absolute poverty.

## Geographical distribution

According to the 2011 census the distribution of Roma is as follows:

| County | Roma in <br> numbers | Roma in \% |
| :--- | :--- | :--- |
| ZAGREB COUNTY | 258 | 0.08 |
| KRAPINA ZAGORJE COUNTY | 3 | 0 |
| SISAK MOSLAVINA COUNTY | 1,463 | 0.85 |
| KARLOVAC COUNTY | 26 | 0.02 |
| VARAZDIN COUNTY | 711 | 0.40 |
| KOPRIVNICA KRIZEVAC COUNTY | 925 | 0.80 |
| BJELOVAR BILOGORJE COUNTY | 391 | 0.33 |
| PRIMORJE GORSKI KOTAR COUNTY | 1,072 | 0.36 |
| LIKA COUNTY | 21 | 0.04 |
| VIROVITICA PODRAVINA COUNTY | 14 | 0.02 |
| POZEGA SLAVONIA COUNTY | 13 | 0.02 |
| BROD POSAVINA COUNTY | 1,178 | 0.74 |
| ZADAR COUNTY | 12 | 0.01 |
| OSJEK BARANJA COUNTY | 1,874 | 0.61 |
| SIBENIK COUNTY | 22 | 0.02 |
| VUKOVAR SYRMIA COUNTY | 253 | 0.4 |

[^19]| SPLIT DALMATIA COUNTY | 8 | 0 |
| :--- | :--- | :--- |
| DUBROVNIK NERETVA COUNTY | 11 | 0.01 |
| MEDJIMURJE COUNTY | 5,107 | 4.49 |
| CITY OF ZAGREB | 2,755 | 0.35 |

## Other Information (including highlights of data gaps)

It has not been possible to cover all types of indicator. One of the main obstacles in data collection is the fact that Croatian National Institute of Public Health and Croatian Institute of Health Insurance - two main institutions responsible for conducting healthstatistical research - do not collect data on health conditions or the accessibility of health services based on ethnicity ${ }^{114}$.

Additionally, there is limited scientific research in this area, apart from several articles focusing on a small sample.

## Mortality and Life Expectancy

Concerning the indicators on life expectancy ${ }^{115}$ - expected life expectancy of nonRoma is 76.6 years ( 73.50 for men and 70.60 for women) while the estimates for average life expectancy for Roma is 10 years less -66.6 years.

As for infant mortality ${ }^{116}$ there are some indicators of a higher infant mortality rate among Roma population.

Thus, according to the Report on Implementation of Action plan of Roma Inclusion for 2009 and 2010, Roma infants, in almost 50\% of cases did not receive any medical treatment prior to death and have died outside of medical institutions, in $63 \%$ of cases they have died at home compared to a non-Roma average of $95 \%$ of infants who were medically treated and have died in hospital.

The main challenge with the existing data is that there are no ethnically disaggregated data so these only present estimates.

## Prevalence of Major Infectious Diseases

As regards prevalence of major infectious diseases there is a complete lack of data due to the fact that data are not collected based on ethnicity we could not identify any sources.

However, according to the UNDP/WB/EC regional Roma survey $2011^{117}$ the perceived vaccination_rate is as follows:
(0-6) Roma - 97\% (97\% male and 96\% female) and non-Roma - 99\% (97\% male and $100 \%$ female)
(6) Roma - 98\% (98\% male and 95\% female) and non-Roma - 100\% (100\% male and 100\% female).

[^20]Thus, it can be concluded that the level of vaccination is high, almost $100 \%$.
This data is consistent with the National Strategy ${ }^{118}$ which provides data on child vaccination among Roma ${ }^{119}$ 120. Accordingly, absolute vaccination in 2010 was 75.8\%, partial vaccination was $6.4 \%$ and the percentage of non-vaccinated children was 17.7\%.

## Healthy Life Styles and Related Behaviours

With reference to tobacco usage the UNDP/WB EC Regional Roma Survey ${ }^{121}$ observed $52 \%$ more Roma smokers than non-Roma in Croatia, thus existing data report the number of smoking adults $(+16)$ at 64\% Roma and $31 \%$ non-Roma.

The same survey includes data on malnutrition which is present in $38 \%$ among Roma and 5\% among non-Roma.

Access and Use of Health Services and Prevention Programmes
There are several reports on self-reported health status. These include ref 1 and 5 with the difference that ref 1 refers to the region while ref 5 refers to data collected in Croatia.

Thus, according to Ref 1 the perception of the general health status of the Roma population is lower, compared to neighbouring non-Roma, but with a small difference. Altogether $16 \%$ of the Roma sample has a negative perception of their health status, compared to $14 \%$ of the non-Roma population. In general, $85 \%$ of the entire surveyed population (both Roma and non-Roma) are positive about their health status - an unexpectedly positive perception.

Another indicator of the perceived health status used by the survey is the reported limited activities because of a health problem during the last six months. In total, no significant differences between the Roma and the non-Roma exist according to the data - 82\% of respondents, equally for the Roma and non-Roma, report "no limited activities". There are some statistically significant differences in the responses "strongly limited", showing higher vulnerability of the Roma sample. However, the overall data verifies similar levels of reported restricted activities due to health problems for the Roma and their non-Roma neighbours.

Furthermore, the Regional Roma Survey data ${ }^{122}$ confirms that the perceived health status of the Roma is not significantly lower, as compared to the control non-Roma sample. On the contrary, the reported prevalence of chronic disorders shows, in total, $17 \%$ of the Roma sample has such a disease or problem, while it is $18 \%$ for the nonRoma sample.

Expectedly, the reported long-standing illnesses increase with age, both among the Roma and the non-Roma sub-samples. It is important to note that the age factor is

[^21]significant for both populations. However, the increase of reported health problems, among the Roma in older age groups, is much steeper, reaching 70\% for those 65 years old, compared with $56 \%$ of the non-Roma. The reported long-standing illnesses are more frequent among female respondents for both samples.

Furthermore, differences between the Roma and the non-Roma are found when looking at inpatient stays. The number of adults (16+) who have visited hospitals during the last 12 months (with and without insurance) is higher among Roma than among non-Roma - $17 \%$ versus $12 \%$ for the insured respondents, and respectively $14 \%$ versus $9 \%$ for the people without the health insurance.

When it comes to access to health care, the overall regional data prove a very high disparity between Roma and their non-Roma neighbour samples - 74\% of the Roma in the region report having medical insurance (...either in your own name or through another member of your household) compared to $90 \%$ of the non-Roma living in their proximity.

When it comes to financial affordability of medicines, there is a difference between the Roma and the non-Roma sample which is very high. 55\% of the Roma sample report instances in the past 12 months when household members could not afford to purchase prescribed medicines. Only $25 \%$ of the non-Roma sample reports such instances.

Report data proves a lower quality of accessed services among the Roma, compared with their non-Roma neighbours. At the individual level, $10 \%$ of the interviewed Roma report to be very dissatisfied with the services provided at their last visit, compared with $6 \%$ of the non-Roma respondents. The difference is even higher for the perception of health safety - $24 \%$ of the Roma households do not feel safe, compared to $12 \%$ of their non-Roma neighbours.

In reference to this data it is important to point out that data covers all interviewed households in the region, not only Croatia.

When it comes to Croatia ${ }^{123}$, the share of people with bad health assessment is $12 \%$ Roma and $11 \%$ non Roma while the share of people with a good health assessment is $78 \%$ Roma and $71 \%$ non-Roma. Thus, we can conclude that there is a positive perception of health and no significant difference between Roma and non Roma.

When it comes to access to medical insurance the data show that $82 \%$ of Roma have insurance in comparison to $97 \%$ of non-Roma, thus showing disparity between these two groups.

The same report collected data on incidence of specific medical check-ups and the data shows the following:

- Dental check-ups - $34 \%$ Roma and $44 \%$ non-Roma participated
- X-ray, ultrasound or other scan - 29\% Roma and 34\% non-Roma participated
- Cholesterol test - 25\% Roma and $40 \%$ non-Roma took them
- Heart check-ups - $27 \%$ Roma and $35 \%$ non-Roma participated.

In terms of barriers to accessing health care, the survey ${ }^{124}$ shows that when it comes to access to essential drugs there is a high disparity between Roma and non-Roma.

[^22]Thus, 44\% Roma reported having no access while only $16 \%$ non-Roma reported the same.

Additionally, in accessing health services, 92\% Roma have access compared to 98\% non-Roma.

## Prevalence of Major Chronic Diseases

When it comes to prevalence of major diseases, the only available data is from 200506 and refers to the prevalence of hypertension. However, it should be noted that the research refers only to a small group of Roma, more precisely to 423 members of the Bayash Roma minority population living in two regions of Croatia (144 men and 279 women, aged 18-84yrs).

Accordingly, hypertension was found in 24.8\% Bayash Roma (21.5\% men and 26.5\% women). The prevalence increases from $5.9 \%$ in the age group $18-34 ; 35.0 \%$ in the age group $35-64$, and $51.4 \%$ in the age group $65+$. The prevalence of hypertension in the Bayash Roma is almost half of what is usually reported for the general population of Croatia. It is also lower when compared with other European populations and this finding is not due to comparatively younger average age of the Bayash sample ${ }^{125}$.

## Health Factors Related to the Role of Women in the Roma Community

We could identify two indicators for health factors related to women.
Cervical cancer screening:

- The gap between Roma females (74\%) and their non-Roma neighbours (86\%) in cervical testing widens for the older age groups, while there is even a reverse vulnerability for the youngest age group (15-24 years), where the cervical attendance rate among Roma is higher. The latter is understandable, taking into account other research showing that the Roma start sexual life at a younger age, compared to the national majorities ${ }^{126}$. However, this data refers to the region as a whole. Country specifics, however, emerged as the strongest factor showing the high level of access to maternity health services in Croatia. Probit analysis shows increasing probabilities of cervical testing if living in Croatia ( $+15 \%$ ). Similarly, the probability of attending a gynaecological test is significantly higher in Croatia (+19\%).
- In terms of becoming a mother at 15 years of age, according to the National Strategy ${ }^{127} 60 \%$ of girls starts with sexual relationships and are mothers already at the age of 15 . This data is taken from the Ombudswoman for Gender Equality Report from 2005. Additionally, according to Roma NGOs this data should be taken with caution.

[^23]
## Environmental and other Socio-Economic Factors

When it comes to data on the environmental and the socio-economic status of the Roma in Croatia, the majority of data is taken from the UNDP survey (ref 5). Additionally, a recent FRA report ${ }^{128}$ includes data on Roma population in Croatia and basic information about education, employment, housing, health, poverty/economic situation, active citizenship/rights awareness of Roma in Croatia.

The employment rate is $14 \%$ for the Roma and $49 \%$ for the non-Roma (15-64 of age) (ref 5). Furthermore, In 2009, a non-governmental study carried out in five counties of the Republic of Croatia and Zagreb found that there were 7\% Roma women verses $16 \%$ Roma men employed ( $13 \%$ vs. $33 \%$ registered, respectively ${ }^{129}$.

Unemployment rate is $65 \%$ for the Roma (significant gender difference: $59 \%$ male vs $76 \%$ female) and $23 \%$ for non- Roma (15-64 age group) ${ }^{130131}$.

## Educational level

Literacy rates show that 84\% Roma (significant difference between gender: 92\% men vs $77 \%$ women) are literate compared to $99 \%$ of non-Roma ${ }^{132}$.

Also, when looking at the enrolment rate in secondary school there is $31.42 \%$ Roma enrolment in comparison to $77.05 \%$ of non-Roma. Additionally, a nongovernmental report published in 2009 highlighted issues in the situation of the Roma in education in five counties and Zagreb and provided an insight into the gender inequalities in this regard. Considering the younger generation, the study showed that 23\% Roma men vs. $17 \%$ women finished elementary school and $21 \%$ men vs. $15 \%$ women finished secondary school ${ }^{133}$.

When analysing data on the highest completed education (25-64) the data show that $40 \%$ Roma in comparison to $2 \%$ non-Roma have no formal education. There is a significant gender difference in Roma population - $29 \%$ of men and $50 \%$ of women have no formal education.

In terms of primary education, $34 \%$ of Roma have finished only primary education in comparison to $9 \%$ non Roma. 16\% of Roma have finished lower secondary education in comparison to $21 \%$ non-Roma while $9 \%$ Roma have finished upper secondary education in comparison to 60\% non- Roma ${ }^{134}$.

[^24]However, the number of Roma enrolling in primary education appears to be on the rise. According to official statistics, Roma enrolment in elementary schools quadrupled (from 1,013 to 4,186 ) between the school years 2005/06-2009/10. ${ }^{135}$

This is in line with UNDP survey which showed that average years of education (ages $25-64$ ) is 4.49 years for Roma compared to 10.58 years for non-Roma ${ }^{136}$.

When it comes to housing and number of rooms per household member the ratio is $0.48 \%$ for Roma in comparison to $1.20 \%$ for non-Roma ${ }^{137} 138$.

The proportion of the population not having access to secure housing: 26\% for Roma and 4\% for non-Roma ${ }^{139}$.

The proportion of the population not having access to improved water source: 35\% for Roma and $4 \%$ for non-Roma ${ }^{140}$.

The proportion of the population not having access to improved sanitation (not having a toilet or bathroom inside the dwelling): $45 \%$ for Roma and $5 \%$ for non-Roma ${ }^{141}$. According to FRA ${ }^{142}$ this ratio is $53.91 \%$ Roma in comparison to $6.30 \%$ for non-Roma.

Access to electricity: 88\% for Roma and 99\% for non-Roma ${ }^{143}$.
EU material deprivation index. Material deprivation: 88\% for Roma and 42\% for nonRoma ${ }^{144}$. Severe material deprivation: $70 \%$ for Roma and $24 \%$ for non-Roma ${ }^{145}$.

Absolute poverty rate $\operatorname{PPP}^{146} \$ 4.30$ expenditures based: 5\% for Roma and 5\% for nonRoma ${ }^{147}$. PPP\$ 4.30 income based: $9 \%$ for Roma and 5\% for non-Roma.

Relative poverty rate (60\% equalized median income): 92\% for Roma and 42\% for non-Roma ${ }^{148}$. Hence, the relative poverty rate in Croatia is twice as high for the Roma when compared to non-Roma. There are also significant differences in income levels between the two groups: 3,517.15 HRK for Roma and 5,646.92 HRK for non-Roma. According to the People's Ombudsman, ethnic discrimination is the most frequent type of discrimination, and Serbs and Roma are the most discriminated against ethnic minorities. In most cases, discrimination is indirect and consists of excluding Roma

[^25]because of their poverty, low education level, poor language skills, unemployment, etc ${ }^{149}$.

It is important to note is that some data (e.g. employment/unemployment/poverty rate) has been presented in various reports ${ }^{150} 151 \quad 152 \quad 153 \quad 154$. However, the time period it refers to is different and the data are not always comparable. For this reason the latest data has been presented in this section.

Bibliography
References: Methods, types of surveys and other sources used for the references
Ref 1: The structure of the paper aims at covering three main thematic areas that are normally covered in evaluation and analytical studies of public health: Health status; Access to health services; Quality of health services. Locations: Croatia, Slovakia, Bulgaria, Bosnia and Herzegovina, Serbia, Montenegro, Macedonia, Albania, Bulgaria, Czech Republic, Hungary, Republic of Moldova. The study consists of: (i) all the households in Roma settlements or areas of compact Roma population; (ii) non-Roma communities living in close proximity to Roma. Face-to-face interviews at the respondent's household. Year: 2012

Ref 2: This paper provides data on: total country population; official number of Roma (last census); minimum and maximum estimate; average estimate and \% of total population (from average figure). It was updated in 2010.

Ref 3: Eurofound has carried out a literature review and secondary analysis of survey data in order to gain an overview of the housing and health conditions of the Roma and how both domains are interrelated. The data used for the analysis come from the United Nations Development Programme (UNDP), the European Union Minorities and Discrimination Survey (EU MIDIS) and the EU Roma Health Survey. Year: 2012

Ref 4: This paper provides data on Roma population in Croatia and basic information about education, employment, housing, health, poverty/economic situation, active citizenship/rights awareness of Roma in Croatia. It was conducted through desk research (different papers, UNDP unpublishedl data from the UNDP Household survey (2011), Croatian Bureau of Statistics (2001 census), etc. They year is unknown, probably 2011.

Ref 5: The UNDP/WB/EC survey was conducted in May-July 2011 on a random sample of Roma and non-Roma households living in areas with higher density (or concentration) of Roma populations in the EU Member States of Bulgaria, Czech Republic, Hungary, Romania, Slovakia, and the non-EU Member States of Albania, Bosnia and Herzegovina, Croatia, FYR of Macedonia, Montenegro, Republic of Moldova and Serbia. In each of the countries, approximately 750 Roma households and approximately 350 non-Roma households living in proximity were interviewed. Year: 2011.

[^26]Ref 6: Statistical data on Roma population; poverty; unemployment rate and primary education for Croatia (and other countries).

Ref 7: National strategy - analysis of the situation based on available research on Roma in Croatia. Year: 2012

Ref 8: This report is based on ERRC research and documentation of discriminatory practices and other forms of human rights abuse against Roma in the provision of health care as well as exclusion from access to health care and factors which prevent Roma from the ability to realise the right to the highest attainable standards of physical and mental health, as guaranteed by international law, in - Bosnia and Herzegovina, the Czech Republic, Croatia, Greece, France, Italy, Kosovo, Romania, Serbia, Slovakia and Slovenia, as well as material from ERRC legal databases. Year: 2006

Ref 9: Data on employment, housing and living conditions, education, gender equality and access to modern communication of Roma in Croatia based on surveys. Year: 2005

Ref 10: Data collection and analyses of health status of Roma in Međimurje County. Year: 2010.

Ref 11: Report on the evaluation of the Action plan for Roma in Croatia (in the area of health). Year: 2010

Ref 12: Results on blood pressure levels and prevalence of hypertension in Bayash Roma minority population of Croatia and comparison to surrounding populations; assessment of the importance of some traditional CVD risk factors (BMI, smoking) in this population; research of the association of blood pressure values with some indicators of socio-economic status (SES indicators of poverty) in this population. The dataset used in this study is a subset of the extensive material collected in field studies carried out in 2005 to 2006 in Bayash settlements in Baranja and Međimurje regions of Croatia. Year: 2008

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## Country Profile: Cyprus

## Main Characteristics of the Roma in Cyprus <br> Demography

The first mention of Roma in Cyprus dates back to the middle of the $16^{\text {th }}$ century. It is believed that they came originally from Corfu, employed later by the Ottomans for military purposes and later converting to Islam ${ }^{155}$. However, there is also a minority of Roma who are Christian.

The country is divided between the Cypriot and the Turkish-Cypriot areas, where the majority of the Roma live nowadays: because of this jurisdictional separation collection of data on Roma population is not precise.

Roma in Cyprus are estimated to be between 1,500 and 2,500 . According to the Administration of District Officers, there are between 650 and 700 Roma who live in areas where the Republic of Cyprus exercises effective control. Moreover, there are Romanian and other Balkan Roma living in Cyprus, although their number is not officially known ${ }^{156}$.

## Geographical distribution

Roma in Cyprus are mainly Muslim, therefore when the country was split in two parts they were deemed to be part of the Turkish-Cypriot community, although this was not self-determined. In the late 1990s and early 2000s, a number of Roma crossed from the Turkish-controlled north to the Greek Cypriot-controlled south and settled in the old Turkish quarter of Limassol. They settled in properties abandoned by Turkish Cypriots many decades ago, which are in a poor state of repair. There, they faced extreme poverty, exclusion and hostility from the host population and were treated with suspicion and intolerance by the authorities ${ }^{157}$.

This internal migration from the North to the South of the island has put the recognition of Roma ethnicity in the government agenda ${ }^{158}$.

Mortality and Life Expectancy
The research team have not found any qualifications for this indicator

| Prevalence of Major Infectious Diseases |
| :---: |
| The research team have not found any qualifications for this indicator |
| Healthy Life Styles and Related Behaviours |

[^27]

[^28](ECRI) observed that there is a disproportionately high concentration of Turkish Cypriot (including Roma) children in particular schools, indicating a certain level of segregation ${ }^{164}$. This disproportionate concentration may be a result of the fact that Roma pupils attend schools that are closer to where they live. However, this does not explain the lack of attendance in rural areas.

An ethnographic study (2012) based on interviews carried out in two schools in Cyprus found that teachers have insufficient understanding of Roma cultural practices, beliefs and attitudes towards schooling, making the integration of Roma students more difficult ${ }^{165}$. However, a study from 2009 reports some improvement in primary school attendance due to supportive measures such as providing school meals, uniforms and school materials. Secondary school enrolment and attendance are still poor in comparison to non-Roma populations.

- Employment

Both qualitative and quantitative studies illustrate a sub-optimal labour situation for the Roma in Cyprus. The NRIS study observes that the main barrier to employment is language The majority of the Roma do not speak English or Greek, the local government is providing Greek classes for citizens not able to speak the language.

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[^29]
## Country Profile: Czech Republic


#### Abstract

Main Characteristics of the Roma in the Czech Republic

\section*{Demography}

The total country population of the Czech Republic is $10,526,214$. $^{166}$ The Roma population is estimated to be approximately 200,000 (1.9\%). Moreover 13,150 ( $0.2 \%$ ) inhabitants reported their nationality as Czech and Roma and 5,199 reported themselves as Roma exclusively. The majority of Roma reported themselves as Czech, Moravian and other non-Roma nationality. The trend of self-reported Roma nationality is declining from 32,903 in 1991 to 11,746 in 2001. ${ }^{167}$ It may be caused by increased Roma integration into Czech mainstream society and/or a wish to integrate. Another explanation could be the increasing indirect discrimination in the job market, services and other parts of society. It is possible that this has had knockon effects for Roma civic participation, with turnout to the previous national election extremely low - $26 \%$ of Roma citizens voted compared to $60 \%$ of non-Romas. ${ }^{168}$


## Geographical distribution

The Roma live on over 300 socially excluded localities ${ }^{169}$. A locality is a village or a part of a house in a town Although inhabitants are not exclusively Roma nevertheless localities are characterised by poverty and social exclusion. They are spread throughout the country, however larger and/or poor Roma communities are concentrated geographically on the Northeast (Ostrava, Holešov, Přerov, Jesenicko), Northwest: Frýdlant, Rumburk, Ústí nad Labem). Slovak and other foreign Roma have immigrated to those regions and consequently increased the number of inhabitants in these poor and excluded communities. Roma migrants combine two burdens or causes of exclusion: unregistered migration and poverty. The Central Bohemia is a region with Roma population which is highly integrated, less poor, has higher levels of education and employment and is thus less excluded ${ }^{170}$.

## Other Information (including highlights of data gaps)

Due to personal data protection policy, data on Roma are generally difficult to find in official statistics. Official statistics and data on Roma population ceased to be available after 1990. Most of data on health and related to health are available from scientific studies and surveys published in professionals journals, from NGOs working with Roma, from governmental reports (annually since 2003) or reports on the status of Roma communities (monitoring). Data is generally collected by questionnaires or through face to face interviews with Roma and sometimes with non-Roma people as a control group. Few data are collected from medical or other professional records. The most important sources of data are studies and surveys undertaken by international organisations such as FRA, World Bank, UNDP, Open Society Fund and EU - Eurostat and Euro Barometre statistics. Data from these studies (health status,

[^30]health indicators, life style, use of health services and other issues related to health of Roma) have been collected from questionnaires or interviews with Roma.

Gaps in knowledge on Roma health include verified health indicators as mortality, life expectancy, and diseases prevalence.

Interviews and questionnaires are the only channels thourgh which information Roma health can be gatherered. The selection and information bias therefore needs to be carefully interpreted.

Other data gaps stem from a lack of comparison of findings and data with the controls - non-Roma population, both, living in proximity as Roma in under a survey or controls with similar social economic determinants or with official data for the general population. Such data should better help to find causes of differences and/or inequalities in health status of Roma and non-Roma population and distinction among differences caused by genetics or biology and inequalities or inequity caused by social economic and culture determinants.

## Mortality and Life Expectancy

Estimates suggest that the mortality rate of Roma is higher than in the general population. However, no exact data are available on this.

Life expectancy is predicted to be about 10-15 years lower than the general population. This is an estimate that is generally accepted for the Roma population in Europe. Data that is more precise has not been found (very probably it is not available). Czech life expectancy at birth in 2011 is 74.3 years for men and 80.5 years for women. ${ }^{171}$ The estimates for Roma are 64 year for Roma men and 70 years for Roma women. However, the average age of death in 2011 was 59.2 years for Roma men ( 65.6 years for non Roma men) and 63 years for Roma women ( 80.2 for non Roma women) according to data from a questionnaire which included the question: "At what age did your parents die?" in a study ${ }^{172}$. Differences between age of death and/or predicted life expectancy are more pronounced for women: 17 years, while for men this discrepancy is seven years. As this is an alarming finding and will need further research to find causes and prevention.

If we compare life expectancy of Czech people to social economic determinants like education, we find that less educated men live 18 years less than university educated men. ${ }^{173}$ For women, the difference in education has a lesser influence on life expectancy - three years. It is generally observed that social determinants have gender gradient; they influence men more than women. Poor education is a typical social determinant for Roma communities and mortality and life expectancy should remain different between the sexes in the Roma group. In reality, the opposite model seems to be valid: women are more vulnerable to social economic determinants of health than men in Roma communities.

Infant mortality was $24 \%$ for Roma children in 1985, which is twice as much as for non-Roma children (12.5\%). Nowadays it is commonly assumed that Roma infant

[^31]mortality is decreasing, but still remains 2.5 times higher than in the non Roma population ${ }^{174}$. Causes for this higher infant mortality among Roma are suggested to stem from poorer life styles of pregnant women, especially smoking in common in pregnancies $\left(57 \%{ }^{175}\right)$, poor environmental conditions, especially housing, low education levels of mothers and inadequate care for infants.

Causes of higher morbidity in children and higher frequency of doctors' visits among adults could be the result of poor living and hygenic conditions, especially housing, and related to low income and unemployment, or low level of education but also to specific cultural characteristics insofar as a smaller value is put on education and disease prevention. Prevalence of disease among Roma children is very high as studies published in 2008 have stated. This causes high absenteeism of children at school and leads to a low educational performance.

Poorer life styles of pregnant women could also be related to lower birth weight and other non-favourable outcomes ${ }^{176}$. Birth weight was less than $2,500 \mathrm{~g}$ in $14.1 \%$ of Roma newborns, in comparison to 3.6\% of non-Roma newborn. These unfavourable birth outcomes also included preterm birth (less than 37 weeks): 9.9\% for Roma 3.9 for non Roma women. Intrauterine grow retardation (IUGR) was prevalent in 22.2\% of Roma babies and $8.9 \%$ non-Roma babies. Other source states that $50 \%$ of Roma newborn babies have a weight of less than $2,500 \mathrm{~g}{ }^{177}$.

As positive trend in the country is that $90 \%$ of Roma women give birth in hospitals (maternity wards) in comparison to $97 \%$ of non-Roma women. Moreover7\% Roma women give birth at home with health care (midwife) assistance compared to $2 \%$ of non-Roma women. Only 3\% of Roma women give birth at home without health care assistance (non-Roma women $1 \%$ ). ${ }^{178} 179$ These could however be non-intent cases (not reaching a hospital in time).

## Prevalence of Major Infectious Diseases

Child morbidity and paediatric visits are higher for Roma children according to a study published in 1993. ${ }^{180}$ More recent data was not found. The frequency was calculated based on medical records: 2.2 diseases were suffered by a Roma child per year in comparison to 1.5 diseases by a non-Roma child per year. The total number sickness day per year was 16.5 for a Roma child in comparison to 12.4 for a nonRoma child. The difference was statistically significant for Roma and non-Roma girls, 13.88 sick days for Roma girls and 9.64 sickness days for non-Roma girls. Very small differences were found between Roma boys (17, sickness days) and non-Roma boys (18).

[^32]The main diagnosis was respiratory diseases for both Roma and non-Roma children. More Roma children had been prescribed antibiotics (45\%) than non-Roma children (32\%).

Vaccination rates for nine obligatory vaccinated diseases (tetanus, pertsusiss, diphtheria, measles, rubeolla, parotitis, hepatitis $B$, polio, hemofilus influensae) are high in the Czech Republic. Child vaccination is obligatory by law and free of charge. Estimated vaccination rates for Roma children is $95 \%$ in comparison to total population $98 \%$. ${ }^{181}$

Measles prevalence: 17 cases in 2011 in total, most of them foreigners or migrants, no data on Roma ${ }^{182}$.

Vaccination against Hepatitis A is not obligatory according to the law. It is easily accessible but not free. Vaccination rates among Roma population are estimated as being low, together with lower hygiene standards in some Roma communities. Moreover two epidemics of the disease have been recorded:

- In 2009 30\% of Roma from all reported cases were ill.
- In 2010 more than $50 \%$ of Roma from all reported cases were ill. ${ }^{183}$

The public health response was immediate: vaccination against Hepatitis $A$ for the population at risks was provided for free. Vaccination against hepatitis B is free of charge and obligatory for all children (citizens of CR), hepatitis A is voluntary and must be paid for.

Pulmonary tuberculosis prevalence is $12 / 1000$ among Roma persons, 10 times more than in non Roma population $0.12 / 1000$ non Roma persons. The data state this are from a study based on medical records for Roma people and from a National Health information study for non-Roma population. ${ }^{184}$

Data on HIV was not found on the Roma population.

## Healthy Life Styles and Related Behaviours

The life style of Roma is worse than of non-Roma population.
Nutrition, diet: meat, sweets, processed food, sausages, cakes and dumplings are the most frequent foods (463\% of recommended daily value), vegetables ( $19 \%$ of recommended daily value), fruit ( $20 \%$ of recommended daily value), dairy products ( $32 \%$ of recommended daily value), and fish. (6-14\% of recommended daily value) 185186

[^33]Physical activity: 0-15 years: 4\% play sports more than once a week, 43\% sedentary activity (e.g. TV), 44\% occasional walking, cycling, and other light physical activity ${ }^{187}$.

No more than 2\% of adults are engaged in regular physical activity or sport, $70 \%$ do not engage in any physical activities ${ }^{188}$.

Obesity as a results of high energy intake and low energy uptake among Roma, $27 \%$ of the Roma is overweight, $17 \%$ suffer from obesity, (17.4\% in the for Czech Republic), men are slightly more out of the normal weight range, the age group 45+ is $70 \%$ overweight and/or obese, $28 \%$ of children 1-9 years are obese, $5 \%$ children $10-15$ years are obese ${ }^{189}$. Differences between men and women are less pronounced than in non-Roma population: 45.5\% non-Roma men are overweight and 17.3\% obese, non-Roma women are overweight in $29.9 \%$ and in $17.5 \%$ obese ${ }^{190}$. The data on obesity are based on self-reported height and weight and might underestimate the prevalence of obesity. Culturally, overweight people are perceived as normal.

We can assume from this reviewed data that the percentage of obesity in the Roma population is the same as in the non-Roma population.

Smoking: 56\% of women and $65 \%$ of men in the Roma population smoke every day. Children smoke regularly from the age of 16 but occassionally also in younger age. Self-reported numbers slightly differ in different sources. 191192193194 Smoking among non-Roma population is prevalent in $30 \%$ of men and $19 \%$ of women. ${ }^{195}$

Pregnant women admitted to smoking in pregnancy - 58\%, in comparison with $20 \%$ of non-Roma pregnant women. $85 \%$ of pregnant Roma women reported smoking before pregnancy ${ }^{196}$.

Illicit drugs: $2.5 \%$ of the $16+$ Roma population admit to illicit drug use ${ }^{197}$.
Illicit drug abuse is increasing among young people and children - volatile chemicals inhalation is one of the most widespread, and is also cheap.

[^34]Other substances include cannabis and stimulancia. Illicit drugs are quite easily accessible in communities and the number of addicted young people is increasing ${ }^{198}$. Increased criminality is associated with illicit drugs abuse. ${ }^{199}$ Only $2.5 \%$ of 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 to take an illicit drug, most often marijuana. 200

It is generally believed that Roma drink more alcohol than the non-Roma populations. Results of sociological studies where self-reported data is used should be interpreted carefully due to possible information bias, misinterpretation and positive stylisation.

According to a study, only 9\% of men and $23 \%$ of women did not drink alcohol in the last 12 months ${ }^{201 .}$ Frequency of drinking alcohol decreases with age in both the Roma and non-Roma population. It seems that alcohol drinking in Roma population does not exceed alcohol drinking among non-Roma population.

Beer is consumed every day in $20 \%$ of the Roma population. The equivalent number for strong alcohol is $5 \%$. Roma children begin to drink alcohol later than they start smoking, at 15-16 years. Almost all of adult alcohol drinkers admitted that they started to drink before the age of $18^{202}$.

## Access and Use of Health Services and Prevention Programmes

According to numerous documents and surveys, Roma's barriers to use health services stem from poor accessibility (distance) and financial burdens. Yet if we analyse data for the Czech Republic we can see that the opposite seems to be the case.

The Czech health care facilities network is well developed. Accessibility issues are no different for Roma than the population generally. Social capital among Roma is high; wider family members care for each other and mutual help is more frequent than among the non-Roma population.

On the contrary, an obstacle to use health services is the perception of disease and health. Roma people take disease seriously if it is life threatening or very disabiling. However once treated, there is a tendency to cease to access medical care ${ }^{203}$.

Health care services are paid for by universal health insurance which is obligatory for Czech citizens. If a Czech citizen is not able to pay, insurance is paid for by the state. If a respondent reported that he/she has no health insurance, he/she is probably not a citizen of the Czech Republic. This holds true for migrants and Roma migrants, too. It is possible to have health insurance debts but it is not an obstacle for accessing care.

[^35]Roma people reported more obstacles to access health care, however they use it more than the majority population: $44 \%$ of the Roma use it every month ( $28 \%$ for majority population 18+), 34\% at least once a year and $23 \%$ less than once a year. Only $1 \%$ of Roma population has never contacted a doctor during his/her lifetime. The number of visits does not differentiate among GPs or specialists ${ }^{204}$. Some studies state that inpatient ward or emergency wards are more frequently visited by Roma than the majority population, others conclude the increased frequency of doctors' visits by Roma is only true for GP visits ${ }^{205}$. 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 the social economic group; the less wealthy people visit GPs more often than the most affluent part of population but make fewer visits to dentist and specialists ${ }^{206}$.

Moreover, there are fewer seniors (60+) in the Roma population; however, they are the most health care consuming population group among the non-Roma ${ }^{207}$.

It is important for the analysis and interpretation of results and outcomes of different sources that not only different methods of data collecting are noted but also the locality where respondents live. Roma in the Czech Republic are not a homogenous group regarding their inclusion, poverty, or education. The main difference could be length of living in one place - the most excluded, poor and hard to be reach are Roma who have recently immigrated from Slovakia and Romania. That community has a triple burden: to be poor, to be migrant and to be Roma.

Causes of higher frequency of doctors' visits among adults could be the result of poor living and hygenic conditions, especially housing, and related to low income and unemployment, or low level of education but also to specific culture characteristics insofar as a smaller value is put on education and disease prevention ${ }^{208}$.

## Access and use of preventative services

All Czech citizens have the right to health insurance by law ${ }^{209}$ and are entitled to free preventative checks including dental checks once a year (twice for pregnant women), general check ups (including blood pressure and cholesterol) once every two years, gynaecological examination including smear test every year from the age of 15 , one in 2 years, mammography for women over 45 years, colorectal cancer early signs for person over 50 once every two years. Children have preventative health checks by pediatricians every month in the first year, and subsequently less frequently up to the age of 19 .

[^36]Data from the WB, FRA and UNDP survey ${ }^{210}$ on use of preventative services among the Roma and non-Roma populations show lower user rates from Roma, expecially men. The reasons for these differences may stem from different cultural perception of health, different views of the benefits of preventative checks, and a lack of information about the affordability of the services.

Disability benefits (fully or partially) are more frequent among Roma: 9.4\% has full disability benefit (3.2\% of non Roma population), $9.2 \%$ has partial benefit (1.2\% of non-Roma). The main causes of working disability are diabetes, mental health diseases and musculoskeletal impairment. ${ }^{211} 212$

Preventive check at dentists

| $33 \%$ Roma | $79 \%$ non-Roma both sexes |
| :---: | :---: |
| 29\% Roma | $77 \%$ non-Roma men |
| Cholesterol checks | $36 \%$ Roma |
|  | $81 \%$ non-Roma women |
|  | $19 \%$ Roma |


| Prevalence of Major Chronic Diseases |  |  |  |
| :--- | :--- | :---: | :---: |
| Self-reported prevalence of diseases in the Roma population $16+.2^{213}$ <br> Prevalence of diseases among non-Roma population is included in brackets. ${ }^{215}$ The |  |  |  |

- Headache, migraine $28 \%$ ( $8.8 \%$ )
- Hypertension 19\% (24.4\%)
- Depression 14\% (5.1\%)
- Ulcer peptic and duodenal 12\% (4.6\%)
- Arthritis 11\% (12.6\%)
- Coronary heart diseases $10 \%$ (4\%)
- Allergy 10\% (17.9\%)
- Bronchitis and pulmonary disease 9\% (4\%)
- Mental diseases other than depression 6\% (1\%)
- Diabetes 9\% (6.7\%)
- Cancer 1.1\% (3\%)

Data comparison is limited as surveys use different methods, a slightly different wording of questions and the age of respondents may vary. Studies tend to use older non-Roma control groups compared to the Roma group as a result of the different demography. The higher prevalence of disease is, taking in account the data bias, notable as these occurred at an earlier age in the Roma age group than in nonRoma.

[^37][^38]Headache, migraine and depression are more frequently found among women in comparison to men. Generally, as in majority population, diagnosis of diseases is more frequent among women. Level of education and employment status influence number of reported diseases; lower education and unemployment increase number of reported diseases.

The high prevalence of mental health problems and psychiatric diagnosis are related to alcohol abuse among Roma men. ${ }^{216217}$ Moreover, Limited daily physical activity is largely the result of pain and musculoskeletal impairment especially of spin and joints (osteoarthritis) ${ }^{218}$.

## Health Factors Related to the Role of Women in the Roma Community

General overview: Almost double the number of Roma women self-reported bad health compared to their non-Roma counterparts. This ratio is largely unchanged in both the over 16 and over 50 cohorts. ${ }^{219}$ This may not be entirely separate from the issue of health insurance facing the female Roma population in the Czech Republic where $8 \%$ of women are uninsured and $3 \%$ of non-Roma women reported being uninsured. The overall figures on uninsurance may be low internationally yet a significant disparity still exists on ethnic grounds. ${ }^{220}$

Fertility rate: the last official number from 1970-1980: 5.8 children per Roma woman, 3.6 per non-Roma woman. Now Roma women have mostly two ( $17.7 \%$ of families) or three (15.3\%) children, more than in the non-Roma population. ${ }^{221}$ Smaller families and fewer children among Roma seems to be a trend as a study published in 2003 found that 40\% of Roma mothers had more than three children, in comparison with only $5 \%$ of non Roma mothers ${ }^{222}$.

Younger age of first conception: $18-19$ is the average age of the first pregnancy of Roma women (Non Roma: 29 years)

A higher proportion of children are born outside marriage: this is partly because marriages between Roma are often not fully legalised by the authorities. However, numbers of children born outside marriage among Roma copies trends in non-Roma society. The percentage of women being single mothers at the time of the child's birth is 62\% among Roma and 22\% among the non-Roma women. ${ }^{223} 224$

[^39]Low birth control: hormonal pill: expensive and regular intake is more difficult to maintain. 10\% of Roma women reported use of some form of female contraception ${ }^{225}$. Men do not use any contraception

Gynaecologist's checks (antenatal visits) and prevention checks: 80\% of women reported to visit their doctors regularly from the beginning of the pregnancy. The frequency decreases with age and the number of pregnancy - older women use antenatal consultancy less often ${ }^{226}$.
$58 \%$ of women reported gynaecologist's visits every year when they are not pregnant.
Preventive screening - mammography: $42 \%$ of Roma women were invited or received information about preventative screening, compared to $28 \%$ women in the same age group to whom cervical smear test were recommended ${ }^{227}$.

Female sterilisation is a very sensitive issue for all women and for Roma women especially as tradionally, higher fertility and more children mean higher status for a Roma woman. Forced sterilisation or sterilisations without prior knowledge were undertaken in Czech hospitals during the 1972-1991 period. Women and Roma women especially, were sterilised without consent or knowledge during childbirth or gynaecologicals procedures either as a discriminatory measure or the woman may have been offered a financial reward if she agreed to sterilisation. This human rights violating practice has now stopped. New legislation is in place to better protect and inform women, including Roma women about medical procedures and sterilisation. During the period the sterilisation took place, around 80 lodged a complaint against their treatment. The Czech Government has since issued an apology ${ }^{228}$.

## Environmental and other Socio-Economic Factors

In socially excluded (poor) areas housing can be an environmental risk: because of overcrowding, problems with property owners and authorities waste management, lack of water supply and storage of food (if no refrigerator) Moreover, in some areas there are rats and insects. ${ }^{229}$

The average number of persons per room in Roma households are (excluding kitchen, corridor, toilet, bathroom): 2.2 (non-Roma 1.2)

Roma persons living in households without at least one of the following basic amenities: indoor kitchen, toilet, shower, bath, electricity $15 \%$ (non-Roma $3 \%$ ) ${ }^{230}$.

Household at risk of poverty (income less than $60 \%$ of the national median disposable income): Roma $81 \%$, non-Roma $38 \%{ }^{231}$.

Households with severe material deprivation: 70\% Roma, $21 \%$ non-Roma ${ }^{232}$.

[^40]In the 1990s, the housing situation for some Roma began to deteriorate. High unemployment rates and a lack of financial resources gave Roma a poor reputation as tenants. Roma are considered to be a problematic population group and they are concentrated in outskirts of towns and villages. Social housing is not a universal concept in the Czech Republic. ${ }^{233}$

Education: Only 15\% of Roma women have completed further education after completing lower secondary education (schooling is obligatory until the age of 15 in the Czech Republic) ${ }^{234}$. $27 \%$ of Roma men have completed upper secondary and/or higher education. This is below national standards - 95\% of the majority population has finished upper secondary education.

Kindergarten and/or other pre-school facilities are used less by Roma parents. An international study concluded that slightly more than 30\% of Roma children aged 4-7 attend pre-school facilities in comparison to $80 \%$ of non-Roma children ${ }^{235}$. However, just $2 \%$ of Roma women and $1 \%$ of Roma men over 16 have reportedly never attended school. ${ }^{236}$

Reasons for very low education among Roma are rooted in cultural values: education is not a priotity. Evidence suggests that children are not motivated to go to school or to learn ${ }^{237}$.

Employment: A survey indicates that around 38\% of Roma are unemployed ${ }^{20}$ but other estimates suggest that $70-100 \%$ of Roma are unemployed in some excluded areas. ${ }^{238} 239$ An FRA survey found that $36 \%$ of Roma women declared themselves to be in paid work, with the male figure slightly lower (33\%). ${ }^{240}$ Furthermore the Roma employee is often not entitled to paid days off or sick leave. In the cases where employment is legal - jobs are often short-term, part-time or in other way insecure. Social benefits, child benefits, disability benefits are the main incomes for many, especially excluded, Roma families. ${ }^{241} 242$ Although a similar number of Roma and non-Roma are entitled to pensions, discrimination in the job market is endemic $42 \%$ of Roma males and $35 \%$ of Roma females reported experiencing a degree of ethnicity-related discrimination when looking for a job in the last 12 months. ${ }^{243}$

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## Country Profile: Denmark

| Main Characteristics of the Roma in Denmark |  |  |  |
| :--- | :---: | :---: | :---: |
| Demography |  |  |  |

There is a lack of clarity around the number of Roma in Denmark with estimates ranging from 1,000-25,000.

The Council of Europe estimates the Danish Roma population to be 1,000-10,000 ${ }^{244}$ although the basis for this estimate is unknown. The Danish Ministry of Social Affairs reports 2,000 citing a Danish Refugee NGO (Dansk Flygtningehjælp) ${ }^{245}$. An international study from $2009^{246}$ states that this figure $(2,000)$ is often cited for Denmark without proper reference and that it is unclear where it actually derives from ${ }^{247}$. The study further cites "some Roma organisations" as estimating the population to be 15,000-25,000. When "Danish Roma NGOs" are cited in Danish newspaper articles, 10,000 is the estimate most frequently provided. ${ }^{248}$

The Raxen study suggest that most Roma in Denmark are settled (i.e. not travellers) and prefer to register according to nationality and to hide their Romani identity in public to avoid discrimination from the authorities and others active in the communities ${ }^{249}$.

Most of the persons with Roma background in Denmark arrived in the 1960s and 1970s as migrant workers. As a result of the war in the Balkans in the 1990s, Denmark also received approximately 21,000 refugees from the former Yugoslavia, of which an unknown number have a Roma background. It is thought that the early immigrating Roma have almost fully integrated into Danish society whereas a greater body of the more recent refugees have struggled to settle in. Many of these may also suffer from trauma and depression following the war in former Yugoslavia. ${ }^{250}$ Denmark occasionally experiences seasonal influx of a small number of Roma with temporarily stay in the country from other EU Member States, but generally the number of persons with a Roma background in Denmark is estimated by the authorities to have been relatively constant for the last decade ${ }^{251}$.

[^42]
## Geographical distribution

The largest Danish Roma population is found in the town of Elsinore approximately 50 km North of Copenhagen estimated to total $1,000^{252}-1,200^{253}$. The majority of the remaining Roma are according to a Roma NGO concentrated in the greater metropolitan area of Copenhagen ${ }^{254}$.

## Other Information (including highlights of data gaps)

No information is collected on the Roma population as such in Denmark. According to a Danish journalist and author of a recent book on Roma in Europe ${ }^{255}$, Denmark is the country in Europe collecting the least amount of data in the area ${ }^{256}$.

The Danish National Health Board has produced a rich literature on the health of ethnic minorities in Denmark. This includes indicators for sickness and the use of healthcare services ${ }^{257}$, social risk groups ${ }^{258}$, prevention, and health promotion ${ }^{259}$. The majority of these studies draw on register data which in Denmark offer a wide range of individual data records associated with the social security number (CPR). In public registers it is possible to distinguish between ethnic minorities on the basis of birthplace and citizenship of their parents ${ }^{260}$. Neither of these indicators, however, reveals the ethnicity of the individual in question, which may explain why publications in the area do not consider Roma as a distinct group ${ }^{261}$.

A publication from 2008 of the Danish authorities on the health of ethnic minorities in Denmark was based on a survey carried out among seven ethnic groups. 424 of the included respondents were immigrants of ex-Yugoslavia or their descendants ${ }^{262}$. However, this group constitutes a poor proxy for the Roma population as many Roma who have integrated into Danish society have acquired Danish citizenship and figures as "ethnic Danes" in public registers ${ }^{263}$. Also this population presumably comprises a large majority of persons from the former Yugoslavia, which are not Roma. However,

[^43]where appropriate data on this group has been reported below.
In the late 1980s and throughout the 90s the local authority of Elsinore recorded ethnicity of Roma in relation to social work. The practice has now been abandoned due to concerns about the legality of providing social services on the basis of ethnicity ${ }^{264}$.

The remainder of this country report has derived data and estimations from academic literature and health data collected by the Danish authorities on the immigrants of the former Yugoslavia and their descendants.

Mortality and Life Expectancy
The study team has not found any quantifications of this indicator for Roma in Denmark.

Prevalence of Major Infectious Diseases
The study team has not found any quantifications of this indicator for Roma in Denmark.

Healthy Life Styles and Related Behaviours

A survey based study ${ }^{265}$ from 2008 by the Danish health authorities finds the following diseases to be more prevalent among immigrants from ex-Yugoslavia and their descendants compared to the general population (age 18-66) ${ }^{266}$ :

|  | Danes | Immigrants from $x$-Yugoslavia and their descendants |
| :---: | :---: | :---: |
| Smoking | 25\% | 33\% |
| Heavy Smoking | 16\% | 24\% |
| Daily intake of sugar containing soft drinks | 25\% | 33\% |
| Walks maximum 30 Min. per day | 24\% | 22\% |
| Physical activity max. once a week severely overweight | 25\% | 36\% |
| BMI > 30 | 11\% | 17\% |
| Access and Use of Health Services and Prevention Programmes |  |  |
| The study team has not found any quantifications of this indicator for Roma in Denmark. |  |  |

[^44]
## Prevalence of Major Chronic Diseases

A survey based study ${ }^{267}$ from 2008 by the Danish health authorities finds the following diseases to be more prevalent among immigrants from ex-Yugoslavia and their descendants compared to the general population (age 18-66) ${ }^{268}$ :

|  | Ethnic Danes | Immigrants from $x$-Yugoslavia and their <br> descendants |
| :--- | :--- | :--- |
| Diabetes | $2 \%$ | $12 \%$ |
| High blood pressure <br> Heart problems | $9 \%$ | $27 \%$ |
| Chronic Bronchitis | $2 \%$ | $2 \%$ |
| Rheumatism | $10 \%$ | $8 \%$ |
| Ulcer | $2 \%$ | $29 \%$ |
| Migraine | $12 \%$ | $15 \%$ |
| Osteoporosis | $1 \%$ | $36 \%$ |
|  |  | $4 \%$ |

Other diseases covered where no significant differences with the general population were identified include: asthma, allergy, cancer, and HIV/Aids

Health Factors Related to the Role of Women in the Roma Community
The study team has not found any quantifications of this indicator for Roma in Denmark.

## Environmental and other Socio-Economic Factors

## Housing

A main source of data for housing is the 2009 study commissioned by the Fundamental Rights Agency of the EU - the Raxen National Focal Point for Denmark ${ }^{269}$. This study undertook a thorough assessment of the housing situation of Roma. Although the study found no specific data on Roma and housing, the following key findings for ethnic minorities are presented below:

- Sixty per cent of ethnic minorities - compared to $14 \%$ of the majority population - live in social housing and many live in multi-ethnic areas where more than $40 \%$ of the population is from an ethnic minority background ${ }^{270}$. In other words, two out of three immigrant families live in social housing areas.
- Ethnic minorities generally have fewer square metres per inhabitant than ethnic Danes. On average, the population occupies 60 square metres per person. The latest immigrants to arrive have on average 32 square metres per person and 'older' immigrant groups a little more. Immigrants who have obtained Danish

[^45]citizenship, descendants and immigrants in mixed families have more square metres per person, but still considerably less than ethnic Danish households.

- No good practices and major national projects targeting the housing situation of Roma have been identified.
- Some of the interviews carried out indicate that the government's strategy with regard to 'ghettoising' seems to have changed the situation in some municipalities where many Romani families live in the same neighbourhood.
- Authorities estimate that there are approximately 70-80 homeless Roma in the greater Copenhagen area.

An additional survey carried out on five homeless Roma in Copenhagen pointed to a strong experience of discrimination and exclusion in the society in general. ${ }^{271}$

## Employment

Anecdotal evidence: in a newspaper article from 2010, a senior social worker in the town of the largest Roma community, Elsinore, states that approximately 100 out of a total Roma community of 1,200 are unemployed ${ }^{272}$. It is likely that due to lower education levels, employment poses more of a challenge for the Roma minority. Attempts to reduce this problem in Elsinore have often been deemed discriminatory and thus abandoned.

## Education

For a period of approximately 20 years the authorities in Elsinore introduced specialised classes for Roma children. This practice was found illegal by the Ministry of Social Affairs and terminated in 2004 after having received international criticism ${ }^{273}$. In a study from 2004 of these classes an absenteeism rate was found to be approximately $66 \%{ }^{274}$. This type of data is no longer collected. However, the use of "morning ladies" (city council consultants who pick up truants from home) in Elsinore is hoped to reduce the problem. Although statistical data does not exist on the topic, the municipality assesses that Roma adults have a typically lower level of education to their non-Roma counterparts and likewise, Roma children have higher levels of absenteeism. ${ }^{275}$

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## Country Profile: Estonia

| Main Characteristics of the Roma in Estonia |
| :--- |
| Demography |

The official number of Roma in Estonia, according to the Council of Europe, is 584. However, the estimated number of Roma living in Estonia is between 1,000 and 1,500 persons ${ }^{276}$. The estimate from average figures ( 1,250 ), Roma population would then translate into $0.1 \%$ of the total population of Estonia ${ }^{277}$.

However, according to Statistics Estonia, the national statistics office, there are 215 Roma males and 241 Roma females living in Estonia in 2011, which makes a total of 456 enumerated permanent residents of Roma in Estonia ${ }^{278}$.

There are some official data concerning the numbers of Roma in Estonia. However, the data are somewhat unreliable, since it has been reported that some members of Roma are reluctant to describe themselves as Roma ${ }^{279}$. Moreover, Roma in Estonia is not a nationally recognised ethnic minority, because Roma doesn't reach the necessary threshold of $3,000^{280}$.

The most common native language for Roma in Estonia is their home tongue Romani, followed by Russian and then Estonian. A little under half of Roma had Estonian citizenship; the next common was undetermined citizenship; and finally citizenship of another country. ${ }^{281}$

The majority of Roma in Estonia today has arrived from former USSR and Latvia after WW2. Few descendants from Roma communities that lived in Estonia before WW2 exist. Many were victims of the National Socialistregime and later were subjected to assimilation attempts by the USSR ${ }^{282}$.

Thus, there is very little available information on Roma in Estonia, both from national surveys as well as academic research.

Due to the lack of data collection concerning Roma in Estonia, this country research relies mostly on national statistics (or the lack thereof), European (EU) and regional commissioned studies, non-formal sources, such as NGOs, and reports by EU organisations as well as academic literature, which mainly provide qualitative information and/or an analysis of secondary sources.

| 276 | $\mathrm{C}^{\mathrm{OE}}$ | Roma | and | Travellers | Division | (2010) | Population | Statistics. | Available | from: | www.coe.int/t/dg3/ |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| romatravellers/Source/documents/stats.xls |  |  |  |  |  |  |  |  |  |  |  |
| 277 | COE | Roma | and | Travellers | Division | (2010) | Population | Statistics. | Available | from: | www.coe.int/t/dg3/ |

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${ }^{282}$ FRA. (2012), FRANET National Focal Point: Social Thematic Study: The Situation of Roma", FRANET, [Online], Available:
http://fra.europa.eu/e
-data/2013/country-thematic-studies-situation-roma.

## Geographical distribution

The majority of Roma communities are found in Southern Estonia, (185 Roma), NorthEastern (92 Roma) and Western Estonia (69 Roma) ${ }^{283}$.
$78 \%$ of Roma live in urban settings. The largest Roma community lives in Valga by the Latvian border, followed by the capital city Tallinn. ${ }^{284}$

The majority of Roma population is sedentary and not traveller. Roma are usually found in small concentrated communities in settlements or towns throughout Estonia, apart from 2 of the 15 counties $^{285}$.

## Other Information (including highlights of data gaps)

Estonia does collect ethnically disaggregated data. There are insufficient data available for Roma, as they are not recognised as a national minority group. Other minority groups are included in the official data. It is thus assumed here that Roma are usually included within official data in 'other ethnic nationalities' or 'ethnic nationalities unknown ${ }^{286}$.

Publication is scheduled for a report on population with native background on 21 June 2013; Health of the population on 30 June 2013 and households and families on 28 Aug. $2013^{287}$. Whether Roma will be included as a minority is unclear.

There is no information on the number and activities of Roma, and there are no separate data on the movement and citizenship of Roma in Estonia. However, a survey of sub-cultures is being conducted during 2012-2013, where Roma are one of the target groups. The results will illustrate how the target group cope in society as well as map the needs of Roma ${ }^{288}$.

The national census is conducted online, as an e-census, where citizens can access and fill out the form themselves. Those who fail to partake may be interviewed, if previously agreed by enumerators at home. Data is collected in all 2000 'enumeration areas', overseen by supervisors in supervision areas (12). The head of each district (15) manages the conduct of the census ${ }^{289}$.

There are no ethnically disaggregated data concerning:

- Poverty and social exclusion,
- Employment,
- Education,
- Health,
- Housing ${ }^{290}$

[^47]

## Prevalence of Major Chronic Diseases

The study team has found no quantifications of this indicator.
Health Factors Related to the Role of Women in the Roma Community

The study team has found no quantifications of this indicator. Anecdotal data and evidence cover:

Economic difficulties have been reported in the majority of families where both parent are ethnic Roma. For many families, state support is very important as it provides a permanent source of income. A widely used option, even among young Roma women, is the pension for incapacity to work ${ }^{293}$

[^48]According to one study undertaken by the Estonian Institute of Humanities of Tallinn University (2007), awareness amongst Roma women regarding social benefits varies greatly ${ }^{294}$. This would suggest that there is a wide discrepancy amongst Roma women who access social benefits.

Furthermore, inadequate housing and overcrowding has been reported to be acute problems for some Roma ${ }^{295}$.

It is reported that most Roma women in Estonia earn their living through selling goods at the market, fortune telling as well as simple cleaning and kitchen work. Men are reported to earn their living by gathering scrap metal, auxiliary farm work as well as auxiliary work in workshop ${ }^{296}$.

## Environmental and other Socio-Economic Factors

Due to prejudice and stereotyping, Roma continue to face discrimination in all spheres of society, in particular when it comes to health, housing and employment ${ }^{297}$.

Education: Although there are no data concerning dropout rates amongst Roma children, Estonian authorities have reported a high dropout rate as well as late entry into the education system for Roma children ${ }^{298}$.

Furthermore, Roma children are often found in 'special needs' schools. This creates a further barrier to a future life as it provides Roma children with a second-class education as well as segregation from non-Roma children and society ${ }^{299}$.

Data from the census of 2000 found that almost $50 \%$ of Roma aged 18 and older lacked basic education. One third had completed basic education whereas even fewer had completed secondary school (15.6\%). Only one Roma was recorded as being in higher education ${ }^{300}$.

According to the Ministry of Education and Research there were, at secondary level, 22 ethnic Roma studying in Estonian schools during the school year of 2011/2012. Five of these pupils were studying in 'special schools' and one pupil in the adult gymnasium ${ }^{301}$.

[^49]According to a study conducted among Roma women in South Estonia two main factors were highlighted explaining why Roma children are more likely to go to 'special needs' school. Firstly, because of the lack of Estonian language skills and secondly for economic reasons; parents send their children to 'special schools' as they provide boarding ${ }^{302}$.

Employment: It is said that Roma have high unemployment rates due to lack of knowledge of the Estonian language as well as lack of education ${ }^{303}$. According to data in one report, $30.2 \%$ of Roma aged 18 and over were unemployed; $54.4 \%$ were inactive in the labour market, while only $15.1 \%$ of Roma population were in employment ${ }^{304}$. ECRI estimates that approximately $90 \%$ of Roma are unemployed ${ }^{305}$.

It is also noted that Roma do not register their unemployment officially, which affects their access to unemployment benefits and other social assistance. Of those Roma who do register, lack of education and local language skills prevent them from accessing social assistance, which they are entitled to ${ }^{306}$.

Housing: There is no information on the housing situation of Roma in Estonia. FRA have conducted research and produced National Focal Point Studies on the housing conditions of Roma and Travellers in 24 European countries. However, Estonia, together with Malta and Luxembourg, were excluded from the research because of the small numbers of Roma living in these countries. This in turn is an indicator of the lack of data on the housing situation of Roma in Estonia ${ }^{307}$.

However, according to the Estonian Ministry of Culture, the housing situation for many Roma families is often of moderate nature. The report does not explain further what this description implies. However, a study on women in Estonian Roma communities reported that overcrowding, and in some cases very poor living standards were acute problems ${ }^{308}$. This would suggest that Roma often have substandard living conditions and that there are issues concerning the housing situation for Roma in Estonia.

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## Country Profile: Finland

## Main Characteristics of the Roma in Finland <br> Demography

The Kale population comprise of groups of Roma who arrived through Sweden as early as the $16^{\text {th }}$ Century. Russian immigrants in the $19^{\text {th }}$ Century merged with the Finnish Kale, strengthening the group of Finnish Roma. Kale in Finnish Romani language, Roma and the Finnish word Mustalainen all refer to the same group, the Finnish Roma ${ }^{309}$. They are Finnish citizens and were recognised as a traditional minority in Finland in the 1990s. It is the largest national minority in Finland ${ }^{310}$.

Finnish Roma speak both Finnish and Romani, Romani being the original language. However, the majority today consider Finnish to be their mother-tongue, with fewer Roma speaking Romani. The Romani language has been identified as an endangered language in Finland and thus several policy recommendations in order to preserve the language have been made. Furthermore, Finnish Romani has been recognised by Finland as a traditional non-territorial minority language ${ }^{311}$.

There are approximately 10,000 Roma in Finland. Roma make up $0.2 \%$ of the total population in Finland. There are around 3,000 Finnish Roma living in Sweden. However, there are no official data of the number of Roma in Finland ${ }^{312}$. Therefore, estimates are based on the knowledge of various NGOs, studies and authorities' estimates and the Roma community ${ }^{313}$.

There has been an increase of Roma asylum seekers from eastern Europe oer the past few years. Between 4,000 and 5,000 requests have been filed between 1990 and 2004. The majority of applications however have usually been rejected ${ }^{314}$. The Directorate of Immigration has traditionally accepted few asylum applications. The majority of unsuccessful asylum seekers are rejected because the Directorate found no evidence of persecution or threat of persecution in their country of origin ${ }^{315}$.

Roma migrants from Romania, Bulgaria and former Yugoslavia have arrived in recent years. Numbers are unavailable, however it has been estimated they are somewhere in the hundreds ${ }^{316}$.

[^51]
## Geographical distribution

Although there are Roma communities throughout the country, the majority live in cities in western and southern Finland. More than 40\% inhabit the Province of Southern Finland ${ }^{317}$.

## Other Information (including highlights of data gaps)

Finland does not collect ethnically disaggregated data.
The Personal Data Act is enacted to protect private life and to safeguard the right in processing personal data. It is prohibited to process sensitive data, which includes amongst other data items; race or ethnic origin. However, data may be processed in cases where the subject has given consent or for statistical, scientific or historical purpose. Thus, there are insufficient official data concerning Roma in Finland, due to the protection of the Personal Data Act and because the ethnic definition of Roma is problematic ${ }^{318}$.

The reason why the ethnic definition is deemed problematic is because interpretations on who is a member of the Roma community vary greatly. A broad definition based on self-identification is used in National Policy for example. A member of the Roma population is here defined as someone who identifies herself/himself as Roma, lives within the Roma community or is of Romani origin ${ }^{319}$.

According to a report by the Ministry of Social Affairs and Health (2009) Roma usually have a weaker socio-economic and educational position when compared to other Finns ${ }^{320}$.

Finland is one of the first countries to develop administrative structures of the policy of Roma. The National Board on Romani Affairs was founded in 1956 and monitors the development and improvement of the social situation of the Roma ${ }^{321}$.

In June 2008 the City of Helsinki and the Helsinki Deaconess Institute initiated a project called the Rom po drom (the Roma in the Road)-project. Its purpose was to document the living conditions of people who were begging, selling or performing in the streets, and to provide humanitarian assistance. 196 people were interviewed, out of whom 76 were women. The majority of respondents (around 90\%) were ethnic Roma, with most of them originating from Romania. The study found that they were living in tents often, as well as caravans and apartments. The study also found that nutrition was generally inadequate ${ }^{322}$.

[^52]Helsingin Sanomat (2008) reported that there are migrant Roma beggars who live in tents, without sanitation of cooking facilities. The numbers of homeless Roma beggars were unreported ${ }^{323}$.

There are numerous documents concerning Roma in Finland. However, few of them contain quantitative or qualitative data. Most documents concern the inclusion of Roma, such as policy documents and/or a focus on culture and history of Roma. There are insufficient data concerning Finnish Roma and health. Few documents or research studies report on migrant Roma.

According to Eurodiaconia the concept of social inclusion of migrant Roma has not yet been understood or developed in Finland and is so far not a part of the political agenda ${ }^{324}$.

There are no data concerning Roma's need for services and their allocation as well as the welfare and health of Roma ${ }^{325}$. Moreover, there are insufficient ethnically disaggregated data concerning:

- Health and welfare
- Living conditions
- Housing conditions
- Employment

Due to the lack of data collection concerning Roma in Finland, this country research relies mostly on European (EU) and regional commissioned studies, non-formal sources, such as NGOs as well as academic literature, which mainly provide qualitative information and/or an analysis of secondary sources.

## Mortality and Life Expectancy

The study team has found no quantifications of this indicator. Anecdotal data and evidence cover:

It is estimated that Roma have lower life expectancy and higher mortality rates than the average population ${ }^{326}$.

## Prevalence of Major Infectious Diseases

The study team has found no quantifications of this indicator.
Healthy Life Styles and Related Behaviours
The study team has found no quantifications of this indicator.

[^53]
## Access and Use of Health Services and Prevention Programmes

## Anecdotal data and evidence cover:

Roma tend to use health services less than the general population. As Finish citizens, Roma have the same entitlements to health care services as the rest of the population. However, linguistic and cultural differences as well as lack of knowledge of their entitlements concerning welfare related issues and available services are highlighted as factors, which impede the access to health care services by Roma ${ }^{327}$. For example, a stoic outlook on illness is ingrained in Roma culture and according to their perceptions of cleanliness, Roma tend to regard hospitals as dirty and unhygienic places. ${ }^{328}$

One study on the service needs of elderly Roma found that many were unaware of services that are available to them. Low levels of education and cultural barriers hindered the elderly population's access to public services. Services provided by the third sector were equally unused ${ }^{329}$.

Homeless Roma who may not be in possession of a valid proof of identity tend to forgo the use of public services, saving a few euros a day but being ineligible to any healthcare treatments available. ${ }^{330}$

## Prevalence of Major Chronic Diseases

It has been reported through the Ministry for Social Affairs that compared with the majority population, elderly Roma often have 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 ${ }^{331}$.

Another report revealed that there is a high rate of pulmonary and cardiovascular disease among Roma community. This was linked to either their genes or lifestyles, such as smoking, drinking and fatty food ${ }^{332}$.

Health Factors Related to the Role of Women in the Roma Community
The study team has found no quantifications of this indicator. Anecdotal data and evidence cover:

[^54]According to the fifth periodic report of the government of Finland on the implementation of the Convention on the Elimination of all forms of Discrimination Against Women (CEDAW), Roma women face discrimination predominantly in the availability of private services and in the labour market ${ }^{333}$.

Female Roma also suffer health problems related to their traditional dress. The velvet skirt Roma women often wear weighs between six and eight kilos and rests entirely on the waist causing strain on joints in the hips and legs and putting the back, respiratory and other internal organs at risk. ${ }^{334}$

## Environmental and other Socio-Economic Factors

## Education

There is a general concern in regards to the low levels of education amongst Roma based on observations on the basic educational levels, the low participation and difficulties in accessing vocational training together with high levels of school dropouts.

Only $2 \%$ of Roma children go to preschool. This means that they are missing out on learning important language skills and coping mechanisms in order to fully engage in schoolwork at a later date ${ }^{335}$.

Some Roma do successfully navigate the Finnish school system. It is worth noting however, that on average more ethnically Roma children struggle at school. This may be due to a poor socio-economic situation at home. For instance, the Office of the Ombudsman for Minorities handled 23 cases involving Roma children who were victims of violence or had received threats of violence. ${ }^{336}$

## Employment

Unemployment rates are often higher for Roma than the rest of the population. This is usually a result of prejudices of employers and low educational attainment. Finnish Roma have the same entitlement to unemployment benefits and services as the rest of the population. However, less-educated Roma are often unable to access these services, due to a lack of knowledge of this complex welfare system. Some Roma are also suspicious of the authorities, believing they would do more harm than good ${ }^{337}$.

Green European Foundation reports unemployment rates of Finnish Roma at 20$50 \%{ }^{338}$.
However, as young girls and women have pursued further educational attainment in the last few years, the employment situation for Roma women has been developing favourably ${ }^{339}$.

[^55]A study on Roma and labour market participation (2008) reported that there were 1,471 Roma jobseekers in the client data system of the labour administration in 2008. This information was collected based on surname (family name) and does not represent the whole Roma population. However, within this group only $12 \%$ had found jobs through the labour administration, whereas $61.5 \%$ of this group were unemployed ${ }^{340}$.

## Housing

In the 1970s, more than half of Roma lived in numerous inadequate housing conditions or were entirely homeless. Today, Roma are no longer homeless and their living conditions are to a large extent similar to the rest of the population. Nevertheless, the majority live in state-subsidized housing owned by the local authorities and only a few own their own property ${ }^{341}$.

According to a report undertaken by the Ministry of the Interior (2008) the majority of Roma respondents were satisfied with the size of their apartment. 45 immigrants and 12 Roma living in the Helsinki metropolitan area were interviewed for the report. One of the issues highlighted was the feeling of discrimination when seeking housing. Respondents were of the opinion that they had to wait longer for a council flat or that the flat was in bad condition due to their ethnic background. Roma respondents were dissatisfied with the location and public services in the nearby area, or the conditions and size of the flat. 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 ${ }^{342}$.

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## Country Profile: France

## Main characteristics of the Roma in France ${ }^{343}$ <br> Demography

In 2010, it was estimated that 15,000 to 20,000 sedentary Roma lived in France, mostly from Bulgaria and Romania ${ }^{344}{ }^{345}$. These European citizens mainly get theirs origins in the Balkans and in Central and Eastern Europe. Most of them speak Romani (romani chib) They are divided into sub-groups and aren't a united group.

In the Balkans, there are also groups who regard themselves as Roma, but do not speak Romani. These include the Boyash (Beash, Bayash, Banyash, Baiesi or Rudari, depending on the country) whose language derives from Romanian. In France (in particular Alsace), this group is known as "Manouches" which stems from the Romani word meaning human being.

Counter to common belief, $90 \%$ of Roma in Europe are sedentary ${ }^{5}$. In European countries where nomads are the most numerous, as in France, two-thirds are sedentary and semi-sedentary; they are nomadic during certain periods for work, family or religious festivities, or as a result of evictions ${ }^{346}$.

In contrast, Gens du voyage, which used in Europe rather than in France, an administrative term which is also applied to non-Roma groups, mostly of French nationality, with itinerant lifestyles, due to their jobs, interests and so on. It thus covers the various branches of Roma (Roma, Sinti/Manush, Kale/Gypsies, whose ancestors came from northern India), but other communities as well. For the purpose of this report, we will separate the Gens du voyage situations from that of the Roma's.

Romani people and specially women, in Europe, face a significant amount of discrimination, based on their ethnicity and their gender. This negatively impacts all areas of their daily life, including housing, healthcare, employment, education, political or civic participation and family relationships. Furthermore, they have often been victims of human rights violations: trafficking, racially-motivated violence, hatecrimes and coercive sterilisation, in the past century.

## Geographical distribution

In 2010, approximately 5,000 Roma lived in the Paris Region of Ile-de-France, about half of them in Seine-Saint-Denis county north of Paris ${ }^{347}$. Likewise, Roma live mostly in the outskirts of major French cities, such as Lyon, Marseille, Bordeaux, Toulouse, Nantes, Strasbourg or Lille, and in middle-sized cities.

Médecins du Monde provides long-term medical and social support for Roma in the urban areas and outskirts of Bordeaux, Lyon, Marseille, Nantes, Strasbourg, and

[^57]Seine-Saint-Denis. Point interventions have also taken place in Aix-en-Provence, Grenoble, Valenciennes, Montpellier, Nancy and Toulouse ${ }^{348}$.

## Other Information

In France, non-profit organistions such as the FNASAT Association (Fédération nationale des associations solidaires d'action avec les Tsiganes et les Gens du voyage) and Médecins du Monde collect most of the Roma health related data. Consequently, data availability is limited and refers to specific projects.

In 2011, 2,766 Roma sought care with physicians from MdM Roma programmes. Roma have a young population structure: in 2011, the average age of the beneficiaries of MdM Roma programme was 22.06 years old for women (median $=$ 20.95 ) and 18.82 years for men (median $=12.73$ ). At that time, $48.6 \%$ of Roma beneficiaries were under 18 years old ${ }^{349}$.

More women than men seek support from MdM Roma programmes - 57.8\% compared to $42.2 \%$, respectively. It should be noticed that women in general tend to seek medical care more often than men; including for pregnancy care or accompanying sick children.

- According to our research, there are no recent data on Roma in France in the areas ${ }^{350}$ of domestic violence, teenage pregnancies, alcohol consumption, drug consumption, tobacco use, or mental disorders.
- Médecins du Monde systematically collects data on reasons for visit and diagnosis, as well as socio-demographic indicators, using a standardised social and medical questionnaire for every patient coming to the walk-in centres. These social and medical records are analysed by Médecins du Monde's Observatory of Access to Healthcare ${ }^{351}$. It must be noted that those visiting the walk-in centres are unwell, thus some diseases might be overrepresented, or misrepresented in the case of Roma unable to seek care elsewhere.
- Mother and Child Protection (Protection maternelle et infantile - PMI) is a free health service with the mission to provide follow-up for pregnant women in the last six months of their pregnancies and child health maintenance until the child reaches the age of 6 . PMI is also responsible for family planning and education, especially for low-resource families living in hardship conditions. Roms usually refers back to the common Health Law: PMI, to take care of their children.
- Moreover, PMI gives particular attention to the risks of child abuse, linked with the "Aide sociale à l'enfance" (ASE/ Social assistance to childhood).


## Mortality and Life Expectancy

There is no data on mortality and life expectancy.

[^58]
## Prevalence of Major Infectious Diseases

There are only restricted data available on the prevalence of major infectious diseases among Roma in France in general, and among beneficiaries of Médecins du Monde Roma programmes. However, there is data to conclude that Roma are more vulnerable to airborne pathogens that thrive in closed, crowded spaces: diphtheria, pertussis or whooping cough, and invasive pneumococcal infections - despite these being preventable through immunisation.

## Tuberculosis

In 2011, a total of 2,766 Roma patients made 4,303 medical visits at Médecins du Monde, and there were 19 diagnosis of TB, representing $2.7 \%$ of all visits ${ }^{352}$.

In Seine-Saint-Denis, north of Paris, Médecins du Monde Health Care and Guidance Centre (Caso) offer chest X-rays once a week. In 2011, 257 Romanians (almost exclusively all Roma) had a chest X-ray, of which two were diagnosed with tuberculosis (no prevalence should be calculated from this figure). Seine-Saint-Denis has a very high prevalence of TB, 30/100,000 compared to 8.2/100,000 in France as a whole in $2011^{353}$. Thus, Roma living in Seine-Saint-Denis have a higher risk of exposure to the Koch bacillus ${ }^{354}$.

Moreover, in addition to a very low coverage of the BCG (Bacillus Calmette-Guérin) vaccine among Roma in France ( $38.9 \%$ in 2010 in under 30 -year-olds ${ }^{355}$ ), 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 all add up to an easy spread of TB among Roma ${ }^{356} 357$.

Roma in France often settle in vacant plots or squats and are often evicted or face compulsory departure from French territory. For those few who have been diagnosed and are being treated for TB, the lack of a permanent home imposed by evictions prevents them from being followed by the same doctors or from being followed-up at all. This is an important barrier to a continuous access to treatment. Furthermore, a lack of knowledge within the Roma community often makes TB a stigmatised topic, which makes it all the more important to have a certain continuity in a holistic followup that also includes psychosocial interventions.

It has also been reported that, because of the instability of their living place, Roma detected with TB are frequently not offered treatment. Indeed, health care professionals fear they might stop the treatment and in doing so accelerate the development of multi-resistant tuberculosis. Instead of temporarily postponing treatment until durable solutions for the access to healthcare are found, they create a major inequality in the access to health care of Roma ${ }^{358}$.

Moreover, evictions force Roma to seek new settlements, sometimes in vacant plots or squats occupied by other Roma communities. The MdM Roma programme in Seine-

[^59]Saint-Denis have on occasion been forced to look for patients diagnosed with tuberculosis after they were evicted, only to find them in another community, a factor that can favour the spread of the Koch bacillus. Similarly, during compulsory departures to Romania and Bulgaria, Roma are put into buses, in a closed space that favour transmission, travelling for days, thus increasing the epidemic risk ${ }^{359}$.

## Measles

In visits of Roma patients to MdM Roma programs in 2011, measles was diagnosed in 35 cases ( $2.3 \%$ ) where there was a diagnosis of a short term health condition ${ }^{360}$. The 2010 vaccination survey conducted by MdM found that only 50.9\% of Roma under 30 years old had been vaccinated against measles, mumps and rubella ${ }^{361}$, whereas the European target for eradication of measles as defined by WHO / ECDC and the achievement of herd immunity is only reached at a vaccination coverage of $95 \%$ with two vaccine doses. According to the WHO, the average measles vaccination coverage (MMR 1) for the general population is at $89 \%$; this rate quickly drops for the second MMR injection (only 67\%).

Between 2008 and late 2011, France experienced a measles outbreak. In 2011, 15,000 measles cases where diagnosed, among them 1,008 with severe pneumopathy, 26 with neurologic complications and 10 recorded deaths ${ }^{362}$. This major outbreak led MdM to launch a vaccination campaign with local government health institutions in Seine-Saint-Denis, where 288 measles cases were diagnosed in 2011, compared to 79 in 2010 and 38 in 2009. In the 13 settlements where MdM was responsible for the vaccination, 250 persons received a measles vaccine injection ${ }^{363}$.

The same vaccination campaign took place in Roma settlements in Marseille, without the participation of local health authorities. In the city of Marseille, 2,565 measles cases were notified between January and June 2011, as opposed to 497 cases in 2010 and 44 cases in 2009. During the MdM campaign, 326 Roma were vaccinated, representing only $45.3 \%$ of the target population ${ }^{364}$. The high vaccination figures both in Marseille and Seine-Saint-Denis reveal the lack of immunisation coverage among Roma in France. Vaccination among Roma will be further discussed in a later section of this country report.

## Hepatitis A

Several hepatitis A outbreaks have been described across Europe in communities with poor access to water and sanitation. In France, a community hepatitis A outbreak involved a total of 492 cases over the 2008-2009 period, including eight clusters of cases among communities living in sites with poor sanitation ${ }^{365}$.

[^60]
## Healthy Life Styles and Related Behaviours

Roma communities in France frequently live on vacant lands or squats without access to drinking water or water supply, toilets, sewage and waste management, and with overall low sanitary and living conditions. In 2011, 47.5\% of Roma coming to MdM Roma health programmes had lived in a shed or hut in the 30 days prior to the visit, $19.8 \%$ in caravans, $11.1 \%$ in converted squats, $8.8 \%$ in empty squats, $6.1 \%$ in tents and $3.3 \%$ were homeless ${ }^{366}$. Moreover, Roma are often evicted from the vacant plots or squats they live in, forcing them to seek out new places to resettle, often in worse conditions than the previous settlement. The accumulation of waste and the lack of sewage are major problems in most settlements, exposing their inhabitants to infections.

## Nutrition and acute infections

As a result of of inadequate housing conditions, it is common for Roma to have health problems such as dermatitis (psoriasis and acariosis account for $7.8 \%$ of short term health problems diagnosed in 2011) and gastric complaints (among the short term health problems diagnosed in 2011: gastric troubles, 4.2\%, worms and parasites, $4.2 \%$, gastroenteritis, $3.3 \%$, other gastric infections, $0.7 \%)^{367}$. The lack of water to drink, cook or wash cooking utensils - in addition to limited resources to buy food in a state suitable for consumption and the fact that Roma do not dispose of any cooking utilities - hinder many Roma from having a decent and healthy diet.

Indeed, among the Roma who sought care with MdM in 2011, 7.4\% of those with a chronic health condition were obese. Among those with short term health problems, $0.3 \%$ were overweight ${ }^{368}$. We do not have data on malnutrition but, as stated before, many Roma are unable to have a healthy diet or may even undergo difficulties accessing any food on a regular basis.

MdM does not have records on alcohol, tobacco or illicit drug use among Roma beneficiaries.

## Access and Use of Health Services and Prevention Programmes

## Barriers to access health care

The repeated evictions and compulsory removals of Roma from their settlements even in winter - and from the French territory, constitute major barriers to effective health care access and make it challenging for the communities to settle and stabilise.

The current French legislation and the European transitory measures concerning Romanians and Bulgarians are the primary causes for this situation. 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 either a valid work permit or prove to have enough funds to live in France without being a burden to the French social security system, which means subscribing to private health insurance 369370371372373 .

[^61]After this three month period the right to further reside becomes subject to conditions:

- Either the person is engaged in an economic activity (on an employed or selfemployed basis);
- Either the person has "sufficient resources" and sickness insurance "to ensure that they do not become a burden on the social services of the host Member State during their stay";

These evictions have major negative consequences on Roma's health, on their eligibility for social health protection, and thus on their access to health services and effective use of health care ${ }^{374}{ }^{375}$. The instability resulting from evictions and compulsory departures is a further barrier of accessing social health protection and health care as the administrative steps required for social health protection and the links with health professionals are broken. Families and groups are dispersed by evictions and compulsory departures.

Since 2011, the number of Roma compulsorily removed from the French territory and returned to Romania or Bulgaria by the French government has increased. It is estimated that two thirds of Roma living in France have already been compulsorily removed, with most coming back to France in the following months ${ }^{376}$. According to Amnesty International, in 2012 11,803 evictions were carried out in Roma informal settlements, $80 \%$ of them estimated to be forced evictions ${ }^{377}$.

Evictions lead to interruption of treatment, as people must leave the settlements as quickly as possible and can lose personal documents such as health records, prescriptions, medicines or the addresses of health care facilities. As stated before, stopping treatment can lead to resistance to treatment for patients with chronic diseases or infections like tuberculosis.

Evictions have also taken place while immunisation campaigns were being carried out, making it harder to lead preventive actions and tackle epidemics as the measles epidemic in France during 2008-2011 378379380 .

Because of repeated evictions from their living place, Roma are further isolated from the health care system and other public services. Housing instability hinders the

[^62]acquisition of space and time references and prevents families from investing in health issues ${ }^{381}$. The instability and stigmatisation of Roma also makes it difficult for them to learn French, as the majority have not attended school as a result of evictions. Only a minority of Roma women reached by a health mediation pilot project was able to express themselves in French and fewer were able to read and write in French ${ }^{382}$.

## Social Health Protection

Another barrier to the access to health care is the current legislation concerning Social Health Protection. The Aide Medicale 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. Asking for AME is a bureaucratic process, especially for non-French speakers without knowledge of French social and health care and for those unable to prove their domicile, revenues or the time spent in French territory since their arrival ${ }^{383}$. Proof of a lack of financial resources is a delicate issue, as Bulgarians and Romanians are only able to stay in France for more than three months if they hold a work permit, which most Roma do not; nationals from both countries can only be hired for 291 low-wage jobs in France ${ }^{384} 385386$ and usually have informal jobs.

Once one is granted AME, he or she needs to complete the same paperwork annually in order to renew his/her coverage for another year. The lack of a registered address accounted for the majority of refusals for Romanians and Bulgarians in 2011, who also undergo difficulties to renew their AME for the same reason ${ }^{387}$.

In 2011, among the patients of MdM Roma programmes, $22.6 \%$ were not entitled to health coverage because they had been living in France for less than three months at the time. Many of those could have been living in France for years and have been compulsory returned to their country of origin by French authorities or have travelled voluntarily, losing their possibility to ask for health care for three months as they returned ${ }^{388} 389$.

Therefore of the $77.4 \%$ Roma entitled to get AME health coverage among MdM beneficiaries, only $14.10 \%$ had actually received it ${ }^{390} .85 .2 \%$ of Roma beneficiaries of MdM programmes had no health coverage at the time of the visit. The figure is even higher for minors: $87.5 \%$ of those under 18 years old did not have any kind of social health protection. Although all children under six years old are entitled to free medical

[^63]care in Mother and Child Protection health care facilities (PMI), only 14\% of Roma children under six years old were actually being followed-up under the PMI in $2011^{391}$.

The consequence is that Roma without AME cannot go to health care facilities or seek general practitioners without paying. Even for those who have AME, regular visits to physicians can be difficult, since there are reports of general practitioners and hospitals that refuse AME beneficiaries ${ }^{392}$ both Roma and non-Roma. Furthermore, Roma lack information on where to seek medical care and are often not aware of their rights as AME beneficiaries ${ }^{393} 394$.

In 2011, 82.5\% of Roma patients declared having given up the search for health care in the last 12 months. Because they lack health care coverage and general knowledge of health care facilities, Roma only get health attention when symptoms become very debilitating. Indeed, MdM doctors stated that $54.4 \%$ of the health problems seen in surgery in 2011 should have been treated earlier ${ }^{395}$.

## Health Mediation

Health mediation between Roma and health care facilities is a tool to address the lack of information and the barriers to access 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 ${ }^{396} 397$. This pilot programme has been positively evaluated and has illustrated that health mediation is a useful method for closing the gap between the 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 to the access of Roma to the institutions. Interventions took place among Roma to inform and help them acquire AME, accompany them to surgery and carry out health education interventions. Interventions also took place among 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 stigmatizing this population ${ }^{398}$.

The pilot programme was focused on mother and children health, but families also benefited from the mediators' actions. After the mediators' intervention 86\% of Roma women participating in the programme had acquired AME, 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, $40 \%$ of the visits at the end of the 18 -month pilot programme were obtained by Roma women alone. The mediators' action had thus helped them to achieve autonomy of their

[^64]health care, although the language barrier and the lack of knowledge of the health care system still constituted a barrier for Roma to see general practitioners ${ }^{399}$.

Several positive impacts were noted by the mediator's action: at the beginning of the programme, $16 \%$ of Roma needing health care had not been to surgery, and at the 18-month evaluation report this figure had dropped to only 9\%, with other barriers to access health care also overcome: lack of AME, Roma's fear of not being understood by practitioners, and transport issues ${ }^{400}$. The mediator could also support health institutions to visit the areas were Roma live to promote services, such as vaccinations campaigns ${ }^{401402403}$.

## Immunisation

In 2010 a survey was conducted in three Médecins du Monde Roma Programmes to evaluate the vaccination coverage among Roma under the age of 30. It showed that the vaccination coverage among Roma reached by Médecins du Monde teams was insufficient for all of the mandatory and highly recommended vaccines on the French vaccination schedule ${ }^{404}$.

The results from this survey confirmed that although the majority of Roma were vaccinated at some point in their life course, it was very difficult to confirm this. Less than half of the respondents (38.5\%) had a health record or any document showing they had been vaccinated and for which diseases. Interviewers assessed that only $19.4 \%$ of those who had an immunisation record were up-to-date on the recommended or mandatory vaccines schedule in France ${ }^{405}$.

Among those who had immunisation records, vaccination coverage was globally satisfactory, but still below the national French objective of 95\% coverage for the only mandatory vaccine DTP at $84.3 \%$. It is to be noted that in France, the ' $\mathrm{P}^{\prime}$ in DTP stands for polio and not for whooping cough (a cellular Pertussis) as in the rest of Europe. Moreover, DTP vaccination coverage was lower for children under two years old. Vaccination coverage was even lower for other vaccines such as BCG (38.9\%), measles, mumps and rubella (50.9\%), hepatitis B (43.5\%) and whooping cough (70.4\%) ${ }^{406}$.

Many respondents declared having been vaccinated in their home countries, particularly for mandatory vaccines at birth. But since coming to France, they had had little or no access to vaccines, which led to incomplete vaccination coverage for those requiring boosters ${ }^{407}$.

[^65]Children followed in Mother and Child Protection health care facilities (PMI) or attending school are better protected and covered by vaccines, but only $52.7 \%$ of school-age Roma children were effectively attending classes and only one third of children under 6 years old (30.2\%) were effectively being followed in PMI.

The main reason for non-vaccination was the lack of information; most Roma do not know where to go, often ignore that boosters are necessary or the number of injections needed to achieve effective immunisation and/or doubt the utility of vaccines. It should be noted that these families were known and followed by Médecins du Monde and had already had prevention talks, medical visits and follow-up.

According to the Mediation Project Evaluation report, before the mediators' action, only $36 \%$ of children in Roma communities reached by the project had a health record and only $13 \%$ a vaccine record. After the mediators' intervention, $98 \%$ of children had a health record including vaccine records. During the project the vaccination coverage for all vaccines increased to $61 \%$ for BCG ( $10 \%$ before), $73 \%$ for measles, mumps and rubella ( $28 \%$ before), $68 \%$ for hepatitis B ( $15 \%$ before), $72 \%$ for whooping cough ( $70.4 \%$ before), $77 \%$ for DTP ( $17 \%$ before) and $80 \%$ for tetanus ( $25 \%$ before). Although vaccine coverage increased, the mediators identified other barriers after informing the families about vaccines, mostly due to the fear of vaccines and their side effects (fever, pain, etc.) ${ }^{408}$.

The low vaccine coverage and the identified barriers call for adapted prevention and vaccination strategies, particularly partnerships with the public health care facilities involved (PMI, vaccination centres). Awareness and mediation promotion must be achieved through information, explanations, persuasion, verifying that the messages are understood and facilitating the access to services, rights and general practitioners ${ }^{409} 410411412$.

Vaccination campaigns should be organised on Roma living sites, in partnership with public services, to secure the "immediate" protection of the population, particularly during outbreaks, as well as a way for accessing the main health care protection and services. The stability of the populations on their living areas must be secured in order to achieve vaccination campaigns ${ }^{413414415}$.

[^66]
## Prevalence of Major Chronic Diseases

Médecins du Monde cannot establish the prevalence of chronic diseases within the Roma population because it only has data on Roma who sought physicians of MdM Programmes. In 2011, 32.6\% of patients seen in surgery had a chronic health problem or disease ${ }^{416}$.

Chronic diseases are often related to Roma's living conditions and lack of health education. As stated before on mediation, because of the barriers to health care access and the evictions, Roma do not have access to adapted prevention for chronic diseases explained in their 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 to be diagnosed at a late stage. Once diagnosed, they have fewer chances to be followed by a general practitioner and to get periodic control exams or treatment. With the delays in the follow-up, chronic diseases get worse, consequently leading to the worsening of the global health status of the patients ${ }^{417} 418419$.

Among the chronic health problems diagnosed during consultations with MdM Roma programmes in 2011, there were 12.9\% non-complicated hypertension, $7.4 \%$ obesity, $3.6 \%$ non-insulin-dependent diabetes, $2.7 \%$ tuberculosis, $1.1 \%$ insulin-dependent diabetes, $0.9 \%$ complicated hypertension ${ }^{420}$.

As MdM doctors usually see Roma patients 1.56 times per patient, it is difficult for them to diagnose a chronic disease. Moreover, MdM services are not intended to replace the French health care system. Every patient seen by MdM is orientated to get Social Health Protection and with it access the local health care facilities or visit general practitioners: Therefore, MdM seldom diagnoses chronic diseases among its patients and does not have the means to follow-up or treat patients with chronic diseases.

## Health Factors Related to the Role of Women in the Roma Community

## Self-Reported Health

The FRA gender study found that poor health was a significant problem for the female Roma population. 10\% of non-Roma women aged $16+$ reported to be in bad health compared to $19 \%$ of Roma women. This trend worsened higher up the population pyramid with $14 \%$ of non-Roma women above 50 reporting bad health and a staggering 47\% of Roma women in this age cohort describing their condition as in bad health. ${ }^{421}$ It is worth noting that in general, the Roma community concern themselves less with health issues. As a consequence, these inequalities may if anything be an underestimate.

[^67]
## Contraception

The lack of information and the difficulties of access to family planning services account for the low rates of contraception coverage: in 2008, only 10\% of the women surveyed were using a birth control method ${ }^{422}$. In 2011, only $26.9 \%$ of women between 12 and 49 years old and coming to MdM for care were using contraception. The same year, $67.90 \%$ of Roma women between 12 and 49 years old had never used contraception ${ }^{423}$. Although there is a demand for information about contraception, it has been noticed that Roma women have a modest attitude concerning sexual issues and gynaecological examinations ${ }^{424} 425$.

Because of the lack of information on contraception, Roma women might resort to abortion when a pregnancy is unwanted ${ }^{426}$. In 2011, $19 \%$ of pregnant women coming to MdM wanted to have an abortion ${ }^{427}$. $43.3 \%$ of Roma women coming to MdM had had an abortion (the average age was 22 years old) without follow-up for infections or haemorrhages, a fact that can make them vulnerable regarding their health. In 2011, $36.1 \%$ of Roma women who came to MdM Roma programmes had had at least one abortion. Among these, the average number of abortions per woman was $5.20^{428}$.

Mediation has been found to be an efficient strategy to address the lack of information on contraception. In communities where mediation was introduced, the level of awareness of Roma women as to where to obtain contraception rose from $17 \%$ to $65 \%$, and finally reached $89 \%$ at the end of 18 months of mediation ${ }^{429}$.

Almost half of the women followed by mediators (43\%) started using contraception during the project and all went to a public health facility in order to obtain it. These behaviour changes were considered very positive compared to the low figures of women aware where to obtain contraception at the beginning of the project. It also provided evidence that the implementation of mediation among women in Roma communities can have a positive impact ${ }^{430}$.

## Prenatal Care and pregnancies

According to the Mediation Evaluation Report, women in the settlements where the mediation project was carried out had on average three children. One third of the women with children under six years old were below 23 years old, and two thirds were younger than 31 years old. Around $25 \%$ of them had their first child before they were 18 years old, the legal majority age in France ${ }^{431}$.

In 2008, MdM conducted a survey among Roma beneficiaries of a prenatal program that provides information and follow-up of Roma pregnant women to local hospitals for prenatal care ${ }^{432}$. Although prenatal care in France is free and delivered in specific Mother and Child Protection health care facilities (PMI) for those without social health

[^68]protection, Roma women are seldom aware that they can have pregnancy follow-up and do not know where to receive this service. Consequently, MdM has documented miscarriages, in-uterus foetal deaths and many other preventable complications related to pregnancies ${ }^{433434}$.

In 2011, 50\% of pregnant women who came to MdM Roma Programs were not being followed during their pregnancy. $70.8 \%$ of them had a pregnancy follow-up delay as they had been pregnant for more than 12 weeks without any care ${ }^{435}$. Among the $12.7 \%$ of Roma women who had already had at least one miscarriage in 2011 , there were the average was 1.88 miscarriages per woman. Among the $6.3 \%$ of Roma women who had at least one stillborn baby, the average was 1.44 stillborn babies per woman ${ }^{436}$. On average, only two out of four pregnancies result in a living infant among Roma women ${ }^{437}$.

The absence of prenatal care is also 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 (this average age has been confirmed again in the 2011 survey). It should be noted that the average age of the population in both surveys was 22 years old ${ }^{438} 439$.

For the $8.3 \%$ of pregnant women who actually receive PMI, they seldom can complete prenatal care due to evictions that force them to move away further from the health care facility where they were being monitored and 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 result in higher proportions of women not able to access prenatal care 440441 .

In the settlements where mediation has taken place, there was an improvement in the number of follow-ups of pregnancies. At the beginning of the mediation project, none of the pregnant women were being monitored during their pregnancy. After 18 months of mediation of the Roma women, most pregnant women started their prenatal care between the second and third month of pregnancy, having regular visits at medical facilities and ultrasound scans. Any delays in the follow-up were mostly due to an instable living situation as a result of repeated evictions ${ }^{442}$.

## Cancer Screening

The mediation pilot project carried out found that only $23 \%$ of Roma women reached by the mediators had had a Pap smear prior to the implementation of the mediation project. After the 18 months of mediation action, $42 \%$ had undertaken the screening (although the age of these women was not specified). As for breast cancer screening,

[^69]only one 55-year-old woman had a mammogram during the project after receiving information on breast cancer prevention ${ }^{443}$.

## Environmental and other Socio-Economic Factors

## Living conditions and housing

In France, Roma communities usually settle in vacant plots or abandoned fields surrounding urban or industrial areas. $84 \%$ of Roma live in 'deprived' housing conditions compared to just $2 \%$ of the non-Roma population. ${ }^{444}$ They live there because they lack financial resources to pay for decent housing, a consequence of the barriers to employment, and because they lack access social housing by the government, mostly on the grounds that they are undocumented migrants ${ }^{445} 446 \quad 447$.

In the last 10 to 15 years, the main policy towards these settlements has been to evict the inhabitants using police force, without resettlement proposals. Although a recent government circular of August 2012 determined otherwise, it is seldom applied by local public officials. Moreover, the current French Minister of Interior, Manuel Valls, has publicly confirmed in March 2013 that the policy of evicting informal Romany settlements will be pursued, without clarifying how safeguards against forced evictions will be implemented ${ }^{448}$. Roma are thus forced to move to other vacant plots, usually worse than the previous one ${ }^{449}{ }^{450}$. As stated before, the instability imposed by evictions can prevent Roma from treating health problems and receiving health care coverage

Roma communities therefore experience extremely poor and unhealthy life conditions: they live in shanty towns or squats, in dilapidated caravans or in sheds without water or electricity, lacking privacy, overcrowded and lacking appropriate heating and ventilation. The lack of drinking water, toilets, sewage systems and waste management in most vacant lands and squats they settle in generates hygiene issues alongside potentially harmful dermatologic and digestive pathologies (infectious dermatitis, infected wounds, intestinal parasites, diarrhoea...) as previously stated. The squats and shanty towns also present numerous dangers for its inhabitants: fire and collapsing risks, respiratory intoxications, lead poisoning, etc. These precarious life conditions also expose Roma populations to high epidemic risks of tuberculosis, whooping cough, measles, rats and other pests ${ }^{451}$.

Decent housing for Roma communities and halting evictions are major demands from associations reaching Roma. Addressing this issue would greatly contribute to improve Roma's health as it would stop illnesses due to the unhealthy living conditions in the

[^70]settlements. Access to housing and work would also contribute to get Social Health Protection and thus grant Roma communities access to local health care facilities ${ }^{452}$.

## Legal Status and Employment

Employments rates are only about 13\% for Roma aged 20 to 64 years old versus $62 \%$ for non-Roma in France. The current French law requires the possession of a work permit for Bulgarians and Romanians in order to stay in French territory for more than three months. These measures are real barriers to employment in France, This is in stark contrast to the non-Roma surveyed, who report much higher employment rates: in most EU Members, Romas are unemployed, at least, more than double than the number of the non-Roma. Most Roma prefer to consider themselves as self-employed across France (above 20\%), according to FRA survey in $2012^{453}$. The FRA genderbased report on Roma living in Europe points to a discrepancy between female and male employment figures. 49\% of males reported being in paid work (significantly below the non-Roma average) and just $10 \%$ of Roma females reported being in employment. Roma are still a traditional people and as a result, Roma women tend to classify themselves as home-makers. ${ }^{454}$

Although Romania and Bulgaria joined the European Union in 2007, Roma from these two countries and Roma from non EU member countries (Balkans) are not allowed to work in France without a work permit paid for by their employer ${ }^{455} 456457$. Since Roma do mostly low wage jobs that demand few qualifications, the sum for the work permit is almost equivalent to a month's wage (from 70 euros to 300 euros for a work contract of less than a year, $50 \%$ of the wage for work contracts of one year or more ${ }^{458}$. This obligation makes it very expensive to hire Roma, discouraging employers from doing so and therefore contributes to exclude Roma from employment ${ }^{459} 460$.

Work permit requirements for Romanians and Bulgarians were supposed to be lifted in December 2011, but have been extended until the end of 2013461. In October 2012, a list of 291 jobs (low-skilled jobs) allowed for Romanians and Bulgarians was published by the Labour and Interior Ministries, increasing the number of allowed jobs from the previous 62 allowed in $2008^{462}$.

Without access to regular employment, Roma do informal work such as collecting scrap iron, non-declared construction work, as street sellers or street musicians and as

[^71]beggars, usually earning 10-15 euros per average day of working for 6-8 hours up to 12 hours ${ }^{463}$. According to the Mediation Evaluation report, Roma whose resources come from begging or scraping iron or other materials usually earn between 250 and 350 euros per month ${ }^{464}$. As these activities are not included in the labour laws, Roma are thus exposed to exploitation and do not have access to social security. Because of the low earnings of this kind of work, Roma are not able stop working in fear of lacking resources to live on ${ }^{465466}$.

Adding to the fact that these activities do not allow Roma to live normal lives, they also expose Roma to stigma as they usually interact with the population and experience depreciating looks and racist attitudes or discourses ${ }^{467}$. It is also a source of self-depreciation and shame for Roma that can have consequences for their mental health and general wellbeing, which is added to the constant fear of being evicted or deported, the identity checks and intimidations from the police ${ }^{468}$. Indeed, as most of the informal jobs require Roma to be visible on the streets, they can be easily spotted by the police for control.

The absence of visa or work permit also excludes Roma families from the social benefits that poorer French and legal foreign families are entitled to. Some families reached by the Mediation Project could benefit from mensal allowances from the local government (Conseil Général) on behalf of the Social Aid for Children (Aide sociale à l'enfance) however there is little evidence that they do ${ }^{469}$.

## Education

Approximately, 5,000 to 7,000 Roma children or teenagers are of school age, and when they arrive in France, they may already lack some education ${ }^{470}$. On average, only one out of two Roma children attends pre-school or kindergarten.

FRA also underline that, in France, most Roma children between 7 and 15, are in education (84\%), albeit a lower percentage than the non-Roma population (97\%). Only 5\% of the Roma 20-24 age group completed any type of upper-education ${ }^{471}$. This may be reflected in the low literacy rate of Roma women aged $16+$ where just $71 \%$ of females and $80 \%$ of males declared themselves to be literate. ${ }^{472}$

[^72]Added to the frequent evictions that prevent Roma children from attending school, the main barrier for education of Roma children is the persistence of mayors to refuse them in local schools, although in France education is a recognised fundamental right and a state duty, mandatory from 6 to 16 years. Although every child is unconditionally entitled to education and cannot be denied this right, schools refuse Roma children on the grounds that they lack health and immunisation records (health records may not exist or might have been lost during the evictions $)^{473}$. Although all children must have been vaccinated to enter school, French law forbids schools from denying children without immunisation or partially vaccinated.

Among other criteria for enrolling Roma children in schools there is the demand of an address from schools, the discrimination in access to school transports, school lunch and the denial of the basic allowances to buy school stationery and decent clothing for children. Among the few who are able to enrol in schools, they usually do so for shorts periods because of the repeated evictions, deportations and stigma. It has been estimated by Romeurope that 5,000 to 7,000 Roma children in France do not attend any school ${ }^{474}$.

This civic isolation is likely to contribute to the remarkably lower voter turnout figures among the Roma based in France - just 13\% of Roma chose to vote in the last French national elections in contrast to $81 \%$ of the general population. ${ }^{475}$

These actions have been documented previously by MdM ${ }^{476477478479480}$ and continue to be a matter of concern in 2013 as mayors put Roma children in separated classrooms or refuse them on arguments of lack of places at local schools according to Réseau éducation sans frontières (RESF). There is also a need for specialised teachers, as many Roma children do not speak French and for those who start school above the recommended age.

Finally, the procedures for work permits, school enrolment and health coverage require Roma to fill out paperwork in French and to navigate bureaucratic processes which, besides the language barrier, constitutes a major obstacle to obtaining these rights ${ }^{481}$. These obstacles have been documented previously 482483484485486487,

[^73]demonstrating that there are few improvements on health status and living conditions as a whole for Roma in France.

On the contrary, in recent years Roma have increasingly faced deportation and exclusion from basic public services, such as health care and education. These actions contradict human rights principles and public health policies principles ${ }^{488} 489490$.

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 grounds of denying Roma living in France of their rights and access to their rights. Specifically, the Committee condemned the French government for 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 ${ }^{491}$.

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 a discriminatory treatment and requested that France change its policies towards Roma to ensure their rights ${ }^{492}$. It was the fourth condemnation of the European Committee of Social Rights against France concerning its treatment of Roma, thus making urgent that the French government change their policies towards Roma and to apply already existing laws and regulations ensuring their rights.

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## Country Profile: Germany

## Main Characteristics of the Roma in Germany <br> Demography

Roma and Sinti have lived in Germany for around 600 years. Sinti refers to those of Western and Central Europe origin and Roma refers to those living in Western and Central Europe ${ }^{493}$. Three different groups of Sinti and Roma may be differentiated:

- Those members of Sinti and Roma, which have been living in Germany for many generations and are officially recognised as a national minority;
- Roma migrant workers from former Yugoslavia, that arrived between 1968 and 1973 and have been living in Germany for many years; they have in general a strong legal status and are entitled to enjoy the same rights as Germans;
- Roma refugees, asylum seekers from mostly (south-) eastern European countries, in particular since the 1990s; many of them have still to obtain refugee status and thus are not eligible for full social protection and housing rights ${ }^{494}$.

During the National Socialist regime, Roma were persecuted and faced extermination. Furthermore, many were deported from Germany to allied countries, such as Italy, Croatia, Romania and Slovenia during WW2 ${ }^{495}$. The Roma and Sinti who survived the camps, had a difficult time to rebuild their lives, having lost family members and friends, their property destroyed or confiscated and many had developed serious health problems. After the war, some tried to seek compensation, but their requests were rejected for many years ${ }^{496}$.

It is estimated that there are between 70,000 and 140,000 Roma and Sinti in Germany. Most estimates are around 70,000 Roma with German citizenship, and between 40,000 and 50,000 who are refugees or migrants without full citizenship ${ }^{497}$. There is no national census of disaggregated data on the basis of ethnicity in Germany. It is therefore difficult to provide an accurate demographic picture of the Roma and Sinti population living there. All figures are estimates and may include or exclude members of different backgrounds and legal status within Germany.

[^75]According to the average estimate $(105,000)$ by the Council of Europe, Roma make up $0.13 \%$ of the total population of Germany. This is a fairly small number in comparison to other European countries ${ }^{498}$.

According to one study, the absolute majority of Roma and Sinti in Germany are sedentary. The study found that some Roma still owned caravans, used to go on holiday during the summer or to visit family and friends in other parts of Germany and Europe ${ }^{499}$.

## Geographical distribution

The majority of German Roma live in large or medium-sized cities of Western Germany. Cities mentioned are Berlin, and surrounding areas, Hamburg, Dusseldorf and Cologne as well as East Friesland, Palatinate, Hesse and Baden. It is estimated that 35,000 Roma and Sinti live in North Rhine-Westphalia, 12,000 in Bavaria, more than 10,000 in Baden Württemberg, 8,000 in Rhineland Palatinate and 5,000 in Schleswig-Holstein. The biggest concentration of Roma and Sinti can be found in Hamburg, with an estimate of 37,000 living in the city ${ }^{500}$.

Due to the already mentioned restriction of available data from national census as well as non-formal sources, estimates may be precarious concerning the geographical distribution of Sinti and Roma.

## Other Information (including highlights of data gaps)

The national statistic bureau of Germany does not collect ethnically disaggregated data. However, one variable in the official census 2011 is persons with migrant background, which is defined as "all foreigners who have immigrated or not immigrated as well as all Germans who have immigrated to today's territory of the Federal Republic of Germany after 1955 and all Germans with at least one parent who has immigrated to today's territory of the Federal Republic of Germany after 1955. Foreigners are persons who do not have the German citizenship." Another variable is 'migrant background by region', which is divided into four values; EU28 country, other European countries, Rest of the world and unknown foreign country. The last variable includes stateless persons and persons with uncertain citizenship without information on immigration as well as persons without foreign citizenship ${ }^{501}$.

However, there is no official data that show further details of ethnicity and/or different nationalities living in Germany. Moreover, information from non-formal sources regarding the number and status of Sinti and Roma living in Germany are equally insufficient.

[^76]Federal statistical surveys are mostly conducted in a decentralised way. Data is usually collected and processed by the statistical offices of the 16 federal states, and aggregated at the federal state level (Statistisches Bundesamt 2013) ${ }^{502}$.

There is a large gap within the literature on demographics and the status of Roma and Sinti in Germany. There are some data concerning living conditions of Roma and Sinti from 2002, which was compiled by the association of Sinti and Roma in Baden-Wurttemberg. This was a (unpublished) non-representative regional survey, which showed that $22 \%$ of the questioned Sinti and Roma lived in private flats, $11 \%$ owned their own homes and $67 \%$ lived in council flats. There is no quantitative data on regulated encampments, due to the fact that the majority of Roma and Sinti encampments no longer exist ${ }^{503}$.

There is no quantitative information concerning Sinti and Roma in Germany. The majority of information concerning Sinti and Roma is based on qualitative research, showing a wide information gap of quantitative data. This is likely to be due to several different reasons:

- The official collection of ethnic data is greatly restricted by the Federal Data Protection Law, partly due to the historically sensitive nature of the subject.
- Roma and Sinti often do not identify themselves as belonging to the ethnic minority.
- The number of Roma and Sinti are not large enough to warrant nation-wide surveys.
- Roma and Sinti are often inclined to neglect official data collection efforts ${ }^{504}$.

Official demographic data on Sinti and Roma divided into gender, age and employment status is non-existent. Moreover, there is an even a greater information gap concerning migrant Roma and Sinti with weak legal status ${ }^{505}$.

Due to the lack of data collection concerning Roma and Sinti in Germany, this country research relies mostly on European (EU) and regional commissioned studies, non-formal sources, such as NGOs as well as academic literature, which mainly provide qualitative information and/or an analysis of secondary sources.

Mortality and Life Expectancy
The study team has found no quantifications of this indicator.

## Prevalence of Major Infectious Diseases

The study team has found no quantifications of this indicator, but anecdotal data and evidence cover:

[^77]An epidemiological study into the outbreaks of measles in Hamburg from December 2008 to June 2009 found that a local Roma community in one of the seven boroughs of Hamburg notified comprised more than $50 \%$ of the notified cases. Stratified analysis found that there was a difference in the incidence between Roma and non-Roma of the age distribution: $33 \%$ among the non-Roma measles cases were infants ( $0-11$ months), whereas in the Roma community only 4\% belonged to this stratum. $50 \%$ of measles cases within the Roma community were found in the older stratum ( $5-17$ year-olds), compared with only $8 \%$ of non-Roma cases in the same stratum. These findings may reflect different trends in vaccination preferences ${ }^{506}$.

Healthy Life Styles and Related Behaviours
There are no official data on the health status of Roma migrants in particular. One study looked at the health situation of the general migrant population in Germany instead. This study argues that migrants often face similar health problems, due to their low socio-economic status. The study further suggests that migrants are more likely to have health problems related to physically and psychologically stressful living and working conditions, which would then include migrant Roma ${ }^{507}$.

Access and Use of Health Services and Prevention Programmes
The study team has found no quantifications of this indicator, but anecdotal data and evidence cover:

Statutory Health Insurance Statistics and other health statistics do not record ethic origin, which means that there are no official data on the state of health of Roma and Sinti in Germany. All German citizens are obliged to contribute to the statutory or private health insurance scheme, which then guarantees the provision of healthcare. This also applies for nationals of other EU countries as well as nationals of Contracting States to the agreement of the European Economic Area, once they have established their residency in Germany. Third-country nationals are also required to contribute to a health insurance scheme, which means that foreign Roma living in Germany are in general required to be insured. There are various non-governmental organisations (NGOs), which help migrants and refugees and in some cases particularly Roma and Sinti to access healthcare services as well as other assistance ${ }^{508}$.

[^78]One field research in the district of Neukölln in Berlin found that there were insufficient vaccination certificates amongst Roma communities and especially amongst children ${ }^{509}$.

There is very little information available on the health situation of Roma and Sinti in Germany. There are however some indications that Roma and Sinti lack awareness of their entitlement to benefits, in particular of public health services. The literature also draws attention to mistrust of health providers and personnel, which in turn limits access to health services by Roma and Sintif ${ }^{510}$

## Prevalence of Major Chronic Diseases

The study team has found no quantifications of this indicator, but anecdotal data and evidence cover:

It is suggested that poor living conditions (overcrowding, poor housing quality) result in a higher risk of health problems, such as respiratory illnesses, tuberculosis, psychological problems, chronic illnesses, being overweight and disability ${ }^{511}$.

According to one study, specific health problems among Roma in Hamburg seem to be heart disease, asthma and rheumatism. Another study shows that obesity and associated health problems such as metabolism disorder and hypertension are of concern within the migrant Roma population ${ }^{512}$.

A German study of Roma, Ashkali and Egyptian children from Kosovo found that children also deal with psychosomatic problems, such as post-traumatic stress disorder often expected within migrants from war-torn regions, such as Roma immigrating to Germany in the '90s. ${ }^{513}$

Health Factors Related to the Role of Women in the Roma Community
There is no official disaggregated data based on ethnicity, gender, age, and health status.
Lack of education opportunities often result in difficulties to access public services, such as health care providers.

Poor housing and living standards normally affect women disproportionately, as they tend to spend more time at home than men do.

[^79]Furthermore, there is a general distrust of healthcare providers and personnel especially amongst Roma and Sinti women. There is also a reported lack of cultural sensitivity amongst healthcare providers. This has most likely a negative effect on Roma and Sinti women's access to healthcare services ${ }^{514}$.

Inadequate nutrition and lack of access to healthcare services are of particular concern for pregnant Roma and Sinti women. One report states that dystrophy, caries and anaemia have been observed in German Roma and Sinti children at birth. It has been noted that many foreign Roma and Sinti women often suffer from depression. Many have to cope with traumatic experiences. Additionally, many have to cope with the uncertainty of expulsion, which itself can be a cause to stress and depression ${ }^{515}$.

Environmental and other Socio-Economic Factors

## Housing

According to the Federal Government, there is little or no difference in the provision of housing to Roma and Sinti compared to the rest of the population ${ }^{516}$. However, qualitative research indicates that Roma and Sinti are still classified as a low socioeconomic group, with higher levels of unemployment, lower educational attainment and lower standards of living than non-Roma ${ }^{517}$.

The majority of Roma and Sinti are sedentary and there are few encampments in Germany. German citizens and migrant face different housing situations. German citizens are entitled to housing benefits, unemployment benefits and other social welfare means as a support when faced by unemployment. Roma often live in segregated communities, which has resulted in the emergence of segregated neighbourhoods in several cities ${ }^{518}$.

Overcrowding appears to be a significant problem within Roma and Sinti populations in Germany. Furthermore, Roma and Sinti appear to be usually living in the outskirts of cities, often with poorer infrastructure and at times close to industrial zones and waste sites. This may contribute to a higher level of health related problems ${ }^{519}$.

Moreover, several accounts report substandard housing for Roma and Sinti. A report by the ERRC records inadequate living situations where the inhabitants are not protected from the damp and cold. In order to keep warm, they use oil lamps or burnt wood in their homes. Without adequate ventilation this becomes a health

[^80]hazard, particularly for women, who often spend more time within the home than men ${ }^{520}$.

## Education

Reports from NGOs working with Roma and Sinti 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, due to early marriage and hence obligations within the family as wife, mother and homemaker. Girls with travelling parents in particular suffer further problems in attaining an education ${ }^{521}$.

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/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 the prosecution under National Socialism influence the relationship to school as an institution. There is little evidence of self-education ${ }^{522}$.

## Employment

The federal Government has put forward objectives in order to increase employment for youth and disadvantaged groups. The objectives are in line with the EU framework for National Roma Integration Strategies up to 2020. By law, German Roma and Sinti and EUnationals are free to take up employment and vocational training in Germany. The federal employment agency has several integration policies in place, in order to help migrants and other disadvantaged groups into employment. Support programme 'Integration durch Qualifizierung - IQ' ('Integration though Qualifications - IQ') to improve labour market integration of adult migrants.

The government has several projects for the integration of migrants into the labour market. ESF is a funding instrument for programmes aimed at integrating disadvantaged groups, including Roma and Sinti, into the labour market, to combat discrimination and ensure equal opportunity for all ${ }^{523}$.

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## Country Profile: Greece

## Main Characteristics of the Roma in Greece

## Demography

It is estimated that there are between 180,000 and 350,000 Roma living in Greece. Roma makes up $2.47 \%$ of the total population, according to the average estimate $(265,000){ }^{524}$.

There is no common definition of what constitutes a Roma identity. The government recognise a large Muslim minority of Thrace as Roma, however, almost all Roma living in the prefecture of Evros, identify themselves as a Turkish ethnic minority. Therefore, numbers of Roma in Greece needs to be treated with caution ${ }^{525}$.

The Roma community is significantly younger than the general population of Europe. The average age for EU-27 is 40.2 whereas it is 25.1 for Europe's Roma population. The average age for Roma in Greece is even lower (21.56). The percentage of persons aged 65 and over within the Roma population in Greece is only 2.16 , compared to the EU-27 at $17.04^{526}$.

## Geographical distribution

Roma are concentrated in four main regions, namely Eastern Macedonia-Thrace, Thessaly, Western Greece and Central Macedonia ${ }^{527}$. Roma can be found in both urban and rural settings in Greece, although Roma are often found in segregated rural settlements. One study found that 63\% of Roma in Greece live in immigrant/minority population areas ${ }^{528}$.

It is estimated that more than $25 \%$ of the Roma population is living in segregated rural settlements, in particular in Northern Greece. Most Greek Roma are sedentary, however some Traveller communities can be found in Greece ${ }^{529}$.

http://fra.europa.eu/sites/default/files/fra_uploads/582-RAXEN-Roma\ Housing-Greece_en.pdf and EC (2012) What works for Roma inclusion in the EU: policies and model approaches.

## Other Information (including highlights of data gaps)

Roma in Greece face multifaceted discrimination, particularly in the areas of housing, education, employment and health.

Roma are not recognised as a national minority and are considered as Greeks without separate ethnic identity. Therefore, ethnic disaggregated national data are nonexistent. The minority term (which is protected by international legal instruments) is only used for groups that are explicitly included in bilateral treaties. For example a minority group of 12,000 Muslim Roma living in Western Thrace is considered a minority group, due to the 1923 Lausanne Treaty ${ }^{530}$.

There is a lack of data on regulated and unregulated encampments, social housing, private renting, ownership and household types, as there are no official or unofficial quantitative data available on the housing conditions for Roma and Travellers ${ }^{531}$.

There are several studies and surveys regarding the health status of Roma in Greece by international agencies, such as the UNDP, the World Bank and FRA. However, a lot of this data has been published before 2008 and thus may now be considered outdated. Some studies use a small sample pool, which means that it will have little statistical value over the national circumstances of Roma in Greece. Others use a selfassessment method concerning the health status of households and individuals. No ethnic disaggregated national statistics exist, as Greek Roma are not considered a minority.

The data gap also concerns quantitative as well as qualitative data of the prevalence of HIV, Tuberculosis and MDRTB as well as the prevalence rates for cancer.

Greece has established a network of 33 socio-medical centres for Roma, which is acknowledged as being the most successful practice for Roma in Greece. A multidimensional approach is adopted by the centres, which not only provide health care and arrange hospital appointments but also provide social services and educational advice. These centres often focus on women and children and are considered to be user-friendly, flexible and multi-faceted, when they function effectively ${ }^{532}$.

## Mortality and Life Expectancy

For this indicator there is no data regarding mortality rates or life expectancy. However, there is data in the form of an age pyramid, which can be compared with both mainstream population of Greece, as well as the age pyramid of EU-27. The data on the age pyramids on EU-27 and European Roma are reliable as the data is based on Eurostat data of 1 January 2008 and the European Survey on Health and the Roma Community, 2009. It is however unclear what sources the age pyramids for the Greek Roma population and Greek population are based on. Therefore, this data may be unreliable. On the other hand, the data for both the Greek and Greek Roma age pyramid are consistent with the data for EU-27 and European Roma, respectively. This would suggest that the data might be indicative of the age distribution of both the Greek population and the Greek Roma population.

[^82]http://www.errc.org/cms/upload/file/improving-the-tools-for-the-social-inclusion-and-non-discrimination-of-roma-in-the-eu-2010.pdf

As mentioned above, the population pyramid of Greek Roma and EU-27 differs significantly. The Greek Roma population is much younger and fewer old people, with the majority of people under the age of 20 . The EU-27 population pyramid, on the other hand shows that the majority of people are between 0-49, and have more old people ${ }^{533}$. This age distribution indicates low life expectancy and high fertility rates for Greek Roma, but may also reflect migration to other areas ${ }^{534}$. Since Greece does not collect data on ethnicity there are no national data on mortality or life expectancy of the Greek Roma population. However, conclusions can be made from the age pyramid, which shows that Roma are much younger with fewer old people than that of both the mainstream national population and that of EU-27. The data suggests that Greek Roma have a lower life expectancy at birth than the mainstream population in Greece, as well as in the EU-27. Even though the survey included a small percentage of the total estimated Roma population, there is a general consensus that Roma are younger than the average population in EU-27.

## Prevalence of Major Infectious Diseases

For this indicator there is data from published medical research papers as well as EU department sources concerning major infectious diseases amongst Roma in Greece.

The first cases of the measles virus D4-Hamburg in Greece were identified in the beginning of 2010, among Roma households of Bulgarian nationality. The virus then spread to Greek nationalities, mainly Greek Roma. In 2010 there were 91 confirmed cases of the D4-Hamburg measles, which subsequently reached to 149 cases ${ }^{535}$. It is estimated that $33 \%$ of the cases belonged to Greek Roma and $29 \%$ to Bulgarian Roma in Greece ${ }^{536}$. In the majority of the cases it was children between $0-14$ years of age, half of whom were 0-4 years old. $88 \%$ of the 106 cases with known vaccination status were unvaccinated. During the first weeks of outbreak, the majority of cases belonged to Bulgarian Roma, then it spread to the Greek nationalities, and after week 21, most cases belonged to Greek Roma ${ }^{537}$. This suggests that Greek Roma is more vulnerable to outbreaks of infectious diseases than the mainstream population. The most significant reason may be the fact that a large percentage of Greek Roma children don't adhere to the vaccination programme. Other factors such as substandard housing, poverty, lower educational attainment, unemployment, discrimination on the grounds of ethnicity may also play a key role.

One study ${ }^{538}$ found that among non-Roma children $32.7 \%$ had detectable antibodies to hepatitis A, compared with $98.3 \%$ among Roma. No past infection of hepatitis B was found among the non-Roma, however $22 \%$ of Roma children showed evidence of past infection, among 4\% were chronic carriers. Only $14 \%$ of Roma children had markers of past vaccination of hepatitis B, compared with $96 \%$ of non-Roma. Substandard housing, lack of child insurance, frequent change of residence and the lack of primary healthcare delivery associated with the prevalence of hepatitis B infection amongst Roma. The data indicates that Roma are more vulnerable to major

[^83]chronic diseases than the mainstream population. Even though the study included a small sample of children for seroprevalence for hepatitis A, B, and C, the data is still an indicator on the differences in health status between Roma and non-Roma. This may also indicate that one of the factors to why Roma children are more vulnerable than non-Roma is the non-adherence to vaccine programmes. Please see below.

## Healthy Life Styles and Related Behaviours

For this indicator there is data from a study compiled by several NGOs with funding from the European Union.

This study found that the majority of the interviewees are daily smokers (56.3\%) compared to $40 \%$ of the mainstream population. $26.2 \%$ of Roma doesn't smoke and has never been a habitual smoker, A smaller percentage of women ( $46.8 \%$ ) as compared with men ( $66.3 \%$ ) are daily smokers ${ }^{539}$.
$42 \%$ of the mainstream population consumes alcohol and 1 out of 5 drinks daily. According to this study, $56.8 \%$ of the adult Roma population had consumed alcohol during the last 12 months. The data shows a gender difference of alcohol consumption, with $77.3 \%$ of men had consumed alcohol in the preceding 12 months, compared to $38.5 \%$ of women.

Furthermore, the overwhelming majority of the Roma population in Greece have no problems with alcohol or drugs. 3\% has problems with alcohol and $0.7 \%$ has problems with drugs. However, when looking at the household level, drug and alcohol problems affect $17.2 \%$ of all Roma households in Greece, which is higher than Europe's Roma average at $11.4 \%$.

Obesity: According to the study, 9.4\% of Roma in Greece are obese, 23.3\% overweight and $35.6 \%$ with normal weight. However, the statistics are unreliable since there is a lack of information from $31.7 \%$ of the interviewees. $57.7 \%$ of the mainstream population are considered overweight ${ }^{540}$.

Even though the study used a small-scale survey, it can be used as an indicator for the need of further research into the health of Roma in Greece. The data does not reveal if Roma are more likely to be obese than the mainstream population, due to gap in the data collection. The data indicates however, that many households are affected by alcohol and to some extent drug abuse. Further research is needed to establish the prevalence of alcohol and drug abuse. The data also indicates that Roma are more likely to be smokers than the rest of the Greek population. However, as mentioned, due to the small-scale sample, it is not possible to draw concrete conclusions.

## Access and Use of Health Services and Prevention Programmes

For this indicator there is data from the same small-scale study compiled by several NGOs with funding from the European Union.

Immunisation: $35.3 \%$ of all the minors in the study have not adhered properly to the vaccination programme, which is higher than the average European Roma (28.4\%).

[^84]The main reason given by parents is "I forgot", whilst other reasons included lack of information (13.5\%) and lack of economic resources (11.7\%). 6,6\% thought it's not useful and possibly dangerous and $2.8 \%$ had difficulties in accessing the vaccination centre. This may suggest that the reason behind non-adherence to vaccination programme is associated with economic difficulties and lack of information. Moreover, significant gender differences were found where girls were less likely to adhere to the vaccination calendar than boys ${ }^{541}$. These gender differences are most likely a reflection of unequal gender structures, where girls are deemed to have lower status than boys.

The data indicates that Roma children are less likely to adhere to the vaccine programme than children from the mainstream population. However, the data is unreliable since it comes from a small-scale survey and thus would indicate that more research into the immunisation status of Roma children is needed.

The same study found that one of the most significant barriers to accessing health services is the economic situation, such as inability to leave work, too expensive, no health insurance and/or no means of transport. Half of the Roma population visit a physician once a month, whereas the rest of the population visit a physician once a year. $5 \%$ 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 ${ }^{542}$.

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.

In terms of access to health services, there is insufficient data to conclude if Roma is worse or not worse off than the mainstream population, because the data comes from a small-scale study. On the other hand, the disproportionate use of emergency services may indicate that Roma are worst off, due to lack of economic resources and long distances to healthcare centres.

Health Insurance cover: For this indicator there is data from a larger-scale study of both Roma and non-Roma, from international organisations (FRA \& UNDP). Although the data for the mainstream population is not representative for the majority of the population, it acts as a benchmark for the Roma, since the non-Roma share the same residential areas and socio-economic environment. The data is reliable because the results represent Roma residing in higher than national average density areas.

There are significant differences between Roma and non-Roma when it comes to health insurance cover. More than $90 \%$ of non-Roma is covered by health insurance, compared to $60 \%$ of Roma. A significant number of Roma (20.5\%) fail to access medical assistance when needed, due to lack of economic means, the insurance doesn't cover the visit or they have no medical cover. Another significant factor is not having healthcare centres in the vicinity ${ }^{543}$. The data indicate that Roma are worse off compared to the mainstream population because a significant number of Roma lack medical insurance, which means that many fail to access healthcare services when needed.

[^85]
## Prevalence of Major chronic Diseases

For this indicator there is data from both the small-scale study by several NGOs, as well as a larger-scale study from international organisations.

According to the small-scale study, $35 \%$ of the mainstream population claims to suffer from chronic diseases, ( $30.7 \%$ male and $39 \%$ female). Most common diseases in the mainstream population are: hypertension 16\%, hyper-cholesterol $9.1 \%$ and osteoarthritis $6.1 \%$. Same study ${ }^{544}$ found that most of the Roma population (over $90 \%$ ) does not suffer from any chronic disease. The most common disease is menopause-related problems suffered by women. 98\% of Roma under the age of 45 have no disabilities or chronic disease. This may also reflect the younger average age of the Roma population as compared to the mainstream population. Moreover, the prevalence of diabetes within the Greek Roma community is $4 \%$, which is slightly lower than within the mainstream population at $6.4 \%$. The data do not reveal if the Roma population is worse off because the data relies on self-assessment on their own health status. Moreover, the study in not representative of the majority of Roma population in Greece, since it is a small-scale survey.

The data from the larger-scale study indicates however that Roma are worse off than non-Roma in terms of health problems. The FRA Roma pilot survey 2011 showed that more than $15 \%$ of Roma respondents aged 35 to 54 said to have health problems that limit their daily activities, compared to less than $10 \%$ of non-Roma ${ }^{545}$.

This contradiction between the two studies may suggest that due to a younger population, the majority are considered themselves as healthy. However, the older generations show tendency to have more health problems than the mainstream population. The data indicates that adult Roma and older generations are more likely to face health problems than the mainstream population in the same age category.

Health Factors Related to the Role of Women in the Roma community
For this indicator there is data from the same small-scale study.
The majority of women from the mainstream population in Greece have never had a pap smear. Moreover, 44\% of women have had a mammography and 54\% have had a breast test.

According to EFXINI POLI et.al. (2009), 21.5\% of Roma women in Greece had never visited a gynaecologist. $35.5 \%$ had only gone for the reason of pregnancy, whereas only $8.6 \%$ had made the visit during the last $1-3$ years for other reasons than pregnancy. The main reason why women had visited the gynaecologist (other than pregnancy) was gynaecological problems. Moreover, the study also showed that $31.9 \%$ have had a pap smear and as few as $8.4 \%$ have had a mammography at some point in their lives. However, the sample base in Greece was too small to have any statistical significance ${ }^{546}$

[^86]A survey from the FRA indicates that Roma women are significantly worse off than their non-Roma counterparts. $13 \%$ of Roma women over 16 reported having bad health compared to $5 \%$ of non-Roma females. This trend is exacerbated as the female population ages with 34\% of Roma women above 50 in bad health in contrast to $9 \%$ of non-Roma women. ${ }^{547}$ This data reflects the trend observed that health problems in the Roma population develop earlier than the general population.

## Environmental and other Socio-Economic Factors

For this indicator (education) there are data from both European studies as well as a study from international organisations.

The data indicate that the Roma population is significantly worse off than non-Roma when it comes to educational attainment.

Education: Less than 10\% of Greek Roma children are reported to be in preschool or kindergarten, compared with less than $50 \%$ of non-Roma. Greece (together with Slovakia) shows the lowest participation rates for children in preschool and kindergarten for both Roma and non-Roma. The data suggests that the literacy rate for Roma in Greece differs significantly by gender - just 43\% of female Roma are literate compared to $55 \%$ of male among the over 16 s . It is worth noting that literacy rates are equal for $16-24 \mathrm{~s}$, hence gender differences may be more pronounced for the older generations. ${ }^{548}$ Additionally, more than $35 \%$ of Roma children aged between 7 and 15 in Greece do not attend school, compared to less than 5\% of non-Roma children. Furthermore, less than 5\% of Roma between the age of 20 and 24 have completed a general or vocational upper-secondary education, as compared to $80 \%$ of non-Roma ${ }^{549}$.

Unsurprisingly, enrolment rates for minors (0-15) are low for Roma. Compared to EU27 (79.8), only 34.9\% of Roma minors are enrolled in school. 56.0\% of Roma minors between 6-15 in Greece are enrolled in school, compared to 99.6\% for EU-27. Only $8 \%$ of 15-24 year olds from the Roma community in Greece are still in school ${ }^{550}$. This data for enrolment rates comes from EDIS S.A. European Survey on Health and the Roma Community and data furnished on EU-27 by Eurostat 2007 (quoted in EFXINI POLI et.al. (2009) Health and the Roma community, analysis of the situation in Europe. Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain). However, the data are unreliable as they are old.

## Employment

Data on employment comes from both the small-scale study by several NGOs, as well as a larger-scale study from international organisations.

One study showed that around $25 \%$ of Roma are in paid employment (excluding selfemployment), compared to more than $40 \%$ of non-Roma. However, a significant proportion (around 20\%) of Roma stated that they were self-employed. More than 1 in 10 Roma children are reported to work outside the home in Greece. ${ }^{551}$

[^87]Another survey ${ }^{552}$ showed that $38.2 \%$ of Roma are economically active, whereas $19.4 \%$ are unemployed and $42.5 \%$ are inactive. These figures are based on the selfperception of the interviewees and therefore not comparable to the official figures of unemployment.

Data suggests a big difference in employment rates between Roma men and women over $16-64 \%$ of males are in paid work compared to just $16 \%$ of females. This can entirely be explained by cultural reasons as $47 \%$ of women are full time housemakers compared to $0 \%$ of men. ${ }^{553}$

The data do not reveal if the Roma are worse off than the non-Roma population. Furthermore, the data are unreliable since the first data exclude self-employment and the second data are based on self-perception. The data concerning child labour are also unreliable. Different cultures understand child labour differently and without using an international agreed definition, child labour will be difficult to determine.

Housing: For this indicator there is data from European studies, international organisations and NGOs.

Both national and international reports on Greece, agree that Roma live segregated from the rest of the population, both spatially and socially ${ }^{554}$. $22 \%$ of Roma population live in shanty towns, whereas $54 \%$ live in rural settings. Almost half of Roma in Greece live in either shanty towns (21.9\%) or in substandard housing (25.5\%). A significant proportion (37.3\%) of the Roma population live in isolated areas and have poor health, compared to Roma that live in integrated neighbourhoods with good health (29.2\%). The majority of the mainstream population have access to health and social services in their neighbourhoods, although a large portion live in areas without health-care services ${ }^{555}$.

There is a considerable difference in housing conditions between Roma and non-Roma in Greece. The average person per room (excluding bathroom, toilet, kitchen, hall, corridor and any rented out room) for Roma is almost 2.75, compared to non-Roma with the average of just over 1 person/room. There is also a significant difference between Roma and non-Roma when it comes to basic amenities, such as indoor kitchen, indoor toilet, indoor shower/bath and electricity. More than 35\% of Roma lack at least one of these basic amenities, compared to an insignificant portion of nonRoma (less than $1 \%$ ) ${ }^{556}$.

According to Eurofound (2012) over 80\% of Roma household experience some kind of housing deprivation. The majority experience lack of space, rot in windows, doors or floors and many cannot afford to keep the place adequately warm. Damp from leaks in walls or roofs is also another common problem. Additionally, more than $30 \%$ Roma in Greece had experienced discrimination in the last 5 years in accessing housing ${ }^{557}$.

The data indicate that Roma are significantly worse off than the mainstream population. Moreover, the data concerning the housing situation are consistent, which indicates reliability. Even though the Eurofound (2012) study is a review of secondary

[^88]literature of which some is slightly outdated, it shows a general trend that the Roma population is worse off than non-Roma population when it comes to the housing situation.

For the poverty indicator there is data from international organisations.
According to FRA Roma pilot survey 2011 around 60\% of Roma respondents said that somebody in their household had gone to bed hungry at least once on the last month due to insufficient resources to buy food, compared to less than $10 \%$ of non-Roma. Moreover, almost 90\% of the Roma live in households at risk of poverty, compared to less than $55 \%$ of non-Roma ${ }^{558}$.

The data indicate that the Roma population are significantly poorer than the mainstream population. The data also indicate that Roma are more vulnerable to unforeseen economic events than the non-Roma population. The data are reliable because the results from the survey are representative of Roma residing in higher than national average density areas.

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## Country Profile: Hungary

## Main Characteristics of the Roma in Hungary <br> Demography

2011 census: 308,957 persons declared themselves Roma (in the 2001 census this was 190,000). The latest representative sociological survey in 2003 estimated the number of Roma to be around 570,000. Based on statistical projection the number now is around 750,000 (more than 700,000 and less than 1,000,000).

The rate of $0-14$ children is $36.8 \%$ for the Roma and $15.4 \%$ for the non-Roma (2003).
$60 \%$ of Roma live in rural areas. Employment rate among men is $20 \%$ and among women is $10 \%$ (2003).

Poverty rate: $70 \%{ }^{559}$.

## Geographical distribution

According to the 2003 (the latest representative) survey the rate of Roma population was about 5\%; counties where their rate was higher than the average: Borsod-AbaújZemlén and Heves - above 11\% (North Hungary region); Békés 9-11\% (South Alföld region); Szabolcs-Szatmár-Bereg and Jász-Nagykun-Szolnok 7-9\% (North Alföld region); Baranya (South Hungary region), Hajdú-Bihar (North Alföld region) and Pest (Central Hungary region) 5-7\%.

## Other Information (including highlights of data gaps)

Except for a few indicators, it was possible to cover almost all types of indicators.
(Indicators missing: maternal mortality; measles; ante-natal care)
As a general observation it can be concluded that we have some representative surveys but they are mainly from the early 2000s and we have some important scientific publications but they usually have a small and focused (e.g. geographical location, age group, life style) sample. As a consequence, official documents still rely on data from the early 2000s.

There are some important indicators from a more recent survey (the UNDP/WB/ECFRA/ 2011), however, it has indicators only on access/barrier to healthcare services, vaccination and health assessment.

Other more recent international surveys usually cover indicators on access/barriers to healthcare services but not on specific diseases.

[^90]
## Mortality and Life Expectancy

Concerning the indicators on life expectancy ${ }^{560} 561$ we have consistent but not the most recent data.

- In one source we have 59 years for Roma and 72 years for non-Roma ${ }^{562}$ but the reference date is unspecified.
- In another source from $2009^{563}$ we have the age of death for Roma men: 59 and non-Roma men: 68; and the age of death for Roma women: 58 and nonRoma women: 76.

As to the infant mortality indicators for Roma there are no ethnically disaggregated data. Nevertheless, there are regionally disaggregated data ${ }^{564}$ that allow for an approximation as to the rate of Roma infant mortality with some limitations.

- The three regions where the rate of infant mortality is the highest are the North Hungary region, the North Alföld region and the South Alföld region.

This indicator is used in the Hungarian Roma Strategy (National Inclusion Strategy) pointing out that regional differences play an important role as to the rate of infant mortality. It is important to underline that infant mortality in the North Hungary region (the highest rate of Roma) is significantly higher ( 8.1 mille) than the national average (5.1 per mille).

Another infant mortality indicator that could be used is the "Mother's educational qualifications, elementary or lower" - given the low educational level of the Roma population.

- That is two times higher for this indicator (10.1 per mille) than the national average.


## Prevalence of Major Infectious Diseases

We have aggregate as well as separate indicators on Hepatitis A, B and C as well as HIV and Syphilis or Chlamydia.

- The aggregate indicators (B) come from a survey carried out in Budapest among drug users in 2005-2006 and it looked at the number of infections among injecting drug users (IDU) ${ }^{565}$. It was found that Roma always had a higher rate of the number of infections than the non-Roma.

These indicators are, on the one hand, useful for they have ethnic breakdown, but on the other hand they are limited in scope for they focus on drug users in the capital of the country using a rather small sample.

[^91]- The separate indicators for Hepatitis A, B, C and HIV are based on a 2004 survey among the residents of an impoverished ghetto of Budapest ${ }^{566}$. Interestingly no HIV infection was found.

The same applies to this set of indicators as to the previous one; it is based on an important scientific work but it is very limited in scope (it is a rapid assessment survey) and cannot be generalised to the more general Roma population. (Dzsumbuj, where the survey was undertaken, is a very specific neighbourhood of Budapest with an extremely high concentration of poverty and all related problems).

The other limitation of the indicators is that they dat back to 2004 and 2006. Nevertheless, they can serve as good starting points to develop a more general survey on these indicators.

The indicator on the rate of tuberculosis dates back to 2000567568569

- The rate of tuberculosis for Roma is 4\% and for the non-Roma it is $\mathbf{1 \%}$. The data is old, nonetheless, the survey was representative which means that by repeating the same survey we could get a solid basis for comparison as to how the health situation of Roma has changed in the course of the last decade.

We have indicators on the vaccination rate of children (0-6 or 6 years old $)^{570}$.

- The level of vaccination is almost 100\% for Roma as well. The data are recent (2011) and come from a big sample size but focus on Roma living in areas with high rate of Roma population.

We could not identify any source with reference to indicators on the rate of measles among the Roma population.

## Healthy Life Styles and Related Behaviours

We could identify one publication with indicators on drug use among the Roma ${ }^{571}$ :

- the rate of adolescents (13-16) who already used drugs. Difference between the rate of drug use among Rome and non-Roma is very high: $22 \%$ as opposed to $2 \%$. The survey is not representative.

Indicators on the use of alcohol among the Roma come from four different surveys ${ }^{572}$. The surveys were undertaken in 2004, 2006, and 2008 (one unspecified).

- One important finding is that Roma men in all age groups had a higher prevalence of abstinence than did all of the general population. ${ }^{573}$

[^92]- There is an indicator on alcohol by a specific group: LBW (low birth weight)/PTB (preterm birth) mothers never having alcohol (hard drink). The result is that slightly more non-Roma LBW/PTB mothers had alcohol than Roma (96.8\% as opposed to $98 \%)^{574}$.
- Rate of adolescents who have already been drunk (survey limitations see above: drug use): twice as many Roma adolescents have been drunk than non-Roma. ${ }^{575}$
- We have one more specific indicator on alcohol use that takes account of religion as well as ethnicity. Taking into account the impact of educational level, religiosity and age, it is found that Roma are 2.15 times more likely to be abstinent than the non-Roma. ${ }^{576}$

The surveys have different indicators (adolescents, mothers, general population) on alcohol drinking habits and except for Roma adolescents, all other groups of Roma are more likely to be abstinent or drink less than the non-Roma. None of the surveys is representative.

We could identify seven documents making reference to indicators on smoking habits among the Roma population ${ }^{577}$.

- The prevalence of smoking was considerably higher among the Roma people older than 30 years than in the lowest income quartile of the general population. Roma persons were younger than the general population when they started smoking. ${ }^{578}$
- The Roma Strategy reported on smoking among the Roma using the sources of the Health Survey, 2009 by the Central Statistical Office and the Roma population state of health survey, 2009. The rate of smoking among the Roma is significantly higher than for the non-Roma: 77\% and 31\%; and it is also much higher among the Roma pregnant women than the non-Roma: $62 \%$ and $25 \%{ }^{579}$.
- The indicator LBW/PTB mothers stopped smoking during pregnancy reveals that 10\% of Roma and 66\% of non-Roma mothers stopped smoking while pregnant. ${ }^{580}$
- Rate of smoking adolescents, both active smokers or those who only smoked once, is significantly higher among the Roma than the nonRoma: 45\% to 18\% ${ }^{581}$.
- Taking into account the impact of educational level, religiosity and age, it is found that Roma are twice as likely to smoke as the non-Roma. ${ }^{582}$

[^93]- Share of smokers among the Roma and the non-Roma and among the Roma and the non-Roma living in poverty is significantly higher for the Roma in both population segments than for the non-Roma (62\% and 38\%; 59\% and $48 \%$ respectively). The indicators suggest that Roma ethnicity plays an important role in smoking habits. ${ }^{583}$

All smoking indicators suggest that Roma ethnicity makes it about twice as likely to be inclined to smoking compared to the non-Roma. There are older and more recent data as well mainly focusing on specific groups and not on the general Roma population.

For BMI, obesity and low weight we identified three sources. ${ }^{584}$

- The distribution of body weight was broadly similar in the 2 populations, except that obesity tended to be slightly less frequent in Roma women in all age groups. ${ }^{585}$
- Low weight among LBW/PTB Roma mothers is twice as high as among the non-Roma, while obesity is less frequent (11\% for non-Roma and 7\% for Roma) ${ }^{586}$.
- Obesity is more likely among the Roma than the non-Roma (20\% and 35\%) ${ }^{587}$.

With the latest source the problem is that the author does not give a reference. In most studies it is found that Roma are less likely to be overweight than the non-Roma or the general population. The contradiction cannot be accounted for because of the lack of reference.

For unhealthy diet we have two different sources. ${ }^{588}$

- Unhealthy diet (less consumption of fruits and vegetables daily) was more prevalent for Roma than for the lowest income quartile of the general population. ${ }^{589}$
- LBW/PTB mothers having fresh fruits or vegetables and meat less than once a week is more frequent for Roma than for non-Roma ${ }^{590}$.

The indicators are limited to specific groups of Roma.

[^94]
## We have indicators on physical activity ${ }^{591} 592$

- No physical activity among LBW/PTB mothers is very high for both Roma and non-Roma but somewhat higher for Roma (94\% and 70\%) ${ }^{593}$.
- The study compares physical activity among Roma and non-Roma and those Roma and non-Roma who live in poverty. Roma are twice as unlikely as the non-Roma to do physical activity both in comparison to the nonpoor and the poor segments of the sample ${ }^{594}$.

However, the indicators are limited to specific groups of Roma.
We also have one indicator on the rate of asiderosis ${ }^{595} 596597$

- The difference between the Roma and non-Roma is significant: 0.9\% of the non-Roma and 13\% of the Roma suffered from asiderosis 598599600 .

The indicator is from a representative survey but it dates back to 2000.

## Access and Use of Health Services and Prevention Programmes

We have several indicators on self-reported health status.
The indicators for good or very good self-reported health status are in: ${ }^{601}$

- The author (government official) says: Roma have a distorted self-image concerning their health condition (56\% says they health is good). For the lack of reference in the document we cannot assess the validity of the data ${ }^{602}$
- The health status indicators show that somewhat more Roma have good health assessment than non-Roma (67\% and 58\%) ${ }^{603}$.
- The indicator is the opposite of the above, somewhat less Roma say they have good health than the non-Roma (40\% and 45\%). ${ }^{604}$
- More Roma living in poverty say they have good health than non-Roma living in poverty ( $34 \%$ and $28 \%)^{605}$.

The indicators for bad or very bad self-reported health status are in ref 3, 9, 12 .

[^95]- More Roma reported bad health status than non-Roma ${ }^{606}$. This is supported by FRA who reported that $68 \%$ of Roma women aged 50 and over declared themselves to be in bad health as opposed to only $37 \%$ of non-Roma women over that age.
- The indicators show that somewhat less Roma have bad health assessment than non-Roma ${ }^{607}$
- Roma have worse self-reported health than the non-Roma both among the poor and non-poor together and the poor alone ${ }^{608}$

We have contradictory data on self-reported Roma health status. We have convincing data on both Roma with more positive as well as with more negative self-reported health status although there are more indicators with the more positive results for Roma.

As to the bad health assessment, we have both more positive and more negative selfreported health status although there are more indicators with a more negative assessment.
None of the surveys is representative.

## Access to medical health insurance

- Both Roma and non-Roma have an almost complete access to medical health insurance. ( $94 \%$ and $97 \%)^{609}$.

This indicator should be interpreted by taking into account that there are estimations that about half a million people do not have medical health insurance (about 5\% of the population).

We could also indentify indicators on the use of healthcare services.
We have one indicator on the rate of people never or rarely using healthcare services ${ }^{610611}$

- The Roma Strategy refers to "The Roma population's state of health" 2009. Eduinvest. There are no general population data; the indicator shows that more than half of the Roma (64\%) never or rarely use healthcare services ${ }^{612}$
- Rate of Roma never or rarely seeing a family doctor 64\%; Rate of Roma never or rarely attending outpatient clinic 63\%; Rate of Roma never or rarely using inpatient health services $69 \%{ }^{613}$

[^96]
## We have an indicator on people having access to healthcare services ${ }^{614}$.

- The indicator is based on the following question: "Does your household have a doctor to approach when needed?" Almost all Roma and non-Roma have access to healthcare services (97\% and 97\%) ${ }^{615}$.

These latter indicators do not contradict each other although they may seem mutually exclusive. In fact, the first one ${ }^{616}{ }^{617}$ is the actual use of healthcare services whereas the second one ${ }^{618}$ is the possibility of the use of healthcare services. The difference between the real and the assumed access to healthcare is significant which means that the UNDP data ${ }^{619}$ should be interpreted carefully.

There is one indicator on the hospitalisation within one year ${ }^{620}$

- People hospitalized in the course of the previous year were close for the Roma and the non-Roma and a bit higher for the non-Roma: 11\% and $16 \%{ }^{621}$

We have several indicators on screening ${ }^{622623}$

- Attending lung-screening: one third of the Roma say they attend but no general population data ${ }^{624}$.
- Share of adult persons (16+) who had x-ray, ultrasound or other scan in the last 12 months as a percentage of all adult persons who replied to this question. More than half of the non-Roma (58\%) and more than one third of the Roma (38\%) attended screening ${ }^{625}$

The screening indicators are rather consistent although the former indicator's reference is unspecified.

Discrimination in the healthcare system has several indicators ${ }^{626}$.

1. More than one third of Roma reported discrimination (35\%)
2. Only $11 \%$ of Roma are said to be discriminated against ${ }^{627}$
3. $40 \%$ of Roma reported discrimination by physician in attendance and $26 \%$ reported humiliation 628629630
4. $18 \%$ of Roma reported discrimination in the past 12 months by healthcare personnel ${ }^{631}$
[^97]Discrimination indicators show a rather high percentage of reported discrimination. The second indicator differs from other findings but for the lack of reference in the document we cannot assess the validity of the data.

## Prevalence of Major Chronic Diseases

We have several indicators for the prevalence of major chronic diseases
Indicators on cardiovascular diseases are very different:

- 70\% ${ }^{632}$ and 16\% (versus 8\% for non-Roma) 633634635

The first indicator comes from the document without reference so it cannot be verified whereas the second one comes from the rather old 2000 representative survey.

There are several indicators on the rate of depression ${ }^{636}$.

- Roma tend to have much more serious depression syndromes: about only half of them are exempt from depression as opposed to two thirds of the non-Roma. Indicators are consistent on that; the difference in value comes from the fact that the different surveys measure different degrees of depression and among different populations: light depression, serious depression, neuroses, depression among Roma with degree or in poverty and no depression syndrome ${ }^{637}$.

The surveys focus on specific Roma populations.
Both indicators on the rate of asthma

- (Roma: 9\% and non-Roma: 1.4\%) 638639640 and
the rate of stomachic ulcer
- (Roma: 17\% and non-Roma: 3\%) 641642643
show that Roma are much more inclined to these diseases than the non-Roma. Both come from the same representative survey from 2000 so the data are old.

As to the rate of diabetes we have slightly contradictory data:

- one source (without reference) claims that Roma have a higher rate of diabetes: $\mathbf{1 2 \%}$ as opposed to $\mathbf{8 \%}$ among the non-Roma ${ }^{644}$,

[^98]- whereas in the 2000 representative survey ${ }^{645646647}$ the rate is very similar for both populations: for the Roma (5.2\%) and for the general population (5.8\%).

The same problem appears for the indicator on hypertension:

- According to the first source ${ }^{648}$ Roma have much higher rate of high blood pressure: $\mathbf{5 7 \%}$ as opposed to $\mathbf{3 2 \%}$ among the non-Roma.
- The second source ${ }^{649} 650651$ has almost equal rates for Roma and for the general population: 21\% and 22\%.

We have one indicator for the rate of cancer ${ }^{652}{ }^{653}{ }^{654}$ from the 2000 survey:

- 3.4\% for the Roma and 2\% for the non-Roma.

The data however is outdated.

## Health Factors Related to the Role of Women in the Roma Community

We could identify three indicators for health factors related to women.
We have an indicator on the rate of people using the health visitor service (it is a service for mothers with children from 0-6):

- among PTB/LWB mothers the rate is high for Roma (80\%) and for the non-Roma (86\%) as well ${ }^{655}$

The scope of the survey is limited to a specific group and to a specific geographical area.

As to the indicator on cercival cancer screening:

- one third of Roma women is said to attend this type of screening ${ }^{656}$

No reference is given for the indicator.
We could not identify any direct data on ante-natal care for Roma women.

## Environmental and other Socio-Economic Factors

We have several general and representative data on the environmental and the socio-

[^99]economic status of the Roma in Hungary. Most of the data, however, use different measurements and breakdown so they are not comparable.

There are only the following indicators that appear in more than one reference:
Employment rate is $20 \%$ for the Roma and $55 \%$ for the non-Roma (15-64 of age) ${ }^{657}$. In the UNDP/EC/WB/FRA 2011 survey ${ }^{658}$ employment rate for the Roma is $23 \%$ and for the non-Roma 41\% (15-64 of age).

The difference can be explained by the following: the UNDP survey focuses on Roma households and on the non-Roma living in the vicinity. So the data on general employment rate is not representative for the whole population.

## Educational level

Highest completed education: primary (eight grades) (15-64): 50.9\% for the Roma and 24.2 for the general population ${ }^{659}$.
Highest completed education (25-64), Primary education - ISCED 1 is 22\% for Roma and $6 \%$ for non-Roma ${ }^{660}$.

Share of people with primary school education (40-49): 58.9\% for Roma and 18.9\% for non-Roma. ${ }^{661}$

The UNDP survey (2011) shows a much lower rate of low educational level than the census (2001) and the other representative survey (2002).

Highest completed education: secondary/vocational (15-64): 9.1\% for the Roma and $26.3 \%$ for the general population ${ }^{662}$.

Highest completed education (25-64), Lower secondary education - ISCED 2: 56\% for the Roma and $35 \%$ for the non-Roma ${ }^{663}$

Share of people with vocational education (40-49): 8.9\% for Roma and 31.2\% for non-Roma. ${ }^{664}$
The huge difference comes from the different categorisation in the education levels in the two surveys: in the UNDP this indicator is the summary of "Upper basic", "Incomplete secondary voc/technical" and "Incomplete secondary general" were summarized as Lower Secondary Education - ISCED 2" whereas the first and third indicators refer to only complete vocational/technical school education.

Highest completed education: secondary/final exam, high school degree (15-64): $2.5 \%$ for Roma and $27.9 \%$ for the general population. ${ }^{665}$ Highest completed education (25-64), Upper secondary education - ISCED 3: 16\% for the Roma and $52 \%$ for the non-Roma ${ }^{666}$

[^100]Share of people with secondary and secondary technical school education (40-49): $1.8 \%$ for Roma and $30.7 \%$ for non-Roma. ${ }^{667}$

Here, we also have very different categorisation: in the UNDP survey this indicator refers to "Secondary voc/technical (3 or 4 yr )", "Secondary general (4 yr)", "Incomplete college or university" were summarized as Upper Secondary Education ISCED $3^{\prime \prime}$ whereas the first and third indicators only cover people with secondary final exam, high school degree.

Highest completed education: university (15-64): 0.7\% for Roma and 12.9\% for nonRoma ${ }^{668}$. Highest completed education (25-64), Post-secondary education - ISCED 4+: 0\% for Roma and 6\% for non-Roma ${ }^{669}$

Share of people with university degree (40-49): $1.8 \%$ for Roma and $17.6 \%$ for nonRoma. ${ }^{670}$
In the UNDP sample there are no Roma with university degrees so it can be assumed that it is due to the sampling of the survey (focusing on Roma households and thus probably excluding more integrated Roma living in integrated areas).

This is supported further in a 2011 survey by the FRA. This showed that Hungarian Roma have the highest levels of continued education past the age of 16 out of the 11 EU Member States covered. 67\% of female Roma and $85 \%$ of male Roma continued education past the age of $16^{671}$.

Other important indicators that only appear in one reference:
Unemployment rate (15-64): 50\% for Roma and $24 \%$ for non-Roma ${ }^{672}$
The high level of unemployment rate for the non-Roma is due to the sampling: focusing on the non-Roma population living close to the Roma, assumably poorer areas (national unemployment rate: $10.7 \%$ end of 2012).

Rate of people felt that they were negatively discriminated in the course of their efforts to find a job in the last 5 years (prior to 2009): $68 \%{ }^{673}$

Rate of people felt that they were negatively discriminated in the course of their efforts to find a job in the last 12 months (prior to 2009): $47 \%{ }^{674}$

These data, however, have been reported on more recently by the FRA (2013). Their findings showed $39 \%$ male Roma and $28 \%$ of female Roma unemployed. They also found that $32 \%$ of men and $23 \%$ of women claimed they had been discriminated against while looking for work in the last 5 years ${ }^{675}$.

People living in segregated housing conditions (not specified as Roma): 3\% ${ }^{676}$
Share of the population not having access to secure housing: 29\% for Roma and

[^101]8\% for non-Roma ${ }^{677}$
Share of the population not having access to improved water source: $30 \%$ for Roma and 8\% for non-Roma ${ }^{678}$

Share of the population not having access to improved sanitation (not having a toilet or bathroom inside the dwelling): 33\% for Roma and 12\% for non-Roma ${ }^{679}$

Access to electricity: 96\% for Roma and 99\% for non-Roma ${ }^{680}$ The indicator does not specify if electricity is in use or not (many poor households are cut off for not paying the bills).

EU material deprivation index. Severe material deprivation: 91\% for Roma and $65 \%$ for non-Roma ${ }^{681}$

Absolute poverty rate PPP\$ 4.30 expenditures based: 4\% for Roma and 0\% for non-Roma ${ }^{682}$.

Relative poverty rate (60\% equlized median income): 71\% for Roma and 33\% for non-Roma ${ }^{683}$.

## Bibliography

References: Methods, types of surveys and other sources used for the references
Ref 1: The sources is an assessment of the prevalence of HIV and selected bloodborne and sexually transmitted infections (HAV, HBV and HCB) among a convenience sample of 64 residents of Dzsumbuj ( $78 \%$ Roma and $22 \%$ non-Roma in the sample), a predominantly Roma (Gypsy) neighbourhood in Budapest. The survey was undertaken in 2004. The age group of people in the indicator is above 18 with an average of 32.8.

Ref 2: The survey carried out in Budapest among drug users breaking down the data by ethnicity (sample size 186). The survey was carried out in 2005-2006 and it looked at the number of infections among injecting drug users (IDU).

Ref 3: 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 limitations of the survey are that it was 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. 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).

[^102]Ref 4: The following sources are referred to in the Hungarian National Social Inclusion Strategy (Roma Strategy):

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Ref 5: The survey was done in 2008 and it compares the impacts of socio-economic status, cultural patterns and life styles of the Roma and non-Roma populations on PTB (preterm birth) and LBW (low birth weight) mothers assuming that the frequency of cases is higher in areas populated by more Roma. Sample: 382 PTB mothers from Szabolcs-Szatmár-Bereg county (one of the counties most populated by Roma).

Ref 6: Presentation by the vice-president of the National Health Council. References and reference dates are missing from the document, however, its importance lies in the fact that it was prepared and presented by a government official. Since we found that the progress report on the National Health Strategy does not contain data on the Roma population, this document needs to be taken into account as an important official government document.

Ref 7: Reference to Eduinvest, 2009. KSH-ELEF, 2009.
Ref 8: It is a survey of which the results were published in 2010. 225 Roma and 182 non-Roma adolescents were interviewed and the surveyed population was selected from areas (settlement segments) with 40-60\% of Roma from the whole county.

Ref 9: Two data sets were used for the UNDP/WB/EC/FRA survey. The FRA sample consists of 1,100 Roma households and approximately 500 non-Roma; in the UNDP/WB/EC sample approximately 750 Roma households and approximately 350 non-Roma households living in proximity were interviewed. For some indicators the two sets are merged and for some others only one is used.

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Ref 12: The indicators are from the 2002 representative survey with a sample of 12,643. Ethnic background was self-declared. 2.1\% (264 persons) declared themselves Roma (rate is identical to the share of Roma in the 2001 census).

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## Country Profile: Iceland


#### Abstract

Main Characteristics of the Roma in Iceland

Iceland has an ethnically homogenous citizenry and there is no Roma population on its territory according to the Council of Europe ${ }^{684}$.

In 2009 Statistics Iceland, for the first time, published statistics on the immigrant population in the country. According to their definition, an immigrant is a person born abroad with two foreign born parents and four foreign born grandparents. Second generation immigrants are defined as persons born in Iceland with two immigrant parents.

Iceland has experienced strong growth in immigrant population since 1996 when immigrants were 5,357 ( $1.8 \%$ of the total population) compared with $25,265(8 \%)$ in 2008. The share of immigrants in Iceland is now comparable to other Nordic countries.

Until the 1990s, the Icelandic population was very homogenous and a vast majority of immigrants came from the neighbouring Nordic countries. As late as 1996, 30\% of all immigrants were from one of those countries. In 2008 this share had dropped to $7 \%$. Now, a vast majority of immigrants come from Europe outside the Nordic countries ( $68 \%$ in 2008 compared to $40 \%$ in $1996)^{685}$.


[^103]
## Country Profile: Ireland

## Main Characteristics of the Roma in Ireland <br> Demography

The Roma population in Ireland can be individuated in two main broad categories:

- Irish Travellers, who are native to Ireland and have been present in the country since the $5^{\text {th }}$ century - this is predominantly a homogenous group;
- Central and Eastern European Roma, who are mainly recent migrants from the Oriental part of Europe, a less homogenous ethnic group who have entered the country mainly via Britain since the beginning of the $19^{\text {th }}$ century ${ }^{686}$.

Although the first ethnic group is an indigenous population, they have much in common with European Roma, Sinti and Gypsies, including their nomadic tradition, a tendency to live in extended families, a history of having to protect their identity from attempts to assimilate them into the majority population and problems of social exclusion and discrimination at all levels of society ${ }^{687}$.

Differences between the indigenous Roma in Ireland and Roma from other parts of Europe are instead mainly related to the activities carried out by the two groups. Prior to the Industrial era, Irish Travellers had been mainly craftsmen and traders whereas, Roma from Europe have traditionally undertaken seasonal work, such as farm labouring, before eventually moving back to England and to Continental Europe. This migration was of a temporary nature and included small numbers so went relatively unobserved. However, after the collapse of communism, the number of Roma who have arrived in Ireland seeking asylum has risen significantly. This is consistent with the overall increase in asylum seekers to Ireland that has occurred since the mid1990s. The first major arrival of Roma in Ireland was from Arad in North Eastern Romania in 1998. Most of this group were granted refugee status. A second impetus for Roma immigration to Ireland arose after the admittance of an additional 15 states - mainly Eastern European countries - to the European Union.

The total number of Irish Travellers recorded in April 2011 was 29,573, accounting for just over half of one percent ( $0.6 \%$ ) of the total population. The figure represents a $32 \%$ increase on $2006(22,435)^{688}$. Figures on Irish Travellers are gathered by the Irish Central Statistics Office, as one of the main variables collected for the Census is 'membership of the Traveller Community ${ }^{\prime 689}$.

In contrast, the number of Central and Eastern European Roma in Ireland is roughly estimated, because even if data are collected on ethnic origin this is based on selfperception of belonging to a specific ethnic group, therefore there is a certain level of

[^104]http://www.cso.ie/en/surveysandmethodology/population/censusofpopulation/censusofpopulation/
discretion. It is estimated that there are 2,500-3,000 Central and Eastern European Roma individuals in Ireland (2005) ${ }^{690}$ with the majority originating from Romania ${ }^{691}$, but also from the Czech Republic, Bulgaria, Hungary, the Former Yugoslavia Republic, Lithuania and Poland ${ }^{692}$.

An estimation by the Council of Europe, which does not make any differentiation among Irish Travellers and Central and Eastern European Roma, established that there are between 32,000 and 43,000 thousands Roma individuals ${ }^{693}$. Another study carried by the School of Public Health, Physiotherapy and Population Science (2010) ${ }^{694}$ estimates that the Traveller population amount to 40,129 people, but the origin of the population is unspecified.

As a consequence of the uncertainty in designing a precise demographic profile of Roma population in the country, both groups - Irish Traveller and Central and Eastern European Roma - will be considered, however when possible they are referred separately in this country report.

## Geographical distribution

The Roma population is spread across the country, mainly concentrated in urban areas. More than four out of five Irish Travellers live in cities, this compares with 62\% for the general population. Of the cities, Dublin (including suburbs) has by far the largest number of Irish Travellers with 5,168 persons. This followed by Galway (West) with 1,667 and Cork (South) with $1,050^{695}$. The majority of the Irish Travellers live in houses rented from local authorities ${ }^{696}$.

A different study illustrates a similar urban concentration of Central and Eastern European Roma, mainly residing in private rented houses in the Irish capital, in Monaghan (North of Ireland) and Carlow (South-East) ${ }^{697}$.

## Other Information (including highlights of data gaps)

In contrast to many EU Member States, Ireland collects data on the ethnicity of its population. Census data has included Irish Traveller as a separate ethnic group since 2000.

[^105]However in spite of this, quantitative data on both Travellers and Central and Eastern European Roma in Ireland is only partly reliable.

For instance the Census count reported a decline of the Roma population between 2002 and 2006 (from 23,681 to 22,435), but this was contradicted by figures from the annual count of families carried out by local authorities and submitted to the Department of the Environment, Heritage and Local Government. This reports show 28.2\% growth in the number of Traveller families from 2002 to 2007. In 2007 there were 8,099 Traveller families, compared with 6,289 families in $2002^{698}$. The most recent data report a total of 9,911 Traveller families (the number on Traveller families living in private house on their own resources are estimated).

Specific data on Central and Eastern European Roma are based on estimation, because even if the Irish Central Statistics Office collects data on ethnicity, this seems to be matched in relation to nationality. In other word, data on Roma are collected not only for those that are Roma/Travellers, but also Irish citizens. This difficulty in obtaining reasonably accurate figures is also compounded by the fact that many Roma do not reveal their ethnicity because of a fear of persecution ${ }^{699}$. Moreover there is a lack of data about their legal status in Ireland (i.e. asylum seekers and/or refugees). This uncertainty about Roma status impedes also the understanding of their entitlement in accessing public health services.

There is consensus about the fact that the Irish National Census undercounted the number of Irish Travellers ${ }^{700}$. For this reason the 'All Ireland Healthy Study' research team relied, first, upon data provided by the Roma NGO's network ${ }^{701}$ (the National Traveller Health Network) and, after, it verified them against data from the Department of the Environment, Heritage and Local Government. The mapping exercise resulted in a Traveller family's population of approximately 9,548 households, which were multiplied for four members in each family, for a total of 40,129 individuals.

From the above it descends that estimation based on the number of Roma family members and households, rather than mere counting it is more appropriate to picture the demographic profile of Roma ${ }^{702}$. This is due to the local 'antenna' gathering data being closer to the Roma community are better able to detect demographic changes in this population.

With regards to health data collection, there are no official records that focus on Roma population in Ireland. Although studies from the mid-1980s raised considerable concern about the health status and inequalities of the Traveller community ${ }^{703}$, there is still a lack of systematic collection on Roma health. In fact, the Department of Health publishes health statistics ${ }^{704}$ and Survey of Lifestyle, Attitudes and Nutrition in Ireland (SLAN) ${ }^{705}$, but data by ethnicity group are of very poor quality.

[^106]Nevertheless, the Irish government has shown a considerable level of commitment regarding Roma health conditions. In particular, The Primary Health Care for Travellers Project ${ }^{706}$ has established a network of 40 territorial care points able to interpret Roma health needs and produce related quantitative and qualitative statistics. One of the outcomes of this project has been the elaboration of the study 'All Ireland Travel Health Study' which gathers, systematised and enriches recent studies on Roma health ${ }^{707}$, offering a detailed overview on this topic, for both Republic of Ireland and Northern Ireland regarding:

- general demographic information (composition of population age, sex, marital status)
- mortality (cases of death and also infant mortality)
- adult and children health conditions (self-assessment health status and life style i.e. smoking, use of alcohol and drugs habits)
- access (and related frequency) to health services
- housing, educational and employment conditions.

The analysis of the existing systems and studies on Roma health in Ireland shows a high level of commitment of the national, regional and local institutions regarding this topic. Both the Census system and the 'All Ireland Traveller Health Study' represent a good starting point to elaborate a feasible and innovative model to be extended to other European countries when facing Roma Health issues. Not all the EU countries gathered data on the base of ethnicity, but the Irish system based on community care networks seems to be a promising model to obtain data through qualitative and quantitative methods. Moreover the attempt to compare and triangulate the results obtained with other studies regarding the sedentary population seem to pave the way for further study in this field.

The research nevertheless has some limitations. First of all it is unclear whether the Central and Eastern European Roma population is included in the census of the families. Second, the assessment about the health of the individuals considered is based on self-assessment and is only partly contrasted with some other information (i.e. hospital and medical institutions' records), making the results partly biased. Third, not all of the variables studied are compared with the majority of the sedentary population, therefore is not always possible to ascertain in relative term the health status of nomadic populations. Finally and more importantly the 'All Ireland Traveller Health Study' is an ad hoc study, whose repetition and sustainability along the time has not been granted.

[^107]
## Mortality and Life Expectancy

Evidence on life expectancy among Roma individuals show that they are estimated to live less than the general population.
'All Ireland Travel Health Study' reports that '[...] compared to the general population, Travellers are dying younger. In general population 59.9\% of deaths occur in those aged 75 years or over. In the traveller population only $17.6 \%$ of deaths occur above that age. For deaths in those aged 85+ the figures are $28.8 \%$ in the general population and $5.0 \%$ in Travellers ${ }^{\prime 708}$. This is also because in terms of age cohorts Traveller population is younger, however the excess of mortality seems to be an endemic problem across all ages. There is discrepancy related to gender, indeed according to the 'All Ireland Travel Health Study' the mortality rate is higher among men ( $4.7 \%$ higher than the general population) than women $(2.3 \%$ higher than the general population), while Clark and Greenfield (2006) report that Irish Traveller women and men are estimated to live 12 years less and 10 years less respectively than the sedentary population.

In a same vein the study on 'The situation of Roma in the EU - Health' carried out by the Fundamental Rights Agency (FRA) ${ }^{709}$ states that Irish Travellers have a lower average life expectancy than the majority of the population. Further, in 1999 the differential in the longitudinal rates in sudden infant deaths was 12 times greater for travellers compared to the settled population. ${ }^{710}$ The Irish Traveller infant mortality is currently one of the highest in Europe. ${ }^{711}$

## Prevalence of Major Infectious Diseases

The study team has found no quantification of this indicator, but anecdotal data and evidence include:

According to FRA study ${ }^{712}$ public health epidemiology for the Roma population remains scant, with indications of higher rates of diabetes mellitus, hyperlipidaemia, coronary artery disease and obesity.
There are higher levels of nutrition-related illnesses than in majority populations.

## Healthy Life Styles and Related Behaviours

Data on life style and related behaviour are mainly based on individual's selfassessment.

According to the Census 2011, Travellers declare in absolute terms a good level of satisfaction with their health $\left(86.6 \%\right.$ of the population considered) ${ }^{713}$, however when

[^108]compared with the majority of the population $27 \%$ of Roma individuals aged between 30 and 49 years old indicate bad or very bad health conditions, a percentage far higher in comparison to $7 \%$ of the majority of the population. This difference increases when considering older segments of the population. Respectively 49\% of Travellers between 50 and 69 years report bad or very bad health conditions, $31 \%$ more than sedentary population of the same age. Similarly the 'All Ireland Travel Health Study' confirms that among the 4,141 individuals interviewed the level of health satisfaction declined when looking at 65+ individuals. However in terms of a general level of satisfaction with their health, Travellers in the All Ireland Travel Health Study score their health as better than Travellers included in the Survey of Lifestyle, Attitudes and Nutrition (SLAN) ${ }^{714}$. The two studies therefore report contrasting results. Regarding the incidence of specific illnesses, the Traveller population appear to have a greater burden of chronic diseases than the general population (as illustrated in the related section below).

Concerning smoking, drinking alcohol and use of drugs, small-scale qualitative studies based on interviews and focus groups show that Roma population are more likely to present these form of risk behaviours. Even when young people have a similar behaviour in consuming drugs in comparison to the 'settled' of the same age, the former are less aware of drug side effects and the related health service available ${ }^{715}$.

The 'All Ireland Travel Health Study' states that the half of the Traveller population was current smokers. Total daily cigarette consumption was high, with a majority of smokers, reporting smoking 16 or more cigarettes per day ${ }^{716}$. This indicates a higher consumption of tobacco than in the majority population.

In relation to illicit drugs, the majority of respondents (65.45\%) considered illicit drugs to be a problem in their community and this was a consistent pattern for both men and women and across age groups.

In conclusion, a more consistent and detailed collection of data to this regard is recommended with a higher level of emphasis on Central and Eastern European Roma.

Access and Use of Health Services and Prevention Programmes
The main document upon which drafting this section is the 'All Ireland Travel Health Study'.

According to the questionnaire targeting 2,373 respondents the main sources of

[^109]information regarding health are the General Practitioners (GP) (90\%) and family and friends (33.8\%). Comparisons with other similar national research ${ }^{717}$ shows that the majority of the population are four times more likely to access information about their health using the internet in comparison with Roma population, whilst the opportunity to access services is perceived as the same as everyone else in both 'All Ireland Travel Health Study' and similar study surveying the majority of the population, about 75\% of the respondents.

The Traveller community have a lower level of satisfaction with the services received and less trust in medical personnel ( $37 \%$ against $80 \%$ ) than the comparable majority population.

According to this study, the Traveller population makes greater use of Accident and Emergency (A\&E) services, this is consistent with the fact that they have higher rates of non-accidental injury and thus a greater need of A\&E services.

The above mentioned study from FRA ${ }^{718}$ confirms that there is a high utilisation rate of A\&E services and paediatrics and obstetrics. On the contrary 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 sedentary population $(2.8 \%)^{719}$. The reason given of paying for the care.

The FRA study confirms a lower level of participation in prevention programmes. For instance $96 \%$ of the general population is immunised against Rubella, whereas among Roma the percentage is lower: $89 \%^{720}$.

## Prevalence of Major Chronic Diseases

While data on infectious diseases are not available, more sources are available for chronic diseases, however specific explanations are not always provided to understand the causes for these illnesses.

The Census 2011 reports Irish Travellers had higher rates of disability than the general population. In 2011, 17.5\% of Irish Travellers had one or more disabilities compared with $13.0 \%$ for the State as a whole ${ }^{721}$.

The traveller population is also at much greater risk from Depression. Much of this may be linked to migrational issues. The depression rate among travellers was reportedly as high as $41 \% .{ }^{722}$

Amongst Irish Travellers, the most common type of disability was 'difficulty with 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\%).

This is confirmed by 'All Ireland Travel Health Study': '[...] regarding the incidence of specific illnesses, the Traveller group appear to have a greater burden of chronic diseases than the general population, with conditions such as back conditions,

[^110]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 SLAN population ${ }^{1723}$.

Finally, the study on 'The situation of Roma in the EU - Health' confirms these data, explaining that the Traveller population is affected by nutrition related illnesses, such as: higher rates of diabetes mellitus, hyperlipidaemia, coronary artery disease and obesity. According to the study analysed Irish Roma consume more fried food ${ }^{724}$.

Health Factors Related to the Role of Women in the Roma community
Women Traveller health conditions in Ireland are mainly assessed with specific regard to maternity and the associated risks.

Census figures report that among 40-49 year olds (women who have typically completed their fertility) those with no children made up just $11.6 \%$ of women amongst Irish Travellers compared with $18.7 \%$ of women generally. $26.9 \%$ of Irish Traveller women had given birth to 5 or more children in contrast to just $2.6 \%$ of women overall. Furthermore, just more than one in 8 (13.0\%) Irish Traveller women had given birth to 7 or more children, compared with $0.4 \%$ of women generally.

In general there is a higher level of spontaneous delivery among pregnant Traveller women (37\%), then the matched groups. In 2008 a higher level of infants mortality was also registered (+ 10.8) of the average of infant mortality. Notably artificial feeding is higher among Irish Roma women (96\%) than the matched population (57\%) ${ }^{725}$.

As a concluding remark it has been reported that generally a small male network of family members accompany Roma women during their maternity hospital appointments and visits. Roma men in these instances translate for women, raising important issues in relation to translation abilities of medical terms, complications and procedures. Translation services are usually refused. This is a relevant issue in relation to bereavement and counselling in cases of infant mortality and access to culturally sensitive support ${ }^{726}$.

## Environmental and other Socio-Economic Factors

The national Census provides abundant data regarding the socio economic conditions of Roma population in Ireland, as a result this section is drafted mainly on the information published in 2011 by the Irish Central Statistics Office in the Profile n.7: Religion, Ethnicity and Irish Travellers. This brief overview contains the most updated data and allows for comparisons with the majority of the population.

Further information is retrieved from: the RAXEN study on Roma housing conditions, the 'All Ireland Travel Health Study' and the Fundamental Rights Agency study. It must be specified that there is overlap among these studies and this section is built only on the most up to date and comparable data.

[^111]
## - Housing

The RAXEN Study on the 'Housing Conditions of Roma and Travellers' (2009) reports that in 2007, of the 8,099 Traveller families accommodated across the state, a little less than a quarter (22\%) were living in Traveller-specific accommodation (halting sites or group housing). Almost half (45\%) were accommodated in non-Travellerspecific housing (i.e. standard social rented, voluntary and co-operative housing, etc.), and a third (33\%) were in other accommodation types (i.e. private rented, unauthorised sites) ${ }^{727}$. In fact the Central Statistics Office reports that between 2006 and 2011 the percentage of Irish Traveller households residing in caravans or mobile/temporary structures halved from $24.7 \%$ to $12.3 \%$, possibly confirming an increasing use of standard accommodation with central heating on the rise (+17\%). However, the rate of home ownership within Roma households is lower than the general population with 1 in 5 (20.2\%) households owning their home compared with $69.7 \%$ for the general population. Moreover, the average number of rooms available for Irish Traveller is inferior to that of the general population (4.3 against 5.5.) and the percentage of households with only one room was higher in the Roma population, in comparison with the matching population (4.5\% against 1.5\%). In general it can be said that housing conditions of Irish Travellers have been improving, however for those households living in mobile and temporary accommodations the sewerage and water supplies are still unsatisfactory (one in five household had no piped water source Irish Traveller and one in three did not have a sewerage facilities) ${ }^{728}$.

## - Education

According to the 'All Ireland Traveller Health Study' (2010) the level of literacy among Roma based on self-assessment is far lower than the rest of the population.

Of the 24,243 Roma considered by the study 6,108 completed primary education, 1,635 reached secondary education and only 942 reached tertiary education. These data are confirmed by the Census 2011, which states that only 1\% of the Roma population considered completed third/advanced studies, whereas within the general population instead $30.7 \%$ completed advanced studies ${ }^{729}$.

Researchers observed that the lack of literacy is not only a factor that might prevent Roma obtaining jobs and then improve their socio economic situation in the long term, but it is also a factor that might hamper access to health services or the understanding of medical prescriptions, in the short and medium term. However, the situation has been improving. The percentage of Irish Travellers who completed upper secondary education more than doubled from 3.6 per cent to 8.2 per cent between 2002 and 2011. Possible explanations of these positive results can be ascribed to the country strategy for Roma education, which focuses on individual needs independently from the ethnicity.

## - Employment

In 2011 the level of unemployment among Roma was 84.3\%. Out of a total labour force of $9,973,86.6 \%$ of the 5,829 males were unemployed while $81.2 \%$ of the 4,144 women were without work. The labour force participation rate among Irish Travellers was $57.3 \%$ compared with $61.9 \%$ for the general population ${ }^{730}$.

[^112]Moreover, the percentage of Roma women looking after home and family was almost double the rate of the general population (32.7\% against 17.5\%). Similarly, the rate of Irish Travellers aged 15 and over unable to work due to permanent sickness or disability was nearly twice the rate of the general population (17.5\% against 4.4\%).

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## Country Profile: Italy

| Main Characteristics of the Roma in Italy |
| :--- |
| Demography |
| The Council of Europe Roma and Travellers Division estimates ${ }^{731}$ that 140,000 Roma |
| live in Italy as an average amount corresponding to $0.23 \%$ of the total population, |
| ranging between 110,000 and 170,000 . The majority of Roma, about $50-60 \%$, are |
| Italian citizens while the remaining 40-50\% is made up of foreign citizens who arrived |
| in Italy within successive flows. According to the European Roma Rights Centrer |
| 2532 are from other EU member states, chiefly Romania and Bulgaria; a percentage |
| $25 \%$ are |
| that translates to around 35,000 -Roma with EU citizenship. However, the European |
| Commission Against Racism and Intolerance estimates a total of 50,000 Roma mainly |
| from Romania. |

## Geographical distribution

Comprehensive and accurate data pertaining to the geographical distribution of the Roma are not available. In fact, data on regional and municipal distribution are partial and fragmented while also tending to be lower than the overall national estimate. Yet, most of the presence is recorded in: Rome with 15,000 to 18,000 people ${ }^{733}$; Lombardy with 13,000 people ${ }^{734}$; Campania and Calabria, with 9,000 people each ${ }^{735}$; Piedmont with 6,500 people ${ }^{736}$. Lastly, in 2008 the Ministry of Interior carried out a Roma census in Milan (Lombardy), Rome (Lazio) and Napoli (Campania). However, since many Roma had removed themselves before the census took place, data considerably underestimate Roma presence ${ }^{737}$.

## Other Information (including highlights of data gaps)

Generally, there is a dearth of data regarding Roma health condition and the few available data mainly derive from small sample epidemiological surveys. Particularly, there are no available data inherent to: maternal mortality rate, mortality aggregate, tuberculosis, MDRTB, hepatitis, diabetes, cancer, and rates of (cervical and breast) cancer screening.

In order to improve data comparability, it would be advisable to carry out further studies that compared similar groups of Roma (Italian, Migrant, EU Migrant) living in similar contexts (authorised and unauthorised settlements, caravans, apartments, etc.) and also holding constant another aspect such as the number of years that the

[^113]target group has resided in the country. On the other hand, the absence of such studies, in a comprehensive fashion, and the reliance on the ones available, are key in helping define the above mentioned variables as conducive to very different health prospects.

## Mortality and Life Expectancy

Data pertaining to infant mortality rates are scarce, outdated and somewhat inconsistent. In addition, there are no available data inherent to maternal mortality rate and mortality aggregate. According to a Save the Children report (2008) ${ }^{738}$, that presents data from 1992-1995 in the Lazio region, the rate of infant mortality at birth for Roma equalled $6,5 / 1000$ as opposed to $3,5 / 1000$ for Italians, while infant mortality within the first week equalled $15,3 / 1000$ for the Roma, as opposed to $4,4 / 1000$ for Italians. The Presidency of the Council of Ministers indicates the same data used by Save the Children with regards to infant mortality within the first week. In addition, it underlines that the main causes of death are infections and hypoxia. The European Monitoring Centre on Racism and Xenophobia ${ }^{739}$ estimates that in 1991 the infant mortality rate for the Roma in Italy was almost three times the rate of the wider population.

Data on life expectancy are even more inconsistent and scarce than mortality-related indicators. Further, there are not any data for life expectancy rates at age 45 and at age 65. According to CEPS ${ }^{740}$, Roma life expectancy is 20 years lower than the national average. However, according to one study ${ }^{741}$ Roma life expectancy is about 40-45 years. The two reports contradict each other as life expectancy for the wider population in Italy is particularly high: 78.8 for males and 84.1 for females. Also, there is no indication regarding how the data were obtained or calculated.

Prevalence of Major Infectious Diseases
There is a dearth of data regarding prevalence of major infectious diseases. In particular, there are no data related to tuberculosis, MDRTB and hepatitis. The scientific literature focuses on describing outbreaks of measles cases and the obstacles in meeting the World Health Organisation's (WHO) target of eradicating measles. In doing so, a common denominator of the reviewed studies pertains to four aspects: a) low vaccine coverage; b) nosocomial transmission; c) age distribution differences between the Roma and the wider Italian population; d) similar methodologies - data were obtained from several sources: the routine infectious diseases surveillance system, field epidemiological investigations, and molecular genotyping of virus by the national reference laboratory

Motta and Geraci ${ }^{742}$ describe a project promoted by Caritas and funded by the Ministry of Health which extended vaccine coverage, firstly in Rome and then in five other cities. Data from Rome show that the coverage before the project totalled a mere $60 \%$ of the local Roma population. During the vaccination campaign, a total of 10,529

[^114]vaccine doses were distributed. The strategy adopted was pulse vaccination either actively administered to the Roma in 24 camps or by the means of guidance to lowbarrier public services in 8 camps. As a result of the campaign the coverage was extended to $80 \%$ of the local population.

In 2010 two measles outbreaks are described ${ }^{743}$ in the Lazio region between 2006 and 2007 and underline the importance of pockets of low vaccine coverage in hard to reach populations (HRP), particularly Roma and Sinti, in sustaining the infection. However, the authors state that the subsequent spread of measles cases was facilitated by non-immunised health staff: to this regard, tackling nosocomial transmission is deemed a vital part of the overall strategy aiming at the eradication of measles. Roma affected by measles were 102 of a total of 409 cases. The age distribution of measles cases was different among the Roma/Sinti population (median age 2 years) with respect to the rest of the population (median age 15 years). Seventy\% (72/102) of Roma/Sinti cases occurred in children aged 0-4 years and over $90 \%(93 / 102)$ were aged below 15 years. The age distribution of cases in the Italian ethnic population was more even among all age groups. Only $23 \%$ of cases (80/347) were aged 0-4 years, and less than $50 \%$ (170/347) occurred in children below 15 years of age.

In 2007 three clusters of measles cases that occurred between June and September 2006 in three different Italian regions are described ${ }^{744}$ : the Autonomous Province of Bolzano-South Tyrol (17 cases); Lazio (161 cases); and the island of Sardinia (9 cases). Again, the authors stress the need of achieving high vaccine coverage in the general population and in the hard to reach population as well as the full immunisation of healthcare personnel.

Roma affected by measles were 13 of a total of 17 cases in South Tyrol. The median age of those infected in this outbreak was 13 years (range 2-29 years); 53\% of cases ( $9 / 17$ cases) were below 15 years of age. Overall, 10 of 17 cases, including 6 of the 13 Roma/Sinti cases, were serologically confirmed, and the remaining 7 were epidemiologically linked. Measles virus genotype D4 was isolated from 3 cases.

Roma affected by measles were 74 on a total of 161 cases in Lazio (the outbreak analysis corresponds to the first of the two outbreaks investigated in 2010745). Overall, children aged 0-4 years were the most affected age group, representing 46\% (74/161 cases) of all reported cases. However, the age distribution of measles cases differed between the Roma/Sinti and the general population. In fact, while $68 \%(50 / 74)$ of Roma/Sinti cases occurred in children aged $0-4$ years and over $90 \%(68 / 74)$ were aged below 15 years; in the general population only $52 \%$ of cases (44/84) occurred in children below 15 years of age. The study underlines that none of the Roma/Sinti cases had previously been vaccinated against measles. Additionally, five of the cases (5.7\%) from the general population had received only one dose of the vaccine.

[^115]The number of Roma cases in Sardinia was 9, representing 100\% of the outbreak. The authors note that four of the affected children had recently travelled to Rome, thus making it most plausible to establish an epidemiological link with the Rome outbreak

There is a report about an outbreak of measles in the Pisa territory in 2008 ${ }^{746}$. In total, 44 cases are investigated, 34 of which refer to the Roma population living in camps. Out of the 34 Roma patients, 20 were males and 14 females. The disaggregation by nationality points to 27 Macedonians and 7 Romanians. The age ranges from 5 months to 16.3 years. In particular, 30 cases ( $88.23 \%$ ) referred to children younger than 8. No Roma patient had been previously vaccinated.

A report by the Ministry of Interior (2006) ${ }^{747}$ mentions targets related to reducing the incidence of HIV and other STDs as well as tuberculosis. However, no measurable target is indicated. Further, no incidence of HIV, serving as a benchmark, is provided.

Healthy Life Styles and Related Behaviours
Data inherent to healthy life styles are particularly scarce and outdated. Five studies deal with at least one of these aspects, albeit in a residual way. Yet, they offer a glance on this domain of Roma health and clear evidence of the greater prevalence of underweight Roma infants as compared with Italian ones. More specifically, available data relate to weight at birth (3 studies); addiction, alcohol and drug abuse (4 studies); and, finally, body mass index (1 study).

Monasta et al ${ }^{748}$ recorded 14 children whose weight at birth was $<2.5$ kilograms corresponding to $17 \%$ of the sample (14/147). The latter consisted of Khorakhané Roma (from Kosovo and Macedonia) who were interviewed, between December 2001 and March 2002, in five cities: Florence (Tuscany); Bergamo and Brescia (Lombardy); Venice (Veneto) and Bolzano (Trentino Alto Adige). Similarly, data by the Epidemiological Observatory of Lazio in the period 1999-2001, found 18.4\% underweight Roma children. According to the same study, the percentage of Italian children below 2.5 kilograms at birth was, at the time, $5.7 \%$. Also, Save the Children ${ }^{749}$ cites UNICEF, data dating back to 2002 that reveal an incidence of underweight birth among Roma of $10 \%$ as opposed to $6 \%$ among the wider population. In fact, the data by Save the Children show a lower incidence than the previous two. However, from the combined analysis of the three studies, it could be stated that Roma children are almost two- to-three times more likely to be underweight at birth than the wider population. Furthermore, this evidence is consistent with the vast array of risk factors Roma women are exposed to during their pregnancy, namely: severe immaterial and housing deprivation, young age of first pregnancy, lower access to health care, especially ante-natal screening, infections, etc.

[^116]Nosotti et al ${ }^{750}$ (2004) analysed data related to 2,483 medical examinations, between 1996 and 2002, of Roma belonging to six different communities based in Rome. The authors mention an increasing trend regarding alcohol and illicit drugs abuse. Also, they record a total of 300 opioid addicted and 400 cocaine/crack addicted. Recent report (2009-2010) data ${ }^{751}$ concerning 1,142 EU Roma mainly from Romania who were visited by the Naga mobile unit. Data regarding healthy lifestyles, however, are available for a limited sample of 665 Roma. In particular, there were 372 smokers, which translate to a percentage of $56 \%$, and 63 heavy smokers or $17 \%$. The authors emphasise that the distribution of smokers was similar between men and women ( $59 \%$ and $53 \%$ respectively); however, men tended to be heavy smokers more than women ( $22 \%$ and $12 \%$ respectively). By contrast, There are ${ }^{752}$ disaggregated results of a sample constituted by 401 migrants, including 70 Roma. Data refer to the period 2000-2002. The proportion of smokers was highest in male Roma, yet only $3.5 \%$ of Roma were smokers and 21.8 consumed alcohol. All women reported that they had never smoked or consumed alcohol. It has also been pointed out that the exposure to risk factors such as smoking, alcohol consumption, coffee and unhealthy food (high content in fat and salt) were all co-factors for high rates of hypertension.

Concerning body mass index, the only study available is on a total of 70 Roma ${ }^{753}$. With regards to women, $15.4 \%$ had a BMI lower than 18.5; $33.3 \%$ had a BMI between 25 and 29.9; and $12.8 \%$ had a BMI higher than 30 . No man had a BMI lower than 1.5; $35.5 \%$ had a BMI between 25 and 29.9; and $32.3 \%$ had a BMI higher than 30. However, there appear to be missing data. Notwithstanding this, the authors note that among male migrants, only the Roma had a mean BMI value significantly greater than that of native Italians. Male Roma BMI value was 27.70 ( 25.2 for Italians and 24.6 for all immigrant groups). Conversely, the mean BMI for each female ethnic group (Roma excepted) was significantly higher than that of native female Italians while female Roma BMI value was 24.5 (23.9 for Italians and 25.9 for all immigrant groups).

Access and Use of Health Services and Prevention Programmes
There is a relative wealth of information related to access and use of health services. By and large, the literature points to both legal and non-legal barriers with regards to access to health care, and relies mainly on site visits in settlements to gather quantitative data. Also, the literature focuses on services aiming at improving accessibility.

Concerning the legislative context, in 1978, Italy adopted a Beveridge-type health care system that favours universal health coverage. However, access still depends largely on nationality and status. Italians, regular third-country nationals and employed EU nationals and their relatives have the right to register to the National Health Service (Servizio Sanitario Nazionale). By contrast, irregular third-country nationals may only receive emergency treatments across the national territory by the means of a special card called Tesserino STP (Straniero Temporaneamente Presente). EU nationals who

[^117]either are not in possession of medical insurance from their country of origin (Romania, Bulgaria), thus are not in possession of the TEAM card (Tessera Europea Assicurazione Malattia), or are not regularly employed in Italy, find themselves in a position of vulnerability since they can no longer access the services of STP. However, albeit heterogeneously, regions have provided for a specific card, called ENI (Europeo non iscritto) which puts them on a par with STP holders. It ought to be noted, that, since EU Roma (from Romania and Bulgaria) face difficulties in being employed, their situation is of particular vulnerability in those regions where the ENI card has not been put in place, such as Lombardy.

Broadly speaking, non-legal barriers pertain to: language issues; bureaucracy-administrative-organisational issues; and different cultural habits. Furthermore, the EU Commission (2008) recognises that Roma women use healthcare services less than the rest of the population, because medical treatments may conflict with their customs, or due to discrimination by healthcare professionals. Also, lack of information at the individual level hinders their overall access.

Four main studies have recorded Roma access to health services, such as: registration to the SSN or possession of the STP, TEAM and ENI cards.

A study in $2008^{754}$ conducted field research over a two week period in Roma settlements (EU origin unspecified). In fact, not all the people were of Roma ethnicity but $75.63 \%$ (1494/1970). In total, $22 \%$ were registered to the National Health Service (SSN), $50 \%$ were not registered to the SSN but held the STP card. The remaining persons did not have any access to health care.

A 2009 study ${ }^{755}$ records access to health services in various Roma camps. In the Quaracchi. Osmannoro and Longinotti camps (Florence), of a total of 65 Romanian Roma, 1 was registered to the SNN, 20 had the STP card, and 43 did not have any kind of access to health service (data is missing for 1 interviewee). In the Villaggio 1 (former Poderaccio camp) and Villaggio 2 (former Masini camp), in Florence, out of a total of 101 non-EU Roma, 95 were registered to the SNN while 6 were in possession of the STP card. In the Favorita camp (Palermo), out of a total of 118 non-EU Roma, 60 were registered to the SNN while 33 were in possession of the STP card and 25 did not have any kind of access to health services. In the Messina-based S. Ranieri Camp, out of a total of 70 (mainly) non-EU Roma 38 were registered to the SNN while 30 were in possession of the STP card and 2 did not have any kind of access to health services. While mainly from Montenegro and Kosovo, there were also 7 Italian Roma: all of them were registered to the SNN. In the Maregrosso Camp (Messina), out of a total of 44 EU Roma no one was registered to the SNN, 24 were in possession of the ENI card and 20 did not have any kind of access to health services. According to these data, it seems that the situation of EU Roma is the least optimal. The same trend is confirmed in Trento, Milan and Rome: low access to health services, excluding emergency ones (STP or ENI), and even lower access for the EU Roma from Romania.

Using data collected by the mobile unit of Naga, a voluntary association based in Milan, during two years of activity (2009-2010) found that 850 EU Roma from

[^118]Romania had no access to any health service (SNN, TEAM; ENI; STP) out of a total sample of $907^{756}$.

By contrast, a FRA/UNDP survey (2012) ${ }^{757}$ found access to health care as high as $80 \%$. The proportion, which is similar to that related to Italians (living in the same neighbourhood), seems very high. However, the FRA/UNDP survey includes Roma not living in settlements. Therefore, the data reinforces, instead of undermining, the view that spatial segregation is key in limiting access to health care. Also, it should be noted that Roma living in settlements, especially unauthorised ones, may face higher obstacles in obtaining a job or accessing education, thus reinforcing the vicious cycle of exclusion.

In view of both legal and non-legal barriers, Caritas has developed considerable experience in increasing vaccine coverage and facilitating access to health services by the means of a holistic and tailor-made approach. A holistic approach includes all the aspects of discrimination, namely: health access, housing, employment, and education. A tailor made approach is one that can be synthetized as "explicit but not exclusive targeting". More specifcally, the approach is informed by some methodological milestones, such as: creating a network of public and private sector intervention; multiprofessional approach (physician, anthropologist, psychologist, cultural mediator/facilitator) including a Roma component; empowerment of the Roma community; bridging the gulf of mistrust; guaranteeing health services in the camps, in the short run, while aiming to normalize the access to public health services in the medium run ${ }^{758}$.

## Prevalence of Major Chronic Diseases

Data on prevalence of major chronic diseases are particularly scarce as there is no data regarding diabetes and cancer. However, there are data regarding hypertension and asthma.

Respiratory difficulties and asthma prevalence in children aged 0-5 in the 5 Roma settlements were found in a 2004 study ${ }^{759}$. $23 \%$ 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 4 times in the previous 12 months). Asthma period prevalence equalled $17 \%$.

Monasta et al ${ }^{760}$ single out the risk factors associated with diarrhoea, cough and respiratory difficulties. Risk factors are divided into two main categories: camp-related and household-related ones. The former category includes: presence of water stagnating because of ruined paving or inappropriate drainage systems, size of the

[^119]camp (number of people and square metres), camp overcrowding (less than 25 m 2 per person), presence of rats in the camp, and prolonged stay in the camp. The latter category includes: poor condition of housing, overcrowding (more than 2.5 people per room), no indoor access to sanitation, use of wood-burning stoves.

With regards to hypertension, one study ${ }^{761}$ found $33.3 \%$ hypertensive male subjects and $23.5 \%$ female subjects. Further, the main waist circumference (WC) for Roma male was 95.1 and for Roma female 80.5. As the study analysed 401 migrants, including 70 Roma, among men, the highest prevalence of cardiovascular disease (CVD) risk associated with hypertension in overweight/obese subjects with high WC values (> 102 cm) was found in Roma. Similarly, among women, the highest prevalence of CVD risk associated with hypertension in subjects with WC $>88 \mathrm{~cm}$ was found in Roma. The authors warn, however, that a limitation of the study might be the extension to different ethnic groups of the WC cut-off points associated with obesity in Caucasians.

Lastly, GrIS (2008) found 384 hypertensive subjects (19.5\% of the sample) aged 060. Disaggregating by age range, a percentage as high as $77 \%$ was found vis-à-vis people older than 35.

## Health Factors Related to the Role of Women in the Roma Community

There is a paucity of data pertaining to health factors related to women. In particular, there is no information for rates of (cervical and breast) cancer screening. Available data includes: average age of first pregnancy, average number of children, number of abortions, and use of contraception. However, data are not comprehensive but, rather, refer to small samples.

It was reported in $2009^{762}$ that, in the Florence-based Quaracchi. Osmannoro and Longinotti camps, there is a general mistrust by Roma women in undergoing antenatal visits: this situation depends on cultural barriers between the Roma and the wider population; and also depends on the fact that sometimes they have been asked to pay. The study also emphasizes how abortion is used as a method of contraception; further, the average age of the first pregnancy is 16 , the average number of abortions is 1.6 and the average number of children is 2.8 .

Another source reports the average number of children is 2.8 for women older than 15 (similarly to the abovementioned study) ${ }^{763}$. Disaggregating by age range, the average is 1.2 for women aged between 15 and 25 and 3.6 for women aged between 36 and 46. It should be noted that according to ISTAT (2013) the average number of children for an Italian woman is 1.4. Further, $32 \%(146 / 453)$ of women had undergone at least one abortion. Only $7.8 \%$ of women made use of contraception while the use of prophylactics seemed to be rare and aiming at avoiding STDs.

[^120]In 2008 Save the Children ${ }^{764}$ recorded 15 women out of 76 who used contraception: 8 used spiral, 6 pill and 1 prophylactic. The percentage of women who did not undergo any ante-natal screening equalled $18 \%(14 / 76)$ as opposed to $0.5 \%$ of Italian women. More specifically, 46 underwent ante-natal ultra-sound scan, 53 ante-natal gynaecological visit, 48 ante-natal blood exam and 37 all three ante-natal examination.

The Ministry of Interior ${ }^{765}$ mentions the target linked to the improvement of the assistance to pregnant women and the reduction of abortion. However, no specific, measurable, target is indicated.

In addition the self-declared health status of Roma women was shown to be much worse than the non-Roma population. Women aged 50 and over who described their health status as 'bad' or 'very bad' was $67 \%$ in the Roma population compared to only $9 \%$ in the non-Roma population. This is the largest difference of this kind shown by Member States included in this FRA report ${ }^{766}$.

## Environmental and other Socio-Economic Factors

There is a wealth of information regarding this section. This is due the fact that the topic as defined is quite comprehensive - dealing with housing, employment, and education, and the fact that these areas are the most studied. The scope and objective of the present study necessarily demands to limit our analysis to few key reports. It is important to note that the main reason for the interest in these areas is due to the understanding that housing, employment and education impact deeply on the overall situation of Roma. To put it concisely, housing deprivation directly influences the overall health status of Roma, education is paramount in fostering integration and enhancing chances of upward social mobility that ameliorates the health status, and employment is linked to the resources available to oneself as well as to access to social rights in case of migrant Roma. In all three domains, Roma score considerably lower than the wider population.

With regards to housing, Tarnovschi et al ${ }^{767}$ reports that $70 \%$ of the sampled EU Roma (mainly from Romania) respondents lived in unstable conditions: 43.4\% in shanty towns and caves, $18.7 \%$ in temporary barracks, $3.2 \%$ in mobile homes, $2.4 \%$ in caravans, $2.2 \%$ in spaces designed for other purposes other than housing. Only $14.6 \%$ lived in apartments and $11 \%$ lived in a house or part of a house. By contrast, a quarter of Italian Roma families lived in single-family houses, $20 \%$ lived in condominiums, while nearly half of respondents (48.5\%) lived in unstable conditions. More generally, it is estimated that about a third of the Roma population in Italy lives in either authorised or unauthorised camps on the peripheries of large cities (ECRI, 2012). The existing literature also points to the fact that there are substantial differences among the various Roma groups living in Italy. As a result, Romanian and Bulgarian Roma face the direst housing conditions as they live predominantly in shacks in unauthorised settlements. Results of an FRA survey also showed that the difference in housing conditions between Roma and non-Roma was one of the largest

[^121]in the EU Member States represented (35\%). This report states that 36\% of Roma households had no piped water or no sewage or no electricity ${ }^{768}$.

Focusing on employment, it has been ${ }^{769}$ found that only $45.8 \%$ male Roma and $46.9 \%$ female Roma were employed. According to FRA/UNDP (2011) ${ }^{770}$, household members aged 20-64 in paid employment equalled 10\%. Data, however, do not include selfemployment. Additionally, around $25 \%$ of the Roma surveyed said they were selfemployed. In 2012 it was reported ${ }^{771}$ that Roma employment were only 37\%; unemployment rate equalled $22.5 \%$ and the rate of inactivity was as high as $39.8 \%$.

Finally, the picture with regards to education illustrates inequity. In $2009^{772} 36 \%$ of male and $38.2 \%$ of female Roma had no education at all; that primary education attainment ranged from $32 \%$ for males to $35.3 \%$ for females. The percentage decreases considerably for women vis-à-vis secondary education (26.5\%) while it remains constant for men. However, according to FRA/UNDP household members aged 20-24 with at least completed general or vocational upper-secondary education roughly equalled 15\%. Further, Tarnovschi et al. (2012) report a lower education attainment of $94.3 \%$ that drops to $5.2 \%$ for middle education and as low as $0.5 \%$ for higher education. Additionally, they provide an illiteracy rate of $15.7 \%$.

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## Country Profile: Latvia

## Main Characteristics of the Roma in Latvia <br> Demography

Latvia is within those countries in Europe with a large proportion of ethnic minorities: 156 are present in the country, Roma is one of those ${ }^{773}$.

There are three main broad categories of Roma in Latvia according to the language that they speak:

- Polish Roma
- Russian Roma
- Latvian Roma ${ }^{774}$

The three groups are mainly homogenous and they have a sedentary lifestyle. In Latvia the Census assumes ethnicity as a variable. Figures from 2012 report that today there are 8,482 Roma, which constitutes $0.4 \%$ of Latvia's population ${ }^{775}$. Nevertheless, a 2009 RAXEN study pointed out that according to unofficial information provided by leaders of Romani NGOs, the total number of Roma in Latvia may reach 13,000 or 15,000 . This discrepancy is based on the fact that many Roma do not indicate their true ethnicity because of fear of discrimination and they instead declare other ethnicities/nationalities (Latvian and Russian) ${ }^{776}$.

## Geographical distribution

The three groups of Roma living in the country are mainly urbanised. In particular the Latvian Roma live in Riga and Kurzeme (by the Baltic Sea, in the western part of Latvia), whereas Russian speaking Roma live in Latgale (region close to the Russian border).

## Other Information (including highlights of data gaps)

The Ministry of Health publishes a yearbook of health care statistics. The main information collected concern demography, mortality, hospitals services, maternal and infant health care and figures on health insurance, which in Latvia is compulsory. Nevertheless, those data are no collected on the base of ethnicity. As a result data on Roma health are very limited and only little information can be obtained regarding the following indicators:

- Drugs use, extrapolated from the Register on Drug and Substance users and already illustrated in the Fundamental Rights Agency (FRA) study;
- HIV infected persons, because of information derived from a pilot project and NGOs;

[^123]- Children health conditions, from a micro scale academic study carried out in Ventspils;
- Housing, education and employment information because of regional or international (EU) commissioned studies.

Considering the segmentation of the country in several ethnic groups, data collected on ethnicity by the national statistics office should be better used and matched with the health system. Data are instead fragmented and based on qualitative interviews with practitioners and members of the Roma community, therefore data are only partly reliable and might result in bias.

## Mortality and Life Expectancy

The only information available is that Latvian Roma is the only ethnic group with a positive balance of birth rate (births exceed the mortality rate: in the period 20002007, natural population growth was 697.). Despite the positive balance, the birth rate is steadily decreasing among Latvian Roma ${ }^{777}$, also because high level of unemployment has led to migration, causing a demographic impoverishment ${ }^{778}$.

## Prevalence of Major Infectious Diseases

According to the FRA study, 335 Roma were registered as HIV infected (2011). This is noted as 42 HIV infected persons per 1,000 Roma inhabitants in Latvia. The information is available because the Latvian HIV centres supporting patients registered them on the base of ethnicity.

In addition in 2012 because of an awareness project against HIV/Aids, 36 Roma persons were provided of free HIV test ${ }^{779}$.

## Healthy Life Styles and Related Behaviours

Quantifications regarding Roma health status are very poor.

A study from FaFo on poverty in Latvia (2005) states that Roma is the Latvian minority at major risk of social exclusion, low incomes and thus poorer health than the average of population ${ }^{780}$.

The only quali-quantitative research assessing Roma health and prevalence of addictions is provided in a descriptive epidemiological study (2009). The research was carried out, anonymously questioning volunteer Roma children - 59 in Vilnius (Lithuania) and 31 in Ventspils (Latvia) schools. Results were compared with an identical study, carried out in five Vilnius schools ${ }^{781}$.

The main findings were that $45.2 \%$ of the children in the Ventspils school score their health as poor and 19.4 as very poor, whereas within the control group only $3.4 \%$ and

[^124]$0.6 \%$ defined their health as such. The researchers imputed this result to the longterm influence of negative perceptions of the Roma conditions. This is consistent with the fact that within the Ventspils students there were high and frequent level of emotional symptoms concerning loneliness (35.5\%) and depression (32.3\%).

Turning to life style and related behaviour the same research explains that children from Ventsplis have a low consumption of nicotine and alcohol, whereas $10 \%$ have used drugs and within those $3.3 \%$ makes a daily use. The control group reports lower percentage with only $4.4 \%$ having tried drugs, of which only $0.6 \%$ consuming it every day.

Further on the use of drugs in the Roma community, from 2006 to 2011 the Register on Drug and Substance Users registered 166 new Roma becoming addicted to drugs. ${ }^{782}$ It was also noted in the Riga Drug User's Cohort Study that $66 \%$ of Roma drug users have been in prison ${ }^{783}$.

## Access and Use of Health Services and Prevention Programmes

Health insurance is compulsory in Latvia, with the population able to access the health system by paying 30 euro monthly or for free (means tested). Data on insurance are gathered by the Health Compulsory Insurance State Agency, but these are not broken down by ethnicity. Roma have low levels of employment and are therefore likely to be less favoured by this system ${ }^{784}$.

More precise data on the access to health service can be extracted from the abovementioned descriptive epidemiological study. Researches have observed that the rate of Roma's applications to the doctor during the year considered was similar to the children of the control group. These findings contrast to some extent the common idea that Roma have less access to health services.

Prevalence of Major Chronic Diseases
The study team has found no quantifications of this indicator.
Health Factors Related to the Role of Women in the Roma Community
The study team has found no quantifications of this indicator.

Environmental and other Socio-Economic Factors

## - Housing

According to the RAXEN study Ethnic affiliation data are not collected in the framework of household annual surveys. In addition the results of the 2,000 population census are, for the scope of the present study, outdated and the existing reports on Roma in Latvia do no extensively investigate this aspect, focusing instead mainly on policy in the field of education.

From the review carried out it emerges that even if Roma in Latvia are mainly sedentary and thus potentially more likely to rent or buy houses, their low level of

[^125]participation in the labour market prevents them from paying the related bills or obtaining a mortgage. As a consequence Roma families live in old temporary overcrowded accommodations.

Local authorities support social housing for vulnerable groups, however the recent report from the European Commission against Racism and Intolerance (ECRI) in Latvia (2011-2012) states that Roma continue to face discrimination in accessing social housing services because the concrete possibility of obtaining publicly funded accommodation depends on the attitude of the mayor of the town or on whether Roma are present on the committee which takes decisions about social housing concessions ${ }^{785}$.

## - Education

A national programme 'Roma in Latvia' has been adopted by the government between 2007 and 2009 and the main focus of the programme was education. As a result several activities were carried out, for instance 20 Roma assistant teachers and 30 teachers were trained for work in the inclusive groups of the educational institutions. Today, 7 of 20 are working as assistant teachers. In addition several studies prove that the number of Roma children in preschools and institutions of basic education has increased ${ }^{786}$.

These findings contrast with ECRI (the European Commission against Racism and Intolerance) observations, which recognised the efforts of the Latvian authority to integrate Roma into school, but which admonishes the fact that funds for the programme have been diverted.

Further, according to the authorities in 2011, 1,182 Roma pupils were enrolled in Latvian schools; however the number of those attending would appear to be far lower. It has been indicated that $13.7 \%$ do not complete basic education. Several reasons justify this: seasonal migration of parents; early marriage age for girls; and lack of sufficient transportation arrangements, especially for those groups that live in the countryside ${ }^{787}$.

## - Employment

The national programme 'Roma in Latvia' 2007-2009 has marginally focused on measures for employment, despite the initial intention. Researchers report very low level of employment ranging from $1 \%$ to $5 \%$ among Roma population and despite this very few members of the Roma community are registered as unemployed (10\%) with the State Employment Agency. ECRI has recommended to the government to undertake a programme against discrimination targeting employers.

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## Country Profile: Liechtenstein

## Main Characteristics of the Roma in Liechtenstein

According to the Council of Europe there are currently no Roma living in Liechtenstein ${ }^{788}$.

According to a report from the Human Rights Council of the UN, the benefits of the Liechtenstein health care system are equally available to all persons living in Liechtenstein. With respect to the specific needs of foreigners, the public health sector is, however, not yet adequate. In 2005, the Working Group against Racism, AntiSemitism, and Xenophobia conducted a needs assessment concerning integration measures for foreign patients. Improvement measures concerning information and linguistic and cultural support for foreign patients were initiated ${ }^{789}$.

[^127]
## Country Profile: Lithuania

## Main Characteristics of the Roma in Lithuania <br> Demography

From 1979 to 2011, the proportion of people claiming to be Romany has remained steady at $0.1 \%$, with census data showing an increase from 2,300 in 1979 to a high of 2,700 in 1989, declining to 2,100 at the beginning of $2011 . .^{790}$ However, additional statistics provided by Statistics Lithuania also indicates an increase in the number of Romany from 2,500 in 2008 to 2,900 in 2012, with the proportion remaining steady at $0.1 \%$. Unofficial estimates suggest that the actual number of Roma in Lithuania range from 2000-4,000, with the Council of Europe estimating 3,000 Romani people accounting for $0.08 \%$ of the population in July 2009. ${ }^{791}$

## Geographical distribution

Roma were reportedly living throughout Lithuania according to the 2001 census with the largest number in the Kirtimai settlement located in the industrialised outskirts of the capital Vilnius and concentrated in some of the largest cities in Lithuania: Kaunas, Siauliai, Panevėžys and Klaipėda. These are dynamic values however as emigration, immigration and intra-country movement affect the number of Roma families in any location. ${ }^{792}$

The majority of Lithuanian Roma are sedentary. According to survey data from 2008, more than half of the Roma respondents (52\%) indicated that they had been living in the same municipality for more than 20 years. Roma reportedly changed their type of residence more frequently than location. No data are available concerning itinerant Roma. ${ }^{793}$

No regulated encampments exist in Lithuania and temporary encampments and halting sites are rare. There is also evidence of increased social marginalisation of Roma as they move into cheaper housing and therefore become more geographically and socially distant from urban centres and opportunities for social development. ${ }^{794}$

## Other Information (including highlights of data gaps)

A wide range of national statistics are available in the areas of population and social statistics, including population composition, births, mortality, life expectancy, health, employment, income, living conditions, alcohol and tobacco consumption and culture. Much of this information can be broken down by factors such as age, gender, education and geographical location; however, it is not broken down by ethnicity.

In general there is a lack of current and reliable information on the situation of Roma with respect to the target areas of this study.

[^128]
## Mortality and Life Expectancy The study team has found no quantifications of this indicato

## Anecdotal data and evidence cover:

Average number of children born alive to Roma women is higher than that in the general population. ${ }^{795}$

## Prevalence of Major Infectious Diseases

The study team has found no quantifications of this indicator.
EC data identifies general trends for infectious diseases in the country such as an incidence of 193.54 cases campylobacteriosis per 100,000 of the population in 2009 and an increase in the incidence of salmonellosis in Lithuania since 2004 in contrast to the generally decreasing trend across most of Europe. There is no breakdown available however by ethnic group.

## Anecdotal data and evidence cover:

The RAXEN report ${ }^{796}$ concludes that living conditions in the Roma Kirtimai settlement in Vilnius are conducive to the proliferation of infectious diseases. This is supported by the FRA report which stated the problem as bad quality of water ${ }^{797}$. Also mentioned in this report is an incident of jaundice within the Kirtimai settlement.

## Healthy Life Styles and Related Behaviours

The study team has found no quantifications of this indicator.

## Anecdotal data and evidence cover:

A descriptive epidemiological study ${ }^{798}$ in 2009, anonymously questioning volunteer Roma children - 59 in Vilnius (Lithuania) and 31 in Ventspils (Latvia) schools - and comparing results with an identical study carried out in five Vilnius schools, found that the proportion of daily alcohol, drug users, and smokers was higher in Vilnius Roma than in the general population but that the difference between the Roma and nonRoma groups was not statistically significant. More children in the Roma population in Vilnius reported never trying alcohol while more children in the general population reported never trying drugs.

Access and Use of Health Services and Prevention Programmes
The study team has found no quantifications of this indicator.

## Anecdotal data and evidence cover:

Access to health care (though this does not describe their experience of health care services):

[^129]- A comparative study ${ }^{799}$ of children in Lithuania and Latvia with respect to a Lithuanian control group, found that there was no difference in the rate of visiting doctors between the groups with about half visiting the doctor $1-3$ times in the past year; however Roma children in both groups were statistically more likely to visit the doctor more than 10 times in the past year.
- Another study of employment and the labour market also indicates that most Roma do approach health care institutions (49\% visited 1-3 times and 41\% visited more than 3 times in the past 12 months). ${ }^{800}$

Barriers to accessing health care identified: Roma live in remote areas with poor infrastructure and lack of accessibility to public services. ${ }^{801}$

## Prevalence of Major chronic Diseases

The study team has found no quantifications of this indicator.

## Anecdotal data and evidence cover:

One study ${ }^{802}$ suggests that Roma children are much more likely to self-assess their health as poor or very poor than the general population. It also found that the prevalence of chronic diseases in Roma children was less than that of the general population with the main diseases reported by the Roma children being bronchitis, neurodermitis, heart diseases, and diseases of the immune system. However vomiting and nausea was most prevalent among Vilnius Roma and they were significantly more likely to report being depressed or lonely often or very often.

Health Factors Related to the Role of Women in the Roma community
The study team has found no quantifications of this indicator.

## Anecdotal data and evidence cover:

The total fertility rate for Lithuania exhibits an overall downward trend from 2.40 mean children born to a woman in her lifetime in 1970 to the below replacement level of 1.55 in 2010. While corresponding information is unavailable for Roma women, census data (year unknown) indicates a slightly lower percentage of Roma women gave birth to children as in the general population ( $73.4 \%$ compared to $75.9 \%$ ), they have more children on average than the general population (3.17 and 2.13 respectively). ${ }^{803}$

[^130]
## Environmental and other Socio-Economic Factors

## Housing

A main source of data for housing is the 2009 study commissioned by Fundamental Rights Agency of the EU - the Raxen National Focal Point for Belgium ${ }^{804}$. This study undertook a thorough assessment of the housing situation of Roma; much of the quantitative data was based on old data, however a number of issues arose:

- Six programmes exist under the Lithuanian Housing Strategy covering assistance and social housing development but there is no information on the ability of Roma to access these programmes
- A much greater proportion of Roma are dependent on public housing compared to the Lithuanian population at large.
- The mean size of a Roma household is several times larger than the national average
- To qualify the housing adaptation programme for people with disabilities, houses have to be legally constructed and have certain amenities which likely disqualifies many Roma ${ }^{805}$
- the quality of existent housing for Roma is poor
- there are limited opportunities for Roma to legitimise their present form of housing, which may involve illegal construction works or dwellings on stateowned land, or to change one's place of residence
- There was a great shortage of rental housing, especially for low-income persons and families. In 2008, social housing accounted for only $2.7 \%$ of the total housing stock. Social housing however was also not always a viable alternative for the Roma because it increased living costs and they found it difficult to afford.

Additionally the location of settlements is not ideal - they tend to be remote and in the case of the Kirtimai settlement in Vilnius, located in an industrial and possibly polluted area (the Vilnius International Airport and several factories operate close to it), where, according to the general city plan, no dwelling should be allowed. Data from the Lithuanian Institute for Ethnic Studies shows persistent negative attitutes towards Roma with Roma consistently being voted the people least wanted as neighbours from 2005 to 2012. ${ }^{806}$

Studies in 2008 and 2009 identified two main problems were with Roma housing in Lithuania: 1) the quality of the existent housing and 2) the opportunities to legitimise present housing (illegal structures and status of state land) or change the place of residence.

## Anecdotal data and evidence cover:

## Education

Statistical data on the enrolment of Roma pupils at Lithuanian secondary schools show similar levels of matriculation in 2000-2001 (571 pupils) and in 2008-2009 (579 pupils). ${ }^{807}$ Roma children reported little formal education with only $28 \%$ of 231 surveyed in 2008 had any contact with school in the past 12 months. A high proportion did not attend any form of pre-school (69\%) and many only started their

[^131]education after the age of 10 (32\%). Most (56\%) did not attain an education level higher than their parents. Experts attribute the main barriers to Roma learning to the lack of social skills, linguistic barriers, and poor school attendance. The Roma selfidentified financial problems (clothing, etc.) and lack of educational assistance in areas including extra lessons and homework; and social support in coping with difficulties such as conflicts among children at school and documentation. Schools reportedly did not have any specific plans or positions regarding the solution of problems related to poor attendance.

## Employment

There was reportedly a high percentage on unemployment (57\%) in the Roma population in 2008. Those who were employed (41\%) were mainly engaging in informal individual activities (collection of scrap metal, fortune-telling, or small-scale trade) and only 9\% of employed Roma had formal contracts. ${ }^{808}$

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[^132]
## Country Profile: Luxembourg

| Main Characteristics of the Roma in Luxembourg |  |  |  |
| :--- | :--- | :---: | :---: |
| Demography |  |  |  |

There are no indigenous Roma in Luxembourg.
The presence (immigration) of Roma in Luxembourg is a recent event and the population can be mainly divided into two groups:

- Roma coming from Kosovo during and after the war in 1999-2000 (integrated)
- Roma coming from Western Balkan countries since 2010, connected to their original community of the Former Yugoslavia Republic.

Roma living in Luxembourg are estimated to be between 300 and 500 persons ${ }^{809}$.

## Geographical distribution

The study team has found no quantifications of this indicator.

## Other Information (including highlights of data gaps)

Luxembourg does not recognise the presence of minorities in its territory. Statistics on population are based on country of birth, citizenship and spoken language, therefore no census figures on ethnicity are provided. Data on Roma are retrieved from the number of requests of international protection.

A permanent travelling lifestyle is not contemplated in the country's legal framework; as a consequence nomadic population in Luxembourg can only reside in the country if they settle adopting a sedentary lifestyle.

No National Roma Integration Strategy has been put in place, but rather an integrated set of policy measures. Roma immigration to the country has then been treated as an ordinary one: Roma people are required to have a passport when needed, means to sustain themeselves, or apply for asylum.

Luxembourg is defined as a new hosting country, which see controlled immigration as a means of dealing with potential labour shortages ${ }^{810}$. However administrative barriers complicate hiring of third country nationals and some forms of discrimination have been reported in the labour market ${ }^{811}$.

Statistics on Roma health conditions are not available, the main body dealing with integration in the country is the Office Luxembourgeois de l'Accueil et de l'Integration (OLAI), from which the study team has tried to unsuccessfully obtain data.

Mortality and Life Expectancy

[^133]

Environmental and other Socio-Economic Factors

## - Housing

According to the European Commission against Racism and intolerance Report (ECRI) ${ }^{815}$, there is a certain level of discrimination as a regard to housing. Accommodations are more accessible to some nationalities than others and in general the high cost of housing in Luxembourg is a problem for many households. Public authorities are trying to provide economic support for households to obtain mortgages and the OLAI works to support refugees, immigrants and homeless foreigners through reception facilities. However in Luxembourg there is not a willingness to concentrate vulnerable groups in specific centres.

Turning specifically to Roma, episodes of discrimination have been reported with administrators of camping premises denying them the access to such places ${ }^{816}$.

[^134]
## - Education

Anecdotal data and evidence cover:

The Luxembourg authorities have put in place a series of measures aimed at boosting the educational attainment of immigrants ${ }^{817}$, including specific welcoming classes for Roma student ${ }^{818}$.

- Employment

Anecdotal data and evidence cover:

According to the FRA study, the main reason for Roma migrating to Luxembourg is unemployment in their country of origin. However, persons in the process of their request of asylum being assessed received very little social allowance ${ }^{819}$, they are not allowed to work ${ }^{820}$ and in addition begging in the country can be legally pursued. The level of voluntary returns in the country is high.

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[^135]
## Country Profile: Malta


#### Abstract

Main Characteristics of the Roma in Malta

Malta has an ethnically homogenous population and there is no Roma population on its territory. As a result Malta has not adopted a national Roma integration strategy.

Malta has traditionally been a country of emigration, but since the entrance in the EU shares with other southern Member States the country has become a destination for Northern Africa migrants. This form of immigration might become problematic, especially when a sizeable proportion of the migration is illegal. The extent of this illegal immigration is stretching the capacity of Maltese resources to manage immigration and hampering the observation of international humanitarian obligations. The country's respect of human rights has been the subject of scrutiny from EU Council ${ }^{821}$ commissioners.

The country has been defined together with Cyprus as one of the Transit countries to Europe ${ }^{822}$.


[^136]
## Country Profile: the Netherlands

## Main Characteristics of the Roma in the Netherlands

## Demography

The Council of Europe estimates that there are between 32,000 and 48,000 Roma in the Netherlands. Based on average figures (40,000), Roma make up $0.24 \%$ of the total population. However, there are no official numbers from the last census, thus all figures are estimates ${ }^{823}$.

However, according to a report by the European Commission (2010) there are 6000 Roma in the Netherlands and that most of them now have Dutch nationality. This report divides Roma into five groups; Dutch nationals (most of Roma), stateless people, political refugees, non-Dutch EU citizens and non-EU citizens ${ }^{824}$.

The first mention of Roma in Netherlands was in 1420. New groups of Roma arrived in several immigration waves during the 1950 s and 1960 s from predominantly Yugoslavia and Hungary. Previous to this Roma were almost completely expelled due to new legislation. The Netherlands was one of the preferred countries to go and work abroad in after the fall of the communist regimes in Eastern Europe ${ }^{825}$.

There are two different ethnic groups of Roma heritage in Netherlands:

- Travellers - who live in caravans and usually have their origins in the Netherlands
- Roma and Sinti - are an ethnic group, which originates from outside of the Netherlands. Some Roma and Sinti live in caravans and others in houses. Language, culture and at times geographical origin and type of dwelling differentiate Roma and Sinti from Travellers. They often live in segregated small communities in around 100 municipalities across the country ${ }^{826}$.


## Geographical distribution

Roma in the Netherlands can be divided into three different categories:

- Roma 1900 - 140 households - they arrived around 1900 and live primarily in Noord-Brabant and Limburg and one family can be found living in Groningen. They live in caravans as they always have done and are not represented in any other regions.
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825 RomaniNet, "A Multimedia Romani Course for Promoting Linguistic Diversity and Improving Social Dialogue: Report $\quad$ Roma People", [Online], Available: http://www.romaninet.com/ROMANINET_Cultural_report.pdf
${ }^{826}$ Schriemer, R. (2009) Housing conditions of Roma and Travellers; The Netherlands RAXEN national Focal Point - Thematic Study. [Online], Available: http://fra.europa.eu/sites/default/files/fra_uploads/588-RAXEN-Roma\ Housing-Netherlands_en.pdf
- Roma 1978 - arrived from Eastern Europe during the 1970s. Unable to deport this group, as no other country would accept them, the government was forced to find a solution for them. It is estimated that there are around 550 households. The majority have lived in houses since 1987 within one of the 12 designated host municipalities. The one exception is the municipality of Ede, where several households have been allocated a halting site.
- Roma '1990' - is a small immigrant group of Roma in the Netherlands. They arrived in the 1990s as asylum seekers and refugees from Eastern Europe. However, their numbers are not known. This small group of Roma is less recognisable than other groups as they do not travel much and live in houses ${ }^{827}$.


## Other Information (including highlights of data gaps)

According to the last official count (before 2000) the Traveller population is younger on average than the primary population. 69\% of Travellers were under 40, compared with the rest of the population at $54 \%^{828}$.

Collection of national data is centralised and is conducted by Statistics Netherlands. There are no indicators to suggest that the Netherlands (Statistics Netherlands) collect ethnically disaggregated data ${ }^{829}$.

There are surprisingly very little official data as well as independent qualitative research on Roma communities in the Netherlands, in particularly on health. There are no indicators to suggest that research and other information sources distinguish between Roma groups based on differences in culture and/or geographic backgrounds. It is much more likely that Roma are differentiated based on their legal status within the Netherlands.

Furthermore, large discrepancies in number of Roma in the Netherlands, as well as definition suggest that data is insufficient and unreliable.

There are notable gaps in data collection for the following indicators:

- Education
- Health
- Population
- Employment
- Household size and type (including overcrowding)

Due to the lack of data collection concerning Roma in the Netherlands, this country research relies mostly on national statistics (or the lack thereof), European and regional commissioned studies, non-formal sources, such as NGOs, and reports by EU organisations as well as academic literature, which mainly provide qualitative information and/or an analysis of secondary sources.

[^137]
## Mortality and Life Expectancy

The study team has found no quantifications of this indicator.
Anecdotal data and evidence cover:
A 2005 study by Dokters van de Wereld found that child mortality is twice as high as the Dutch national average, and that the life expectancy of Roma is $15 \%$ lower ${ }^{830}$.

## Prevalence of Major Infectious Diseases

The study team has found no quantifications of this indicator.
Healthy Life Styles and Related Behaviours
The study team has found no quantifications of this indicator.
In 2012, the Trimbos Institute (Netherlands Institute of Mental Health and Addiction) conducted a qualitative study on truancy amongst Roma girls. The study was based on interviews with municipal representatives. A total of 27 Roma girls and parents participated in the study from 10 different cities. Some of the health problems identified in the report were; obesity, bad teeth, high levels of smoking, unhealthy life styles and psychological and psychosocial problems such as depression, anxiety, migraine and tensions ${ }^{831}$.

## Access and Use of Health Services and Prevention Programmes

The study team has found no quantifications of this indicator.
It has been reported that foremost the elderly and disabled are unfamiliar with services designed for them, thus make very little or no use of them ${ }^{832}$.

According to Doktoers van de Wereld (Doctors of the World) health problems are face by many Roma in the Netherlands. However, no further information is provided of what kind of health problems. The report informs of high level of stress due to discrimination and a limited knowledge of the health care system ${ }^{833}$.

Doctors of the World conducted a study on Roma in the Netherlands between 2005 and 2009, called 'Roma and Sinti on the road... to a better welfare' (Roma and Sinti op weg... naar een beter welzijn). The study identified and trained mediators within the community. They then gathered the information through organised information meetings. Around 900 Roma took part in the information activities, which concerned numerous health issues ${ }^{834}$.

[^138]Many Roma have limited access to health care providers. There is a constant miscommunication between health practitioners and Roma due to lack of cultural sensitivity. Some issues within the Roma culture are taboo to talk about and thus some may not want to discuss their health worries. Moreover, many Roma are unaware of their medical rights and may not know where to go for assistance ${ }^{835}$.

Further barriers, which limit Roma from accessing health care services have been identified as; income status, debts, language barriers and discrimination. In some instances it may be due to the lack of identity documents (and thus no health insurance) and/or lack of financial means to pay the medical bill (and hence further treatment) that act as barriers. Stateless Roma or those who lack legal documentation are unable to get medical insurance. Without medical insurance, the only way to access health care is to pay for it. However, even in those circumstances health providers might turn them away ${ }^{836}$.

## Prevalence of Major Chronic Diseases

The study team has found no quantifications of this indicator.
Health Factors Related to the Role of Women in the Roma community
The study team has found no quantifications of this indicator.
According to the Raxen research, the uncertainty of halting sites creates feelings of insecurity about the future. Women also expressed frustration that the redistribution of free sites was carried out in a random way ${ }^{837}$.

It is generally observed that Roma girls are likely to become mothers at a relatively young age ${ }^{838}$.

## Environmental and other Socio-Economic Factors

The study team has found no quantifications of this indicator.
Roma, Sinti and Travellers lag behind the rest of the population in health, education and employment levels. And political will seems to be lacking in tackling the discrimination and subordinate position of Roma, Sinti and Travellers in the Netherlands ${ }^{839}$.

## Housing

Both the quantity and quality of caravans are insufficient, according to an advisor in caravan affairs at the Overijssel Support Office. Moreover, an article in the Het Wiel reported that almost half of Travellers would like to live in a caravan. People expressed their desire for a quality caravan with sufficient space, bedroom and study room for the children; that was exploitable and well isolated as well as having the possibility to obtain a mortgage ${ }^{840}$.

[^139]There is insufficient data about the small immigrant Roma group (Roma '1990') concerning the quality of housing. It is believed that the majority of them live in houses and not caravans ${ }^{841}$.

A study was conducted by the EU-SILC in 2007 on housing conditions of Roma, which included several variables such as shortage of space, adequate plumbing/water installations, dwelling equipped with heating/comfortable warm during winter/comfortable during summer/accessibility of grocery/banking/healthcare services/compulsory school to name a few. The study was based on an ad hoc module. The study found that the Netherlands was one of the countries where most of the respondents were 'very dissatisfied' $(64 \%)^{842}$.

## Education

According to an NGO report in 2002, 90\% of all Roma and Traveller children are attending secondary school. However, a large percentage is enrolled in vocational training or special needs schools. The study was based on the analysis of quantitative data ${ }^{843}$.

Another study reported that the educational needs of Roma children are unmet, which results in higher unemployment rates for Roma and Travellers compared to the rest of the population. Furthermore, Roma and Travellers tend to remain unemployed for longer periods of time. The study was based on the analysis of quantitative data ${ }^{844}$.

According to the EU Network of independent experts on social inclusion (2011) the current issue with Roma education is not the enrolment of Roma and Sinti in primary education. It is rather absenteeism, a lack of "start qualifications" and an overrepresentation of Roma and Sinti in 'special needs' schools ${ }^{845}$.

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## Country Profile: Norway

## Main Characteristics of the Roma in Norway <br> Demography

Norway has since 1999 recognised two separate ethnic Roma groups:

- Roma

On the basis of "information provided by the Roma and persons who have contact with Roma" the authorities estimate the number to be $700^{846}$.

- Romani/Tater or Travellers

In the communication from the Norwegian Parliament recognising the Romani/Tater as a minority no "reliable figures" were available, although it "could be some thousands" according to the document. It is noted that several organisations representing this group have been established in recent years ${ }^{847}$.

According the Council of Europe the number of Roma in Norway (presumably encompassing both subgroups) is estimated to be $4,500-15,700^{848}$

According to a Government action plan from 2009, little information is available concerning the situation of the Roma for the period 1991-1999. When Norway was to consider the Council of Europe's Framework Convention for the Protection of National Minorities and which groups might be affected by the Convention, some Roma were contacted via teachers, who had a certain amount of contact with the group. The Roma that the Norwegian authorities were then in contact with expressed a wish to be included in the Framework Convention as one of the five national minorities. In meetings with the Ministry, Roma have expressed a need for specific measures, such as support for self-organisation, for establishment of meeting places/points of contact and for literacy training via adult education ${ }^{849}$.

During recent years, an increasing number of Roma have arrived in Norway, particularly from Romania. In response to an enquiry from the Council of Europe, the Norwegian authorities have informed that no special measures have been established in relation to this group. The situation of this group of people, who support themselves, among other ways, by means of begging and busking, has been raised by the Equality and Anti-Discrimination Ombudsman ${ }^{850}$.

[^141]
## Geographical distribution

Most of the 700 Roma are according to Norwegian authorities based in the metropolitan Oslo area ${ }^{851}$.

There appear not to be any records for the Romani/Tater ${ }^{852}$.

## Other Information (including highlights of data gaps)

No statistics are on the basis of ethnic background due to the legal provisions on "sensitive personal data" in Section 2 of the Personal Data Act. In addition, Roma and other national minorities oppose according to the Norwegian Government ethnic registration owing to "the use of this type of information in earlier times" ${ }^{853}$.

This could refer to the work of a state sanctioned charity called the Norwegian Travellers' Mission, which among other things carried out forced sterilisation of up to 500 Roma people and travellers in the $1930 s^{854}$.

## Mortality and Life Expectancy



[^142]| Environmental and other Socio-Economic Factors |
| :--- |
| The study team has found no quantifications of this indicator. |
| Bastrup, O.R. (1996), "En Iandevei mot undergangen: Utryddelsen av Taterkulturen i <br> Norge", Oslo: Universitetsforlaget. <br> Council of Europe <br> Det Kongelege Kommunal- og Regionaldepartement. Stortingsmelidng Nr. 15 (2000- <br> 2001), Nasjonale minoritetar i Noreg / Om statleg politikk overfor jødar, kvener, rom, <br> romanifolket og skogfinnar. Tilråding frå Kommunal- og regionaldepartementet av 8. <br> desember 200, godkjend i statsrad same dagen. <br> Ministry of Labour and inclusion (2009) Action Plan for improvement of the living <br> conditions of Roma in Oslo. |

## Country Profile: Poland

## Main Characteristics of the Roma in Poland <br> Demography

The first mention of Roma in Poland dates back to the beginning of the $15^{\text {th }}$ century. Poland hosted Roma who fled persecutions in neighbouring countries. Part of that population settled in Poland permanently, resulting in four main ethnical groups:

- Carpathian Roma (Bergitka Roma), who came from Hungary and Slovakia during the $15^{\text {th }}$ century and who are sedentary.
- Polish Roma who came mainly from Germany between the $16^{\text {th }}$ and the $18^{\text {th }}$ centuries.
- Kelderari, who came mainly from Romania at the middle of the $19^{\text {th }}$ century and whose main profession was boiler making.
- Lovari, who came in the same period of Kelderari, mainly from Romania and Hungary and whose main activities were as horse and textiles salesmen.

These groups are not homogenous although their internal differences are nevertheless not generally picked up to outside observers. Roma in Poland, as in other European countries, have experienced discrimination, racism, and forced assimilation during the communist period and economic hardship after the end of it as their traditional skills have not been valued in a market economy.

Recently ethnic minorities have been recognised under the Polish Constitution (1997) ${ }^{855}$. Roma constitutes one such minority.

Although the Polish census system admits ethnicity as a variable ${ }^{856}$, the fact that the gathered data is based on respondents' self-assessment does not guarantee certainty of the information obtained, given that because of fear of discrimination, ethnicity might not be declared.

The National Population and Housing Census reports the Roma population being 12,731 individuals ${ }^{857}$, whereas the information provided by the territorial self-government entities, indicates that the Roma population is composed of 20,000 individuals. The Council of Europe estimates a population of 37,500 persons ${ }^{858}$, whereas a further study from the European Parliament (EP) claims that the Roma population might amount to a figure in between 20,000 and 60,000 individuals ${ }^{859}$. Population is almost equally distributed among men and women, with the former prevailing ( $+3.4 \%$ ).

The Roma population in the country is very small compared to both the overall population of Poland (about 38.2 million persons), as well as in relation to the size of Roma populations in

[^143]other Member States (i.e. Romania, between 1.2 million and 2.5 million persons; Spain between 600,000 and 800,000 persons ${ }^{860}$ ). As a consequence of this minority status, little attention has traditionally been paid to Roma conditions. Only recently - since the beginning of the current century - has support for the integration of the Roma minority become a priority. This is due to the implementation of the Governmental Programme for the Roma Community in Poland, established by the Council of Ministers on 19 August 2003, and implemented 20042013.

## Geographical distribution

Roma populations tend to live in small communities mostly in towns and cities.
Forced settlements practiced during the 1960 s reduced Roma nomadic groups' mobility; as a result 40\% of the Roma population has been living in a given locality permanently for at least 30 years ${ }^{861}$.
Most recent estimates and analyses on the geographical distribution of the Roma population in Poland are based upon the information delivered by the territorial self-government entities.
According to these entities the population is spread across the country with the highest concentration - mainly Carpathian Roma - in the mountainous areas and in the Nowa Huta industrial district of the Southern Malopolskie region (3,500 persons), and in South Eastern region of Upper Silesia ( 2,500 persons).
Most of the Roma belonging to the three remaining groups live mainly in cities such as Warsaw $(1,600)$, Lodz $(1,200)$ and Poznan (600) and in a number of smaller towns, following the forced settlement policy ${ }^{862}$.

## Other Information (including highlights of data gaps)

Even if statistics are based on ethnicity in Poland, precise quantitative data about Roma health status are not available. The EP study confirms this lack of data on the health situation of Roma in comparison with the national average health status ${ }^{863}$.

Several explanations can be put forward for this lack of data. First of all, there are no special provisions for Roma within general health policy. Second, although the national Programme for the Roma community provides possibilities for special health policies for Roma in coordination with the Ministry of Health, local governments and NGOs, this policy of the Programme different from education ${ }^{864}$ and employment ${ }^{865}$ - does not have a dedicated department or a specific unit responsible for minority health issues and related monitoring. Third, the Polish healthcare system has been undergoing a period of reforms, which has not yet been responsive to the needs of vulnerable groups, the Roma health situation included ${ }^{866}$.

As a result of this paucity of data, this country report mainly relies upon:

[^144]- grey documentation such as national programming documents;
- data collected during preventive screening tests, vaccination campaigns by local nurses and doctors as part of the overarching Programme for Roma ${ }^{867}$;
- regional and international (EU) commissioned studies;
- academic literature, which mainly provides evidence based on micro studies.

Roma conditions in Poland have been improving during the last decade as a result of government action. There is a higher level of awareness regarding Roma conditions. However, there is a need for long-term follow-up of the Roma health situation in order to get a clearer picture of the Roma health status. The initiatives put in place (i.e. white days - please see below) seem not to be sustainable in the long term, because they rely on local level capabilities. These locally led initiatives help because actions targeting Roma are more effective when applied at micro level, but a national action plan for health would give directions in order to avoid fragmentation, making health institutions more accessible for Roma and systematise information and data about the variables that affect Roma health condition (e.g. housing and life style).

Mortality and Life Expectancy
The study team has found no quantifications of this indicator, but anecdotal data and evidence cover:

- The EP study on Roma situation across Europe ${ }^{868}$ - based on NGOs and government agencies opinions - states that Roma poverty results in higher infant mortality and shorter life expectancy. This is confirmed by the National Roma Integration Strategy (NRIS) ${ }^{869}$, which claims that serious illnesses, combined with economic poor conditions and difficulties to access free health services have increased Roma death rate and at the same time made the length of their life shorter compared to the rest of Polish society.


## Prevalence of Major Infectious Diseases

The study team has found no quantifications of this indicator.
Anecdotal data and evidence cover:

- According to the Programme for Roma community, based on the information passed on by the representatives of the Roma community, the Roma population have been affected by diseases such as hepatitis $B$ or tuberculosis as a consequence of living in socially devastated housing estates and homes.
- Some very specific information was produced after a local indigenous outbreak of measles in a Roma community in Pulawy (eastern Poland). From 22 June to 30 August 2009, 32 measles cases were reported, and additionally nine possible cases were actively identified. A mass immunisation campaign was organised to stop measles transmission in that Roma community ${ }^{870}$ (see section on Access and Use of Health Services and Prevention).

[^145]
## Healthy Life Styles and Related Behaviours

There are no specific studies or information about Roma lifestyle and behaviour. The only information retrieved from the NRIS ${ }^{871}$ is related to poor diet and living conditions (see section on Environmental and other Socio-Economic Factors), which both have an impact on Roma health status.

## Access and Use of Health Services and Prevention Programmes

There is a widespread agreement regarding the limited level of access to and use of health services in the Polish Roma community. Both institutional documents and academic literature emphasise this problem. Less clear cut are the justifications for Roma being underrepresented as patients in the health and social care systems.

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 might represent a deterrent, given their nomadic habits ${ }^{872}$. Moreover, 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, when services have to be paid for. Indeed, results from health projects funded by the Programme for Roma show a good level of participation when services are free, and also when they are directly implemented on site, tailor-made according to Roma cultural values and supported by family and community leaders.

The information collected at project level from the districts' authorities show that:

- There were 33 nurses working specifically with Roma in 2009, 23 in 2010 and 33 in 2011. These nurses provide direct medical help, carry out medical guidance service and also deal with distribution of medicines and personal hygiene products purchased from subsidies;
- There were 40 health screening sessions named "white days" with doctors of different specialties, giving free medical advices were 18 in 2010 and 23 in 2011;
- immunisation and preventive examinations and vaccinations covered respectively: 1,526 patients in 2009; 2,098 in 2010 and 2,182 in $20111^{873}$.

The necessity of small scale actions at district level to collect data on Roma and improve health conditions is illustrated by the success of the immunisation campaign launched in Pulawy. This was directed at the Roma residents, between the ages of nine months and 60 years. The invitation - in the Polish language - was disseminated to the Roma community leaders, and through primary health units in Pulawy. It was held at a primary healthcare centre in the proximity of the Roma community. There was a very high level of responsiveness: from approximately 300 Roma registered at the municipality of Pulawy, 195 ( 102 individuals under the age of 20 years and 93 adults) attended the vaccination point and 138 ( 55 individuals under the age of 20 years and 83 adults) received a dose of combined measles, mumps and rubella vaccine.

[^146]
## The study team has found no quantifications of this indicator.

- According to the NRIS ${ }^{874}$, based on the information passed on by the representatives of the Roma community, individuals are especially in danger of diabetes, diseases of circulatory and respiratory systems: asthma, bronchitis and pneumonia.

Health Factors Related to the Role of Women in the Roma Community
The study team has found no quantifications of this indicator.

- According to the NRIS ${ }^{875}$, there is no tradition of prevention and monitoring of pregnant women in Roma communities. Addressing this lack of pre-natal care could help to cure children's congenital defects in early stage.
- However, an FRA survey has compiled information on the health specifically of Roma women. It noted that Polish Roma women aged 50 and over reported the highest incidence of 'bad' health within the 11 EU Member States covered. $75 \%$ of these Roma women declared themselves to be in 'bad' or 'very bad' health compared to $41 \%$ of nonRoma ${ }^{876}$.


## Environmental and other Socio-Economic Factors

## - Housing

Anecdotal data and evidence cover:

- There are no recent official and non-official data on housing conditions of Roma. The last estimation was carried out in 2000 at district level. There is also lack of quantitative research on the impact of housing conditions on education, employment and health ${ }^{877}$. Nevertheless, qualitative studies based on interviews acknowledge that many poor Roma families live in substandard housing or in barracks ${ }^{878}$ and because of prejudice it is difficult for them to acquire their own house. This is also confirmed by the NRIS ${ }^{879}$ which states that the Roma's health problems appear to be a result of bad, and in many cases catastrophic housing situations - no water-supply, sewage system, no heating in the homes, and poor technical conditions of heating systems.


## - Education

The data reported in the NRIS on Roma are based on a study carried out in 1997. These data are outdated when considering that the Roma programme has since 2004 been mainly targeting educational and schooling issues. Indeed, according to the EP study the number of successful Roma pupils and students has apparently increased, despite a situation characterised by high rates of school drop out due to episodes of exclusion, language barriers and long term travelling. In addition to this, an FRA study on Roma populations noted that higher numbers of

[^147]Polish Roma continue in school after the age of 16 than in the majority of EU countries (72\% for male Roma and 64\% for female Roma) ${ }^{880}$.

The long-term effects of the proliferation of initiatives are unclear given the lack of quantitative data and qualitative evaluation of outcomes following participation in such initiatives, but some figures can be reported ${ }^{881}$ :

- the growing number of students of Roma origin - in the academic year 2004/2005-44 students applied for the scholarship and in year 20011/2012-79 students,
- more than 2,000 Roma pupils annually are equipped with books and school supplies,
- there are approximately 100 Roma education assistants
- Employment ${ }^{882}$

The most recent data on Employment regarding the Roma community in Poland is based on three main sources; a study done by the Association of the Roma in Poland in 1999, the 2002 Census and a government report from $2005^{883}$. All these sources confirm that unemployment is as high as $30 \%$ in some areas and that the Roma environment is characterised by structural long term unemployment. The programme currently in place has offered a few job opportunities for students, but it does not provide incentives for employers to hire Roma ${ }^{884}$, which would have increased their chance of work.

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## Country Profile: Portugal

## Main Characteristics of the Roma in Portugal <br> Demography

When the Roma first arrived in Europe they were known by many names including Gypsies, Gitanos and Gitans based on the assumption they were from Egypt. The first written evidence of the presence of 'Gypsies' in Portugal dates from 1521. Four years later, in 1525 they were forbidden to enter the Portuguese kingdom; followed by new laws and subsequent trials leading to convictions and deportation to Africa (Angola was the first Portuguese colony that received Roma) and Brazil. New legislation continued to be introduced against "Gypsies" until after 1640, when the kingdom was in a state of war and needed men for the army. As many Roma enlisted, the group's presence was tolerated, albeit with the imposition of rules. In the early 18th century measures of gypsy expulsion returned under penalty of arrest. Citizenship for "Gypsies" was eventually recognised in 1822 and Portugal became one of the favoured destinations for migration following the fall of the former communist regimes. Usually men go first, and then their wives and children. Preferred jobs are in construction, agriculture, trade and services. Generally only a minority of these Roma settle permanently as colonies; a significant proportion prefer to invest earned money in their homelands, in the construction of family houses, in buying land, animals and cars, in developing their own business. ${ }^{885}$

The Portuguese Constitution forbids the collection of data based on ethnic origin, including in the census therefore it is only possible to estimate the number of Roma in the country. The Health in Europe survey estimated that in 2008 there were 33,338 Roma in Portugal ${ }^{886}$; the RAXEN housing report quoted a range of $40,000-50,000^{887}$; the National Roma Integration Strategy ${ }^{888}$ claimed there were $40,000-60,000$ Roma; and the Council of Europe estimated that there were 40,000-70,000 Roma in Portugal in 2009, accounting for $0.52 \%$ of the population. ${ }^{889}$ Overall this results in a range of 30,000-70,000.

The Roma Communities are characterised by a gender imbalance in favour of the women ( $52.9 \%$ vs $47.1 \%$ ), reflective of the Portuguese population a whole; and are generally young ( $60 \%$ under the age of 25 years) unlike the general Portuguese population which follows the inverted population pyramid with more people in the older age groups. ${ }^{890}$

## Geographical distribution

Roma are mostly identified as living in areas with higher population density, such as Lisbon or Portuguese littoral or near the border. Many were also living in Alentejo (especially in the District of Beja) and Trás-os-Montes. ${ }^{891}$

[^149]
## Other Information (including highlights of data gaps)

The Portuguese health systems consists of:

- the National Health Service (NHS) providing universal coverage to all citizens with payment of a symbolic fee for medical appointments, treatments and surgery; exempting people with low income or on disability pensions
- health subsystems, accounting for $25 \%$ of the population, where special/social health insurance schemes cover certain professions
- voluntary private health insurance and mutual funds, covering 10\% and 7\% of the population respectively ${ }^{892}$

However, Portugal was part of a comprehensive data collection and analysis of Roma health in Europe ${ }^{893}$, published in 2009 and covering 1,673 Roma of both genders and including adults and children. Portugal therefore is one of the few countries in which relatively recent data is available on the Roma. The analysis highlighted however the poor quality of the information available on the Roma Communities and the difficulty in defining a representative sample. The report also indicated that, in 2008, the National Policy for Inclusion did not consider the Roma a priority group and that there was a need for a mainstreaming strategy for the Roma Community that defined integrated and overarching policies in a variety of areas including education, health, housing, justice, employment and professional training to effectively facilitate access to basic goods and services and to the exercise of full citizenship.

With the objective of promoting multiculturalism, ACIDI supports, at various levels, the undertaking of initiatives and cultural events that contribute to raising public awareness on integration and welcoming immigrants and the Roma community in Portuguese society including festivals, exhibitions, publications and documentaries. The Office for the Roma Communities - GACI, was created in 2007 and has developed a set of activities working with responsible organisations in the fields of education, housing, employment / training and health. Its strategic lines of intervention:

- Mobilize and empower Roma communities
- Promoting social inclusion
- Facilitate coordination of existing resources
- Promoting active citizenship
- Promote the dissemination and sharing of information
- Disclose the history and the cultural heritage
- To promote coordination with national and international ${ }^{894}$

Mortality and Life Expectancy
The study team has found no quantifications of this indicator.

Prevalence of Major Infectious Diseases
The study team has found no quantifications of this indicator.

[^150]
## Healthy Life Styles and Related Behaviours

Tobacco consumption is high in adults with $30.1 \%$ stating they are smokers. This is highest amongst younger men, unlike in the general population where there are more smokers between the ages of 35 and 44. Alcohol consumption however is low, with only $37 \%$ reporting having consumed alcoholic beverages in the past 12 months.

Additional evidence indicates that there is a high prevalence of regular TV viewing amongst children, especially amongst girls in the 10 to 15 age group; and there is very little physical activity amongst the Roma ( $33 \%$ do not take part in any form of activity though children are more active than the over 16 s , possibly because the latter are required to undertake physical activity as part of their schooling).

Roma diets are high in breads/cereals (89.8\%) and pasta / rice (84.7\%) but low in vegetables (18.3\%), legumes (12.9\%) and fish (3.4\%). This combination of unhealthy diet and inactivity manifest in a gradual tendency to gain weight after the age of 16 . Overall $41.1 \%$ of Roma are overweight and $13.7 \%$ are obese.

## Anecdotal data and evidence cover:

A genetic study into mutations that cause the maple syrup urine disease (MSUD), a rare autosomal recessive disorder of branched-chain amino acid metabolism, found that a high proportion of patients are of Gypsy origin and all share the same mutation that causes the neonatal severe form of MSUD. These results are of medical relevance since carrier tests and prenatal diagnosis can be offered to families at risk, particularly because the carrier frequency of the mutation was estimated at 1.4\% among the healthy Portuguese Gypsies from the South of the country. ${ }^{895}$

## Access and Use of Health Services and Prevention Programmes

Most of the Roma interviewed in the Health and the Roma report ${ }^{896}$ were covered by the NHS. Most Roma consider their health to be good (82\%). This is especially prevalent for the younger age groups, in contrast to the over-65s, many of whom consider their health status to be mediocre (25\%) or poor (13.5\%).

Most commonly used medications are for the cold//flu, fever and/or pain in both adults and children; and especially of antibiotics and diarrhoea medication in children. These are mostly self-prescribed (55.8\%) rather than physician-prescribed (44.2\%). ${ }^{897}$ Data on frequency of visits to physicians indicate, in decreasing order of frequency, the most frequent visits were:

- More than two weeks but less than a month ago: $43.8 \%$ minors, $48.6 \%$ adults
- Annual: more than one month but less than one year ago: 25.5\% minors, 26.4\% adults
- In the last two weeks: 24.2\% for minors,

The type of health service provider Roma visit depends on the reason for the visit - for check-ups they go to Health Centres with follow-up at hospital outpatients while for other reasons they go to emergency departments at hospitals. Most people seen at hospital did not require any surgery (66\%) and over the past 12 months $73 \%$ of Roma

[^151]had requested emergency services (at both health centres and hospitals). Repeated use of emergency services within the past 12 months was also common, indicating that medical services are used only in need rather than for routine or on-going care and treatment. Roma men reported having more check-ups than women.

## Prevalence of Major Chronic Diseases

The Health and the Roma Community: analysis of the situation in Europe found that the most prevalent diseases were:

- asthma and chronic bronchitis (25\%)
- high cholesterol (15\%)
- high blood pressure (11\%)

Amongst the general population high blood pressure was the most prevalent medical condition; respiratory diseases were not of reported significance. The high prevalence of respiratory diseases in the Roma population is closely related to the poor housing conditions experienced by this group.

In a measure of limitations to daily activity, only $10 \%$ of Roma reported having to reduce their main activity in the past two weeks of which incidence was higher amongst minors (10.5\%) mainly due to fever (69.4\%) and colds, pain and sore throats (30.6\%). Temporary incapacity was high amongst women (10.3\%) especially in the over 45 age group. Main reasons for incapacity were headaches (37.5\%); nervousness, depression and difficulty sleeping (33.4\%); bone, spinal cord of joint pain (32.3\%). However more members of the general population report being on temporary leave than the Roma ( $12 \%$ vs $10 \%$ ).

A high percentage of Roma reported dental problems, especially the adults (95\%) which could be due to most dental services being private unlike the NHS.

## Health Factors Related to the Role of Women in the Roma Community

Most Roma women had given birth (86\%) especially in the younger age bracket of 16 to 29 years. Though teenage pregnancies were common there were indications of changing practice when it came to early pregnancies but regular gynaecological checkups remain infrequent: 24\% of Roma women had never had a check-up, especially in the 16-29 age group. Women generally visited the gynaecologist during pregnancy but $43 \%$ only went once during the entire pregnancy with only $22 \%$ reporting attending every 2 months.

Roma women also visited the gynaecologist for the following reasons:

- counselling family planning: 43.8\% (mainly in the age group 16-29)
- gynaecological problem: 31.3\%
- periodic check-up: 25\%

Portugal is one of four countries in which fewer than the overall average of pap smears was undertaken ( $12 \%$ compared to an average of $28.6 \%$ ). Uptake of preventative screening was low with most women never having had a mammography ordered by a specialist (76.8\%) or a smear test (87.1\%). ${ }^{898}$

[^152]Roma women aged 50 years and over also believe they are in worse health than nonRoma women of the same age group. This is represented in a survey on self-declared health by FRA which shows that 70\% of Roma women state they are in 'bad' or 'very bad' health compared with $35 \%$ for non-Roma women ${ }^{899}$.

## Anecdotal data and evidence cover:

Families and the people one lives with are important to the Roma. The birth of children, especially the first son is of great importance to Roma families - for men it is a symbol of being a true householder with autonomous authority; for a woman the birth of a son, gives her greater influence and power and removes her to some extent from the control of her mother-in-law. ${ }^{900}$

## Environmental and other Socio-Economic Factors

## Housing

The right to adequate housing is in the Portuguese Constitution and housing has been targeted by the Portuguese government for a number of years; however Roma were not specifically targeted. The RAXEN report found varying estimates of the housing situation for Roma depending on which study was considered: 31\% of Roma were found to be living in "precarious conditions" in 2001 according to figures from SOS Racismo; $16 \%$ in 2008 based on data from the Centre for Territorial Studies (CET) and $18 \%$ based on data from National Work on Roma Pastoral. ${ }^{901}$ The findings of the interviews conducted for Health and the Roma Community: analysis of the situation in Europe ${ }^{902}$ in 2008, report a much higher figure of $52.5 \%$ (out of 367 households interviewed, covering 1,673 people) living in sub-standard housing, and in unsanitary and unhygienic conditions. Whatever the estimate, when compared to national statistics on the general population, the percentage of Roma living in poor housing conditions was always above the national average of approximately $0.8 \% .^{903}$

The RAXEN study indicates a shortage of quantitative data in a number of areas relating to housing including numbers of Roma living in unregulated encampments or in segregated settings; household type and setting; access to private and social housing; forced evictions and access to public utilities; or on the housing situation facing Roma from other EU states. Qualitative data and anecdotal evidence however indicate the poor living conditions and continued discrimination faced by the Roma, including lack of access to public utilities such as water; arbitrary and forced evictions; and fabricated legal charges. ${ }^{904,905}$ Roma are thought to have benefited from housing schemes such as re-housing projects launched in the 1990s but there are no estimates of the number of Roma beneficiaries and research projects indicate this may have been at the expense of promoting social and economic inclusion. ${ }^{906}$

[^153]
## Education

Educational attainment is poor with 52.3 \% not having any academic achievements and $36.9 \%$ being totally illiterate. Only $38.3 \%$ of the adult population has completed primary school and only $0.4 \%$ had completed secondary education. However $66 \%$ of children interviewed were currently in the school system. ${ }^{907}$

Marked gender differences are found in Roma education with only 55\% of Roma women literate compared with $77 \%$ of Roma men (aged 16 and over). This is the largest gap regarding literacy in Roma populations in the EU. However, literacy rates for Roma aged 16-24 years have increased the most in the EU with the gender difference decreasing ( $88 \%$ among Roma women v 93\% among Roma men) ${ }^{908}$.

## Employment

The majority of the interviewed Roma are not engaged in active employment. Only $8.5 \%$ are officially counted as actively employed of which $4 \%$ are self-employed and $2.5 \%$ are salaried employees. The remaining $91.5 \%$ are categorised as inactive including the unemployed or working in the informal economy (44.3\%), those living on pensions or social benefits (27.4\%) and people working in the family business of sporadic street markets / street vending (8\%) ${ }^{909}$ of items, likely selling items such as clothing, footwear and carpets ${ }^{910}$.

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[^154]
## Country Profile: Romania

## Main Characteristics of the Roma in Romania <br> Demography

2011 census: 619,000 persons declared themselves Roma (535,140 in 2002 census), which represents $3.2 \%$ of the total population. The latest representative estimation in 2009 estimated the number of Roma to be around 1,850,000, which represents $8.32 \%$ of the total population. Currently, Roma leaders and Roma NGOs estimate that the unofficial number of Roma people in Romania is approximately 2.5 million.

On average, Roma people are more likely to be of younger age than the national majority population living in their close proximity, ${ }^{911}$ with a birth rate of evaluated $1.26 \%$ by Social Observatory for Roma - Bucharest University. The average household size is 4.25 .

If we take the age category $30-59$ as the comparison unit, we can see that:

- For each Roma household member aged 30-59, there are 0.2 elderly members, while for each non-Roma household member aged 30-59, there are 0.5 elderly members.
- The situation is reversed when analysing the younger family members: each Roma household member aged $30-59$ is accompanied by an average of 0.4 pre-school children, 0.8 children aged $7-17$ and 0.7 young adults aged 18-29.912

Poverty rate: significantly bigger than that of majority population or that of other ethnicities even during the years with best economic performances: $31.1 \%$ compared to $5.0 \%$ in $2008 .{ }^{913}$
In 2005, around $60 \%$ of the Roma communities are poor and that more than $50 \%$ of Roma individuals live in these communities. ${ }^{914}$ Amnesty International even considers that 75 per cent of Roma are living in poverty.
Finally, a recent survey showed that $81 \%$ of respondents Roma are living in households at risk of poverty vs. 41\& for non-Roma. ${ }^{915}$

## Geographical distribution

According to the 2011 census, the rate of Roma population was about $3.2 \%$. The persons of Roma origin make up $3.2 \%$ of the total stable population, with a relatively uniform territorial distribution and percentages ranging between $1.1 \%$ in Botoşani County and $8.8 \%$ in Mureş County.

There are relatively higher percentages of persons of Roma origin, of over 6.0\% of the stable population, in Călărași (8.1\%), Sălaj (6.9\%) and Bihor (6.1\%).

[^155]
## Other Information (including highlights of data gaps)

With sample limits, it was still possible to cover almost all types of indicators (missing: F1).

As it was observed in some European surveys, Romanian data are sometimes missing or not included in the comparative reports. Consequently, there is some particular information that is not available (i.e. depression or drug use).

There are indicators on access/barrier to healthcare services, vaccination and health assessment, even if based on subjects' responses, the medical infrastructure serving Roma communities is generally adequate and accessible. ${ }^{916}$
$62.8 \%$ of the sample had taken medicines in the two weeks prior to the interview and significant differences were observed in terms of gender and age brackets. Among adults, three out of four women and one out of two men had taken medicines and consumption increases with age. ${ }^{917}$

More generally, many surveys cover indicators on access/barriers to healthcare services but not on specific diseases.

## Mortality and Life Expectancy

Concerning the indicators on life expectancy (A3):

- In one source we have 6 years lower for Roma than the EU average ${ }^{918}$ but the reference date is unspecified.
- According to respectively the Social Observatory for Roma (Bucharest University) and the World Bank, life expectancy is 12 years lower for Roma than majority (Roma* - 61 years; majority** 73 years).
- In another source from 2011 (Social Observatory for Roma - Bucharest University), the mortality rate is with $1.83 \%$ higher than by non-Roma with 1.28\%.

As to the infant mortality (A1) indicators for Roma, one source ${ }^{919}$ mentions that it is one of the highest in Europe. According to another source from 2011 (Social Observatory for Roma - Bucharest University), the infant mortality rate is with $2.31 \%$ higher than by non-Roma with $1.36 \%$.

In the same study (Social Observatory for Roma - Bucharest University 2011), the maternal mortality rate is with $0.62 \% 15$ times higher than by non-Roma with $0.04 \%$.

## Prevalence of Major Infectious Diseases

Unfortunately, it could be found no indicators neither on Hepatitis $\mathbf{A}, \mathbf{B}$ and $\mathbf{C}$ nor on HIV (B3, B4, B5, B6) or Syphilis or Chlamydia.

[^156]No official statistics or research findings have been found in Romania about drug use or sex work - among the principal risk factors associated with HIV transmission in the region - for different Roma communities. ${ }^{920}$

In a 2003 survey, Roma women in Romania were less aware of the means of HIV transmission than non-Roma women. For example, four times as many Roma women did not know that HIV/AIDS can be transmitted by unprotected heterosexual intercourse. Unfortunately, it is very limited in scope (it is a rapid assessment survey) and cannot be generalized to the more general Roma population. ${ }^{921}$

The indicators on the rate of tuberculosis (B1) come from 2006 and 2010. ${ }^{922}$

- Roma communities are ten times more vulnerable to TB than the Romanian average. The data is unfortunately not specified in its source.
Romania has the highest incidence TB rate in Central and Eastern Europe ${ }^{923}$ and the largest number of yearly paediatric TB cases in all Europe. ${ }^{924}$ According to the WHO report, the number of TB cases among Roma in Bucharest was estimated to 1023.7/100,000 inhabitants in 2001. ${ }^{925}$

In Osorhei, a Roma community, most children have respiratory problems and anaemia; $90 \%$ have parasites; $60 \%$ have TBC and, due to low access to medical care, there have been cases of death by TBC. ${ }^{926}$

The vaccination (B) rate of children (no age specified). ${ }^{927}$

- $45.7 \%$ of the Roma children did not benefit of the mandatory and free of charge vaccines included in the National Immunisation Programme and more than $50 \%$ of them did not benefit of any vaccines.

The WHO investigated a measles outbreak (B2) in Romania and discovered that 90\% of the reported 6,000 infected were Roma. ${ }^{928}$

Data from measles outbreak in 2010 reveals overrepresentation of Roma among the diagnosed cases. ECDC data from 2010 reveals that $37.5 \%$ of the laboratory confirmed cases were among Roma patients. ${ }^{929}$

[^157]Another technical report (2012) from the ECDC pointed out over 8,000 reported outbreaks of measles and rubella that started among unvaccinated members of Roma and Sinti communities and spread to the general population (Romania 2004-2007).

## Healthy Life Styles and Related Behaviours

Unfortunately, in one major comparative survey, no data on indicators on the use of drug use (C2), alcohol (C3) and tobacco (C4) among the Roma: there are no data for Romania because that question was not on the field work questionnaire. ${ }^{930}$

In terms of drug use among Roma, one cannot talk about ethnic identity but drug users. In 2011, according to the annual report of the National Agency against Drugs, the number of injecting drug users who had access in 2010 to syringe exchange services was very high. NGOs have offered assistance in the frame of the project Prevention and care of HIV / AIDS among injecting drug users in community and prisons in Romania, developed with technical and financial support provided by the United Nations report on Drugs and Crime, Romania as follows: ${ }^{931}$

We could identify one document making reference to indicator on smoking (C4) among the Roma population. ${ }^{932}$

- Roma women had 5.2 times the odds ( $P<0.01$ ) of continued smoking vs. nonsmoking. ${ }^{933}$
- A much higher percentage of the smokers were of Roma ethnicity (16\%) compared to the quitters (2\%) and non-smokers (1\%). Another original finding is the very high rate of pre-pregnancy ( $82 \%$ ) and continuous smoking ( $67 \%$ ) among Roma pregnant women. ${ }^{934}$

For obesity and overweight (C5) we identified two concordant sources. ${ }^{935}$

- One out of every two adults is either overweight or obese.
- Overweight $=26.5 \%$ and Obesity $=16.9 \%$.

In many studies it is found that Roma are less likely to be overweight than the nonRoma or the general population, since for instance $61 \%$ reported going to be hungry at least once last month. ${ }^{936}$

We have indicator on physical activity (C). ${ }^{937}$

- 61.5\% do not take any exercise during free time.
- Only $9.8 \%$ regularly take exercise several times a month.

[^158]As to their nutritional habits (C), Roma people have a relatively varied diet but it is calorically unbalanced. Bread, cereals, and similar products are consumed on a daily basis by $86.9 \%$ of the population; the second category of food products in the ranking is pasta and rice which are consumed daily by $63.3 \%$ of the population. The heavy consumption of cereal-based products accounts for excess weight. The study also showed relatively low consumption of fish, eggs and meat leading to a deficit in animal protein, saturated fatty acids and phosphorous. ${ }^{938}$

## Access and Use of Health Services and Prevention Programmes

An important role for the improvement of access to health to the community is played by the health mediation program established in 1996 by a Roma NGO - Romani Criss. The purpose was to close up the Roma communities to the healthcare services through the services provided by the Roma health mediator, who had to satisfy a set of minimum education requirements, to know the relevant Roma community and to be accepted by that community, to know the Romani language, etc.

The Romanian health mediation program is characterized by strong leadership from a Romani Criss and ongoing cooperation between this NGO and the government of Romania. With the exception of one year, the program has grown steadily with increasing numbers of RHMs trained and employed, and the degree of institutionalization growing over time. To support the growing number of Roma Health Mediators, in 2006 Romani Criss established a network of regional centres to monitor and provide programmatic assistance to RHMs. Roma health mediation was further institutionalized in Romania when the National Council for the Professional Training of Adults approved occupational standards for health mediation in 2007. ${ }^{939}$

Regarding the activities carried out by the health mediators, according to the Impact analysis realized by Sastipen Association, the overstrain is visible not only by analyzing the number of Roma areas they cover, but also by analyzing the number of beneficiaries, more than 1,400 Roma on average (according to Order 619/2002 released by Minister of Health, the health mediator activates for 500-750 people). Also, at national level, according to national reports of Minister of Health, 788 Roma health mediators were hired before 2007.

Although the project of sanitary mediation in the Roma communities was considered as a successful project, it is under the risk of dissolution due to the absence of financing and the lack of interest of the local public authorities to ensure the access to basic healthcare services in the Roma communities ${ }^{940}$.

Over $40 \%$ of respondents aged 35 to 54 declared living with health problems that limit their daily activities. ${ }^{941}$

In one survey, ${ }^{942}$ the sample gave a positive assessment of health status (D). $79.8 \%$ of the respondents declared their health to be either good or very good

[^159]whereas only $4.6 \%$ considered they were in a bad or very bad state of health. If positive self-assessment of health status is a common trend in quantitative studies focusing on the Roma population - similar previous research conducted in Romania are consistent in this respect, however qualitative studies as well as the analysis of objective indicators of health status contradict these self-assessments and point to a series of structural problems preventing access to quality health services. ${ }^{943}$

## Access to medical health insurance (D)

There are many reasons for the weakness of Roma's access to health insurance in Romania, which are only very brief contextualised in the following lines. On the one hand it starts with information and communication difficulties to be aware of such medical protection. On the other hand the financial aspect plays an important role since Roma households are relatively poor and cannot prioritize to budget such insurance. Moreover, some attitudes of self-confidence, modesty and mistrust toward State institutions prevent Roma persons from demanding health cover and remain rather depending on their own resources and communities instead of looking for help by third parties.

Consequently, one important related problem to this limited access is for example the over-reliance on emergency healthcare, i.e. Roma people who don't have insurance are using, in extremely situation of sickness, the emergencies unit from Hospitals where staff is already overloaded and not prepared for chronic diseases.

- The records of the Ministry of Health showed that in 2002, only 34\% of Roma benefited of health insurances, compared to the national average amounting to $75 \% .{ }^{944}$

Only 50\% of respondents aged 18 and above declared living with medical insurance, compared to $80 \%$ in national population. ${ }^{945}$
44.3\% of Roma have never accessed dental services and one fifth who needed medical care was denied and have not received a reason for that. ${ }^{946}$

- $9 \%$ of Roma and $4.5 \%$ of majority people in a comparative sample are not registered with a family doctor. ${ }^{947}$

There is one indicator on the hospitalisation (D) within one year:

- Percentage of the population hospitalised during the preceding 12 months: $17.2 \% .{ }^{948}$

[^160]
## Discrimination in the healthcare system (D1). ${ }^{949}$

- 11\% of Roma reported discrimination in the past 12 months by healthcare personnel. ${ }^{950}$

Further discrimination indicators including 9 domains show a high percentage of reported discrimination around $25 \%$. ${ }^{951}$

## Prevalence of Major Chronic Diseases

We have several indicators for the prevalence of major chronic diseases (E).
Over half of the population age 45 and over, with no gender difference, suffers from disabilities or chronic disease. BUT the study does not reveal any ethnic-specific pathology for the Roma population. ${ }^{952}$

The percentage of the Roma population suffering a disability or chronic disease is $14.5 \%$. ${ }^{953}$

Indicator on cardiovascular diseases (E):

- $13.7 \%$ of adults ${ }^{954}$

Unfortunately, in one of our major sources in Romania, the question about depression (E) among Roma was omitted (contrary to other countries). ${ }^{955}$

Indicators on the rate of asthma (E)

- Roma: $3.3 \%{ }^{956}$

Indicators on the rate of stomachic ulcer (E)

- Roma: $5.2 \%{ }^{957}$

As to the rate of diabetes (E1):

- Roma adults have a rate of $6.9 \%$

As to the indicator on hypertension (E2):

- Roma adults have a high rate of high blood pressure: 17.5\% ${ }^{958}$

Over $60 \%$ of adult men and women have cavities. ${ }^{959}$

[^161]
## Health Factors Related to the Role of Women in the Roma Community

As to the indicators on mammography and cervical cancer screening (F2):

- Respectively $\mathbf{8 9 . 4} \%$ and $\mathbf{8 4 . 2 \%}$ of Roma women said they never received this type of screening. ${ }^{960}$
- Percentage of adult women who have had a mammography $=20.1 \%$ or pap smear $=18.6 \%$ on some occasion. ${ }^{961}$

We could not identify any direct data on ante-natal care (F1) for Roma women (F1).
Regarding the self-declared health of Roma women, over two thirds of Roma women aged 50 years or over said that their health was bad ${ }^{962}$.

## Environmental and other Socio-Economic Factors

There are no longitudinal comparable data on the environmental and the socioeconomic status of the Roma in Romania. However, some studies illustrate this issue.

- After including socio-economic variables, Roma had a significantly higher probability of reporting chronic conditions. For the probability of feeling threatened by illness because of unhygienic circumstances, being Roma was a main determinant. ${ }^{963}$


## Employment rate

With regard to Roma persons presence on the labour market, the recent survey conducted within project EU Inclusive ${ }^{964}$ shows a low level of Roma employment by comparison with the national employment rate - 35\% as opposed to $58 \%$ in the group of age of over 15 years old and "a high percentage of instable jobs, which are not providing continuity and stability". Even if data are different, the same trend is seen in a survey conducted by the World Bank ${ }^{965}$ illustrating the fact that Romania maintains a significant gap between the level of Roma persons integration on the labour market (50\%), compared with the rest of the population (63\%). With regard to the average salary, Roma persons' level of income is at $39 \%$ of non-Roma population income.

In another study, only 3 in ten of those interviewed had been able to find paid work in the past five years. ${ }^{966}$
Only $32 \%$ of household members were in paid employment (vs. $46 \%$ non-Roma), $28 \%$ of the respondents considered themselves as unemployed (vs. 12\%), and only $27 \%$ stated that they are or will be entitled to private or state pension (vs. $76 \%$ ) (ref. 19).

[^162]Unemployment rate (15-64): 44\% of Roma (UNDP 2006).
Only 11 percent of 717 Romani women interviewed during a 2005 community research study were formally employed. ${ }^{967}$

- In 2011, among the Roma population of over 16 years old only $27 \%$ of the women declare to have a job, compared to $44 \%$ of Roma men.
- Widely non-contracted employment is $63 \%{ }^{968}$ and employment mostly in unqualified occupations;
- Employment in traditional crafts of 4-5\% of the sample members (who work or receive incomes from such activities in the last month - Zamfir \& Preda, 2002);
- Salary-based employment at low rates and in decrease during the last 20 years: 23.4\% employees within Roma population of and over 16 years old in 1992 (Zamfir \& Zamfir, 1993) compared to $12.9 \%$ in 1998 (Zamfir \& Preda, 2002), respectively, $8.5 \%$ in $2010 .{ }^{969}$

One explanation of these figures could be that more than one quarter of Roma respondents aged 16 and above looking for work in the past 5 years said that they experienced discrimination because of their Roma background. ${ }^{970}$

## Educational level

Roma people are more likely to have no education at all or a low level of education. ${ }^{971}$ $22 \%$ of Roma children aged 7 to 15 are not in school whereas only $13 \%$ of non-Roma aren 't. ${ }^{972}$

The number of pupils assuming their Roma identity, following the educational offer to study the Romani language and literature, has constantly increased from 158,128 in the school year 2002/2003, to 263,409, in the school year 2007/2008. At county level there is a County Board of Education for Minorities, while at local level, a number of more than 1,900 teachers of Romani language and 852 Roma school mediators develop their activity, especially in the communities where Roma prevail. ${ }^{973}$

2 of 10 Roma children of schooling age (6-16 years old) do not go at school because of the lack of financial resources. With regard to the illiteracy, 25\% of Roma individuals of over 16 years old declare that they do not know to read and write, the

[^163]most affected persons being the adults living in the rural environment and in segregated compact communities. The research also shows that the number of illiterate Roma women is by $\mathbf{1 0 \%}$ bigger than the number of illiterate Roma men. ${ }^{974}$

Pre-school attendance rate of Roma children aged 3-6: 36.8\% (vs. 77.1\% national average). Roma children are placed mainly in 'Romani kindergartens' where all or almost all the children are Roma. These facilities tend to be poorly equipped and lack qualified staff. They often do not engage children in cognitive activities and fail to involve Roma communities and parents. ${ }^{975}$
Another study concerning children aged 4 to starting age of compulsory education attending preschool or kindergarten shows similar results with only $45 \%$ of Roma children vs. 75\% for non-Roma. ${ }^{976}$

Further, only $10 \%$ of household members had at least completed general or vocational upper-secondary education (vs. 65\% non-Roma). ${ }^{977}$

Moreover, literacy levels of Roma men and women are in the lowest in European Roma populations, at $76 \%$ and $64 \%$ respectively ${ }^{978}$. This study furthermore states that nearly $20 \%$ and nearly $30 \%$ of Roma men and women never went to school. It is also important to note the differences between literacy and schooling levels between Roma men and women.

People living in segregated housing: "segregated villages" start to be identified. One village or some village neighbourhoods are ghettoised with the risk of becoming a Roma territory with dramatic consequences in terms of segregation, discrimination and socio-economic exclusion. ${ }^{979}$

- Approximately 2,000 ghettoes comprising 1 million people
- very poor infrastructure and housing conditions
- level of spatial segregation of ghettoes: $37 \%$ isolated, $52 \%$ peripheric, $57 \%$ monoethnic, $16 \%$ delimited by natural or artificial barriers
- $25 \%$ of Roma people experienced housing discrimination. ${ }^{980}$

The poor housing conditions have effects on different aspects of individual and community health: first of all, it affects the vital supply of drinking water; secondly, it affects nutrition (the impossibility of cooking properly or of breeding small animals for household consumption); third, it affects individual hygiene and the proper cleaning of dishes, linen and clothes, which then become transmitters of microbes and germs; last but not least, if the water source is polluted (as for

[^164]example in the case of Glod and Byron street in Cluj), it becomes a medium of toxicity, affecting the respiratory system and skin. ${ }^{981}$
For example, $87 \%$ of the respondents considered that they were living in households without at least one of the following basic amenities: indoor kitchen, indoor toilet, indoor shower/bath, electricity (vs. 58\% for non-Roma). ${ }^{982}$

Absolute poverty rate PPP\$ 4.30 expenditures based: 66\% of Roma; PPP\$ 2.15 expenditures based: 20\% of Roma (UNDP).

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## Country Profile: Slovakia

| Main Characteristics of the Roma in Slovakia |
| :--- |
| Demography |
| The Official number of Roma people in Slovakia is not available. Estimations vary from |
| 320 000 to 500000 Roma people in Slovakia. In official census from 2001 only 89920 |
| declared to be of Roma origin. 983 However, the estimations were around 380000 |
| Roma people who were present in Slovakia. 984 In official Census from 2011 there was |
| an increase in the official number of Roma people in Slovakia, as 105700 respondents |
| declared themselves to be of Roma origin. ${ }^{985}$ |

## Geographical distribution

It is estimated that $60 \%$ of Roma people are fully integrated in the majority population and are living in towns or villages. The remaining 40\% of Roma live in municipal concentrations, settlements close to the municipalities or distant from the municipalities, eg. separated by a natural barrier (river, woods). ${ }^{986}$

Most of the Roma people are located in Eastern and South-eastern parts of Slovakia. There are several localities in western Slovakia were Roma are living either in towns, or villages. The majority of Roma live in regions of Prešov, Košice, and Banská Bystrica. ${ }^{987}$

## Other Information (including highlights of data gaps)

Generally, there is lack of any official data on Roma population in Slovakia. This is due to the fact that state authorities are not allowed to collect data determined by ethnicity and therefore the situation of Roma people in Slovakia is not thoroughly mapped and analysed. However, in the 1990s it was possible to collect such kinds of data.

There have been several surveys specifically targeting Roma population, but they only collected data determined by socio-economic status or level of social exclusion/marginalization. Moreover, information on integrated Roma people is even more difficult to collect.

Among the four key areas of Roma integration, health status and access to health is the area with least available official statistics. Therefore this report is mostly based on data and information gathered in an informal way and by various NGOs or international organisations.
Even though Slovakia has an appointed state authority assigned to Roma issues -

[^166]Slovak Government Plenipotentiary for Roma Communities -- this office and its regional branches do not collect any official data on Roma people regarding their health status.

Mortality and Life Expectancy
Compared to the majority population, Roma live shorter and have higher mortality rates. Infant mortality in Roma population is around $2 \%$ whereas in case of majority population it is $0.8 \%$. It is estimated that Roma people live $10-15$ years less than the majority population, ${ }^{988}$ which is mostly due to their poor living conditions. Life expectancy of Roma in settlements is estimated to be around 9 years shorter than in the majority population. Infant mortality rates are 2-3 times higher in segregated communities than in the general majority population. ${ }^{989}$

Moreover, Roma people have more children. Young people comprise of around $43 \%$ of the overall Roma population, whereas among the majority population their share is lower, namely around 25 \%. The average age of Roma men vary from 55 years to 64 years, and in case of women, 59 to 71 years. ${ }^{990}$ Only 2\% of Roma population reach age above 65 years comparing to $12.2 \%$ of majority population.

The largest gap in life expectancy is present in segregated and secluded areas of Roma settlements with poor living conditions. It is estimated that mortality rate in such settlements is twice or three-times higher comparing to the integrated Roma people. Also the mortality rates of Roma children and youth are higher comparing to the majority population.

There are several factors that influence the life expectancy of Roma people and according to a research they can be summarised as follows:

- lower education level (around 3 \% of Roma population does not complete any formal education compared to $0 \%$ among the majority; literacy rate is $97 \%$ whereas in case of majority population it goes up to 100 \%; Roma people, especially from segregated areas, complete their compulsory education and fall out of the school system)
- inadequate awareness raising
- Iow standard of living, housing, community hygiene, ecologically risky environment etc.
- unhealthy eating habits and low physical activity
- occurrence of alcoho, tobacco use, and drug abuse ${ }^{991}$ (around 64\% of Roma people above 16 years are users of tobacco comparing to $39 \%$ in the majority population; far more men are tobacco users, around 62,4 \% comparing to women 44,6 \%, among the Roma population in Slovakia)


## Prevalence of major infectious diseases

According to the available data and information, Roma have quite low vaccination rates against infectious diseases, such as hepatitis $B$ (vaccination rate among Roma children is 59.2 \% compared to $99 \%$ in the majority), measles (62.2\% among Roma children and 98.4 \% among majority population), rubella (48.3 \% among Roma children and 98.4 among children from majority), tetanus (64,5 \% among Roma

[^167]children and 99 \% among children from the majority population). Around $17 \%$ of Roma minors do not properly follow the child vaccination programs, mostly due to the fact that their legal representatives had forgotten about it, but also due to the lack of information. ${ }^{992}$

A little over half of the Roma people have received some sort of vaccination, whereas the vaccination rates among the majority population reach up to the $99 \%$. The fact that Roma are far behind the vaccination level of majority population is a result of the more difficult access to general health services, and thus irregular contact with general practitioners and other health practitioners. Besides this there also lack of awareness on importance of vaccination and lack of useful information. In 2007 Slovakia adopted a program focused on improvement of Roma health that was implemented through assigned health practitioners who visited Roma communities and educated Roma people on health issues, and vaccination, too. ${ }^{993}$ However, this program is currently on hold due to lack of financial resources.

Moreover general prevalence of typical infectious diseases is present in the separated and marginalized Roma communities due to the lack of adequate housing, overcrowding and lack of adequate sanitation. Occurrence of infectious diseases such as hepatitis B, dysentery, scabies, and also tuberculosis are still evidenced among the Roma communities. This is mostly because of the inadequate hygienic conditions in Roma settlements. ${ }^{994}$
These infectious diseases are not common among integrated Roma and their health conditions are similar to those of the majority population.

## Healthy Life Styles and Related Behaviours

According to the available information, Roma are regular smokers of cigarettes, both men and women. The share of smokers among Roma is twice as high as among the majority population. Moreover, young people start smoking at an earlier age. First experiences with alcohol among both Roma and majority population is typically around 16-18 y.

Nearly one fifth of Roma people (around $16.6 \%$ of Roma adults) are obese and have some weight problems. Nearly $20 \%$ of young Roma people (children up to $18 y$ ) are obese. This is mostly due to the unhealthy life style, lack of diverse diet and nonactive spending of free time. Around one third of Roma do not exercise or conduct any physical activity. Though young children declare they are doing sports and physical activities, around $93 \%$ of them are watching television every day. ${ }^{995}$ Also there is a prevalence of unhealthy diet among Roma people that can be differentiated in accordance with the socio-economic status of the individual and the family. Sweets seem to be a favourite food category as $53 \%$ of children up to $18 y$ consume them daily and consumption of fruits and vegetables is much lower than in case of sweets. Besides this nearly one third of Roma adults (around 30\%) and one fifth of children up to $18 y(17.4 \%)$ are overweight. On the other hand there is also occurrence of malnutrition among Roma people, where around $34 \%$ of them went to bed hungry in

[^168]the past month (at the time of research in 2011). The same problem was also declared by $7 \%$ of majority population.

The only positive categories are sleeping habits and breastfeeding of young children/babies. In these two aspects Roma people seem to have a healthy lifestyle. Breastfeeding is still prevailing and often stays as the major form of feeding until the latter months (around 82.3 \% of Roma children between six weeks and three months of life are breastfed comparing to $60.6 \%$ among the children from the majority population). However, when it comes to other aspects such as smoking, healthy diet, exercising and food composition, Roma lead much unhealthier lifestyle than the majority population. ${ }^{996}$

On the other hand Roma people perceive themselves to be quite healthy (around $20 \%$ of Roma people perceive their health in a very positive way, and nearly one third perceives their health to be average), however, this may be due to the lack of information on health risks and diseases, especially in separated Roma localities. Although in Roma and non-Roma women aged 50 years and over more Roma women declare themselves to be in bad or very bad health ( $41 \%$ Roma $v 25 \%$ non-Roma) ${ }^{997}$.

## Access and Use of Health Services and Prevention Programmes

Generally, Roma people face more obstacles in accessing health services and preventive programmes than the non Roma. In case of integrated Roma population, the access to health services is much easier than in the case of Roma people living in segregated or secluded areas and settlements. Socially excluded people face several barriers with regards to available health care and services. Healthcare facilities are located far away from the places of residence of Roma people. Even though, a successful project focusing on access to health services and care for Roma people was implemented, currently it has been suspended for more than a year due to financial issues. ${ }^{998}$
Moreover 42.3\% of Roma people identified a lack of financial resources as a barrier in accessing the healthcare services, as it was too expensive for them.

Another barrier is the fact that people in Roma localities lack health insurance cards or ID documents. Thus, non-insured Roma have access only to emergency care but cannot use other health services. However, around 94\% of them declare that they have access to health insurance.

Roma people perceive themselves to be in good health, which is another reason for the relatively rare visits for check-ups and consultations with doctors. However, the relatively positive health self-assessment may be due to the low level of information about health care, prevention and health treatment. Another common tendency among the Roma is the self-prescription of various available medicines instead of seeing a doctor and asking for prescription. ${ }^{999}$ On the other hand $48 \%$ of Roma people declare that they do not have access to essential drugs whereas in case of the majority it is around 19\%.

[^169]
## Prevalence of Major Chronic Diseases

Around 18.8 \% of Roma population in Slovakia suffers from some sort of disability or chronic disease. ${ }^{1000}$ According to the available data, Roma people are affected by hypertension, high cholesterol, depression and also by cardio-vascular diseases. Cardiovascular diseases are often a cause of death both among Roma and among the majority population.

Hypertension in Roma population - 9.8\% of men and $4 \%$ of women;
High cholesterol in Roma population - 6.8\% of all adults and children;
Depression in Roma population - 2.9\% of all adults and children;
Cardiovascular diseases in Roma population - heart disease 6\% of population; blood circulation problems 8\% of population;
Osteoporosis in Roma population - 4.3\% of adults;
Reuma/Arthritis in Roma population - 7.3\% of adults. ${ }^{1001}$

## Health Factors Related to the Role of Women in the Roma Community

When considering indicators such as cigarette and alcohol consumption, it could be concluded that Roma women lead a healthier lifestyle than Roma men.

However, consultations with health practitioners, and particularly gynaecologists, are infrequent. Only one quarter of the women regularly visit gynaecologists for check-ups (24.1\%). Consultations about planned parenthood and reproduction are infrequent too (only 12.1\%).

Roma women do attend check-ups in the case of mammography screening, where nearly $75 \%$ received such health service. Together with treatment on cervix sample taking, it may be concluded that in some areas Roma women do attend preventive check-ups that are specially focused on prevention of cancer diseases.

Generally there is very low percentage on use of contraceptives in case of Roma women, only around 1.9 \%.

An FRA gender report (2013) on Roma showed that $24 \%$ of Roma women were in paid work as opposed to only $18 \%$ of Roma men ${ }^{1002}$.

Environmental and other Socio-Economic Factors

The health status of the Roma is very much related to the overall socio-economic situation of the minority group. An estimated $20 \%$ of the Roma population lives in deplorable conditions with lack of proper and adequate housing (eg. slums), lack of any sanitation, lack of clean drinking water, electricity supply, etc. An FRA study also reports similar levels of deprivation stating that $61 \%$ of Roma households live without piped water or sewage or electricity compared to $18 \%$ of the non-Roma population ${ }^{1003}$.

Moreover, around 32 \% of Roma declare that they do not have access to secure housing compared to only $3 \%$ of the majority population with similar problem. Also

[^170]44\% of Roma people do not have access to improved sanitation (not having toilet or bathroom inside their dwelling) whereas in case of majority population it is $12 \%$. Furthermore around $38 \%$ of Roma population does not have access to a good water source (piped water inside their dwelling) compared to $17 \%$ of the majority population.

In addition, around $40 \%$ of Roma people are living in segregated, separated, geographically isolated, or marginalized areas. These people have limited access to electricity (91\%), connection to sanitation (only 19\%), gas connection (41\%), and water pipe connection (37\%). ${ }^{1004}$

Furthermore, the FRA study of Roma by gender states that $92 \%$ of mixed gender Roma households with children are classified as at-risk-of-poverty ${ }^{1005}$. However, a positive is that Slovakian Roma have the highest level of entitlement to pension benefits of Roma across the 11 Member States reported on in this study.

The rest of the Roma population lives fully integrated and thus also copies the health patterns typical for majority population.

In case of not fully integrated Roma people there is a prevalence of low income within the families, low education level due to the fact that Roma are segregated in special schools system where they cannot reach an adequate level of education. A survey from 2011 shows that the share of four year old children from the majority attending preschool education is at about $60 \%$, while among the Roma this is less than $30 \%{ }^{1006}$ Moreover only 19 \% of Roma young adults have completed general or vocational upper-secondary education, comparing to $82 \%$ from majority population. ${ }^{1007}$

Also Roma suffer several forms of discrimination in access to education and employment. The unemployment rate among marginalized Roma people is very high as they lack often lack skills and qualifications needed to find regular employment and face numerous barriers in accessing the regular labour market. Around 29\% of Roma adults (20-64y) have paid employment, comparing to $62 \%$ of the majority population. ${ }^{1008}$ Thus, dependency on social benefits among marginalised communities is high. The dependency on social assistance goes hand in hand with low income, which in turn translates into poor conditions living, lack of proper hygiene facilities and lack of diverse diet - all factors that affect negatively the health status of the Roma.

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## Country Profile: Slovenia

|  | Main Characteristics of the Roma in Slovenia |
| :--- | :--- |
| Demography |  |

The first mention of Roma in Slovenia dates back to the $15^{\text {th }}$ century. Roma in Slovenia can be mainly grouped according to their initial territorial distribution in the country:

- Roma settled in Dolenjska (South East), came from Croatia;
- Roma in Pomurje (North East), came from Hungary in the late 14th century;
- Roma in Gorenjska (North West) came from the group of Sinta in Austria ${ }^{1009}$.

Roma communities in Slovenia are not homogenous, they have different lifestyles, traditions and patterns of contact with non- Roma. Roma socio-economic conditions are worse in the South-Eastern part of the country than the North-East, where a longer tradition of establishment (1850) has led to a more beneficial level of integration into the area. Roma have a common heritage of exclusion but in contrast with other groups in Europe, Roma in Slovenia are mainly sedentary.

The demographic profile of Slovenian Roma is difficult to define, because even if the national census system considers ethnicity and religion as variables, the fact that this is based on voluntary self-declaration might imply individuals choosing various options to define their ethnic affiliation. As a result the number of 3,246 Roma ( 1,645 men and 1,601 women) individuated by the Census in 2002 does not reflect the reality. Estimations provided by 20 municipalities to the office for National Minorities in 2004 counted 6,448 Roma persons, and this estimate did not include the considerable number of Roma living in Slovenian urban centres. Cities were instead included in a further survey based on local housing authority responsiveness to a questionnaire. The results show that there were more than 8,416 members of Roma community living in Slovenia ${ }^{1010}$.

In conclusion it can be estimated that that between 7,000-10,000 members of Roma communities live in Slovenia ${ }^{1011}$. This estimation is confirmed by the council of Europe ${ }^{1012}$.

## Geographical distribution

The above section describes the geographical distribution of Roma in Slovenia. The Roma population is mainly scattered across the country's regions and they mostly reside in isolated settlements or on the outskirts of urban areas, with $39 \%$ living in brick houses and $12 \%$ in apartments. The remaining $49 \%$ live in barracks, containers

[^172]or trailers. The Roma live among the majority population only in the region of Prekmurje, although their number is small ${ }^{1013}$.

## Other Information (including highlights of data gaps)

There are no structured statistics on Slovenian Roma health. Information to compile this report is mainly collated from international (EU) commissioned studies and small scale academic studies carried out at district level. These academic studies and district level studies include a comprehensive study on the "Determinants affecting the health of Roma in Pomurje" and another survey regarding women's health. These studies constitute the main source (together with another piece of research conducted in Kočevje regarding Roma fever health care beliefs ${ }^{1014}$ ) upon which the Fundamental Right Agency (FRA) has drafted its research on the situation of Roma in the EU. Consequently in order to avoid duplications the present report marginally refers to these studies, while its more focused on further investigations' findings related to:

- Healthy Life Styles and Related Behaviours;
- Housing conditions.

As a general remark it must be said that quantitative data on Roma health are fragmented, because data on health are not gathered on the basis of ethnicity and evidence is mainly based on qualitative methods of collection and assessment. Considering the small size of the country and the low mobility of the Roma population there is scope for improvement in data collection. For example, the national vaccination registry, which is also fed in through the school vaccination records might be a good vehicle to improve the level of prophylaxis within the Roma community. Further, local authorities managing housing have good potentials to gather data on Roma.

Moreover, the model of integration stipulated in Pomurje, should be assumed as a good practice to be extended to the rest of the country. Further research and policies should be shaped on this existing model.

## Mortality and Life Expectancy

The study team has found no quantifications of this indicator.

According to the available data the demographic profile of Roma in Slovenia shows that half of the population is younger than 18 years, whereas the percentage of people older than 65 is lower than the general population.

These data confirm that Roma have significantly shorter lives than the rest of the general population in Slovenia ${ }^{1015}$.

Prevalence of Major Infectious Diseases

[^173]The study team has found no quantifications of this indicator. (see section Access and Use of Health Services and Prevention Programmes)

Healthy Life Styles and Related Behaviours
No national reports have been found because national data on health are broken down only by sex and age. A survey, based on 259 randomly selected members of the Roma communities in the Pomurje region between 25 and 65 years, reported that more than half of the respondents assessed their care for their health as good or very good, whereas almost a third of the Roma respondents claimed that their health status was poor or very poor ${ }^{1016}$. The Roma self-assessment of their health status appears to be worse ${ }^{1017}$, when compared with data from the respondents involved in similar national surveys: in fact, in two different surveys from 2004 and 2008, only $9.6 \%$ of the comparable population ranked their health as poor or very poor.

A further survey targeting only Roma women (326 Roma women between 15 and 64 years of age in Pomurje) confirms these findings. The share of women assessing their health state as bad or very bad was 25.5 \%.

Although these two surveys are limited in their scope, they could be taken as a good indication of the general health status of Roma because they analysed a community (Pomurje) where the level of integration of Roma with the environment is good, whereas normally the existing studies - not only in Slovenia - focus on the poorest and most segregated communities, with the risk of providing more biased results.

With regards to life style habits, smoking appears to be the most common risk factor for Roma health status (two-thirds of the surveyed men and half of the women were smokers) ${ }^{1018}$

In 2005 a qualitative study on the attitudes of Roma towards smoking was carried out. Three men and nine women were invited to two focus groups, to discuss smoking related issues. The stratified sample selected was representative of the Southern Roma community. The main conclusions reached are: first, that smoking is a strong part of the cultural, ethnic, and individual identities of the Roma; second, that Roma have a basic knowledge about the harmful effects of smoking; third, the belief that smoking related illnesses are caused by old age and fate, rather than the related habit and finally, that attempts and programmes to quit have not been successful ${ }^{1019}$.

## Access and Use of Health Services and Prevention Programmes

Data on the access and use of health service are again provided by the studies carried out in Pomurje ${ }^{1020}$. The surveys reveal that all respondents have basic health insurance. Indeed, in Slovenia insurance is compulsory and when individuals cannot afford it, local authorities are responsible for covering health care expenses. However

[^174]Roma do not always know the procedures and how to administer these rights related to health ${ }^{1021}$. One in 10 Roma women do not have health insurance.

The situation is more positive for children. Data show that $98.8 \%$ of Pomurje children and $94.4 \%$ of the children in other parts of the country have a selected doctor ${ }^{1022}$.

Participation in prevention programmes is high during the first year of life, but then it declines. This could be due to the low level of school attendance of Roma young people. In absolute terms, the vaccinations coverage of preschool Roma children in Slovenia against poliomyelitis, diphtheria, tetanus pertussis and MMR was lower than the national vaccination coverage for preschool aged Slovenia children. This is because not all Roma mothers give birth in hospital, and some vaccinations' doses are given at birth. However, preschool aged children among Roma show higher vaccination coverage than the school aged generation (-6\%), this is because vaccination is spread through school years. Since Roma children have a high rate of school dropout, not all Roma children complete the course of immunisation ${ }^{1023}$. The situation regarding vaccination is nevertheless improving ${ }^{1024}$.

In terms of methodology, the study of vaccination coverage involved a preschool cohort of 436 six year old Roma children and a school aged group comprising 551 Roma children 16 years of age. To obtain data on immunisation the team research relies upon: the lists of Roma children living in the region studied, and in other areas. Information on eligible children and their vaccination status was provided by primary healthcare givers in health services, and by private doctors and social services knowledgeable about the situation. The team then compared two generations of Roma children, who were preschool and school aged in the year 2001.

For the calculation of vaccination coverage for specific childhood diseases, a formula was used with the denominator representing the total number of vaccination-eligible children, and the numerator indicating the number of children who had received the prescribed doses of vaccine.

This methodology for quantification could represent good practice to be applied regularly and extended to the whole country.

## Prevalence of Major Chronic Diseases

Data on diseases are again provided by the studies carried out on Pomurje ${ }^{1025}$. The study reports that:

- One third of the respondents are overweight;
- One fifth have high level of cholesterol;
- One third have high blood pressure.

[^175]In addition, malfunctions of spine and joints, chronic bronchitis, asthma, cardiovascular diseases and diabetes are reported. For example, in Pomurje 70\% of respondents reported back, neck and joint pains during physical activity.

## Health Factors Related to the Role of Women in the Roma Community

The study team has found no quantifications of this indicator.
Women are reported to experience stress, loneliness and depression, as a result of their subordinate role in the Roma community ${ }^{1026}$. The study in Pomurje found that $37.7 \%$ of women reported depression and $73.2 \%$ reported taking medication in the previous week.

Generally Roma women have a prescribed physician, but they do not have a prescribed gynaecologist and apart from screenings during pregnancy, they do not take part in preventive programmes ${ }^{1027}$.

Environmental and other Socio-Economic Factors

- Housing

Data on Roma housing conditions in Slovenia are mainly based on the "Slovenia RAXEN Thematic Study Housing Conditions of Roma and Travellers" which mainly relies on local housing authorities' information. The Roma housing condition varies across regions. Roma from Pomurje live with the majority of the population, with only 3 settlements being built without permits and the remaining 35 supplied regularly by electricity and water. The situation is different when looking at other parts of the country: in 2007 slightly more than $60 \%$ of the Roma settlements were isolated, more than $20 \%$ of settlements were in the vicinity of towns or were part of towns, and less than $20 \%$ of the Roma settlements were in contact with other settlements. In addition some settlements were irregularly built as per the case of Dolenjska, where 39 settlements out of 57 are built without permits, 18 do not have water and 24 are without electricity. In addition, those settlements are very often overcrowded.

This is also connected to the fact that willingness to sell the land to Roma is low (20\%). The reason for such illegal settlements might also be explained by limited access to social and private housing especially for those Roma that are not Slovenian citizens ${ }^{1028}$.

## - Education

The studies carried out in Pomurje ${ }^{1029}$ establish that most children finish the primary level of education, whereas the study carried out in Kočevje points to the opposite with $43 \%$ of people interviewed never having attended primary school and $21 \%$ having completed only the first two years. These contrasting findings are based on the fact that integration of Roma children in the two places has reached different levels,

[^176]with Roma in Pomurje being better integrated. In general, language is the main obstacle to education, the majority of the Roma children first encounter Slovene when they attend school.

Between 2008 and 2011, because of the European Social Funds 31 Roma assistants have been recruited to support the integration of Roma children into school.

- Employment

The above mentioned Pomurje and Kočevje studies are more consistent regarding the level of employment in the two regions. In both analyses the level of unemployment among Roma has a structural and permanent character. In Pomurje $90 \%$ of the population has been living on social assistance and child benefits, and in Kočevje the percentage of unemployed persons reaches $83 \%$ of the sample considered (136 respondents between 15 and 65 years of age, 88 women and 48 men).

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## Country Profile: Spain

## Main Characteristics of the Roma in Spain <br> Demography

Roma people have been present in Spain since the 15 th century, and, as in the rest of Europe, their history has been marked by persecution, attempts at adaptation, and phases of social exclusion. Currently, the Spanish Roma population stands at around 725,000-750,000, figure s that have been used by European institutions in their estimates on the Roma populations for the whole of Europe. However, certain caution must be observed with respect to these figures as the real size of the population is not accurately known, with estimates of overall figures having been made using a variety of methods (projections from previous studies, in addition to local data being calculated in a number of ways, studies on housing conditions that did not consider Roma people who do not live in densely Roma populated areas, etc.). Therefore, estimates may range from 500,000 up to $1,000,000$ people.

In spite of the limitations in determining the total scale of the Roma population in Spain.

All social demographic studies carried out show that it is a young population, wherein around a third are aged below 16 years, and with birth rates substantially higher than the population average, although in the last decade this disparate rate has begun to reduce. In terms of the social situation, the Roma profile is heterogeneous and diverse; it is a common error to associate a given ethnic group to situations of material deprivation, social exclusion or self-exclusion. Some Roma people enjoy medium socio-economic levels and are fully integrated into society. Moreover, a substantial amount of Roma have seen progress in the last decade, although they still manifest, to varying degrees, social shortcomings and inequalities with respect to the rest of the population.

Lastly, a third, minority sector exists, comprising the severely excluded who have seen little progress in terms of their social inclusion. It must be taken into consideration that the current negative economic climate and deterioration of employment in Spain is taking hold throughout the general
population, but particularly so for socially vulnerable population groups, as is the case for many Roma people; it is essential that social inclusion processes for these people receive continued support in order to avoid stalling or even regression.

## Geographical distribution

It is accurately known that the Roma people are distributed across the national territory, with a most concentrated presence in Andalusia, where around $40 \%$ of Spanish Roma men and women reside, as well as in Catalonia, Valencia and Madrid. Although their history has been associated to rural life and geographic mobility, the current trend is for prolonged, stable settlement in urban areas, which consolidated in the 1950s, 60 s and 70 s to coincide with the general wave of domestic migration between rural areas and cities.

## Other Information (including highlights of data gaps)

In terms of health, the results of a study comparing results of the Spanish National Health Survey (SNHS) with regard to Roma and the general population in Spain highlights that Roma show poorer results in a variety of indicators compared to both those of social groups in a better socioeconomic situation and those in a poorer situation, with differences in terms of health condition, lifestyle and access to certain services. Some of the most pronounced are: perception of own health, the greater prevalence of certain chronic illnesses, and the greater frequency of dental, visual, hearing problems and accidents. Likewise, a higher frequency of unhealthy lifestyles was also detected.

In terms of the access and use of the healthcare system, the low use of preventative gynecological services by Roma women is worthy of note ${ }^{1030}$.

## Mortality and Life Expectancy

Although there is no complete demographic studies for Roma, many experts on health estimate that life expectancy is lower among Roma, and that this difference can exceed 7 years.

The data provided by Ministry of Health comparing some countries indicates that Spanish Roma follow the same pattern that other countries in EU. Using longevity and old-age indicators, the former focuses on the proportion of the population age 75 and over in comparison with the 65 and over group while the latter takes the proportion of people age 85 and over in comparison, once again, with those over age 64. Thus, the Roma population's longevity rate is $25.7 \%$ compared to $51 \%$ for EU- 27 while the oldage rate is $4.5 \%$ for the Roma population as opposed to $11.2 \%$ for $\mathrm{EU}-27^{1031}$.

## Prevalence of Major Infectious Diseases

According to the research Characteristics and outcome of HIV infection in Roma in the Spanish VACH Cohort:
"Results: 4819 (48\%) of 10,032 cases included in the VACH database were eligible: 210 (4.2\%) were Roma and 4252 ( $84.8 \%$ ) were Non-Roma. Differences were observed in age, household, academic, inmate, marital, and employment history. Injecting drug use had been the most frequent mechanism of transmission in both groups, but to a greater extent among Roma ( $72 \%$ versus $50 \%$; Po0.000). Sex distribution, CD4 cell counts, and viral loads at the first visit were similar in the 2 groups, as was the percentage of patients with previous AIDS, percentage receiving antiretrovirals, and percentage subsequently starting antiretroviral therapy. Up to 1 April 2005, 416 new AIDS cases and 85 deaths were recorded. The percentage of these outcomes did not differ between groups, but log-rank test showed a shorter time to AIDS and disease progression among Roma.

[^177]The Roma population is the largest ethnic minority among HIV-infected patients registered in the Spanish VACH Cohort. 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 stricken them particularly hard through the high prevalence of IVDU observed in this population in scattered reports.
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, characteristic of Spanish HIV epidemics in the earlier and middle years, 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 in 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.

In this cohort, HIV disease progressed faster to Aids (and to Aids or death) in
Roma than in 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."

According to the research "Prevalence of hepatitis A antibody among disadvantaged Roma children in northern Spain" the unfavourable living conditions of the Roma population (e.g. homes with poor sanitary conditions, overcrowding) may explain the high prevalence of HAV infection. These findings underline the need for specific action which targets disadvantaged populations.

Among the Roma children of this survey, 82\% had antibodies to HAV compared with $9.3 \%$ of the children in the control group. The unfavourable living conditions of the Roma population (e.g. homes with poor sanitary conditions, overcrowding) may explain the high prevalence of HAV infection. These findings underline the need for specific action which targets disadvantaged populations ${ }^{1032}$.

## Healthy Life Styles and Related Behaviours

In all studies there is a prevalence of different problems associated with lifestyle. They are often overweight and obese in older and younger; only half of the Roma population has a weight considered as healthy. Food less rich in vegetables and fruit and abundant in sweets and fats, along with lack of exercise (also in children) explains this prevalence, which in turn has implications for other diseases in adulthood.

Some noteworthy results (FSG, 2009) ${ }^{1033}$ :

## Smoking

Roma men smoke more than their counterparts in the general population (54.9\% as opposed to $31.6 \%$ ). $20.7 \%$ of social class I and $36.6 \%$ of social class V of the general population are daily smokers.

The gap amongst youngsters is even bigger. 56.2\% of young Roma between the ages of 16 and 24 smoke regularly as opposed to $30.5 \%$ from social class V and $12.4 \%$ of

[^178]social class I. On average, Roma smokers begin at age 14.4 compared to age 17 among the general population.

There is a lower percentage of Roma women who claim to smoke on a regular basis in comparison with the general population (14.7\% compared to 21.5\%). On average, Roma women smokers begin at age 16.7.

Average tobacco consumption is higher for Roma men who smoke 20.8 cigarettes per day as opposed to 16.4 among general population smokers. Roma women smokers consume the same number of cigarettes as women from the general population (between 13 and 14 per day).

## Consumption of alcoholic beverages

Roma men start drinking at an earlier age than men of the general population (age 16 compared to age 18).

Roma women consume fewer alcoholic beverages than women from the general population.
Roma men drink less wine on a daily basis than the general population and consumption of beer and other alcoholic beverages is similar. Survey data does not reflect volume of consumption and therefore no conclusions can be drawn in terms of risk behaviour.

## Eating habits

The percentage of Roma boys and girls who do not eat breakfast (5.5\% and 8.4\% respectively) is higher than for the general population ( $1 \%$ of the boys and $2.1 \%$ of the girls).

## Exercise

Data gathered on physical activity is insufficient to properly identify frequency and intensity and therefore it is not possible to determine whether exercise levels are suitable although significant levels of inactivity have been observed.

## Overweight and obesity

According to the ENS, 19.2\% of under 18 Roma girls are obese. This percentage is higher than for general population social class V (10.1\%) and four times higher than for social class I (5.2\%).
$35 \%$ of Roma men compared to $39.1 \%$ of men from the general population (not a significant dif- ference) are within the recommended body mass index for adults (between 18.5 and $24.9 \mathrm{~kg} / \mathrm{m} 2$ ). In contrast, this difference is statistically significant among Roma women ( $40.4 \%$ as opposed to $52 \%$ of women in the general population).

Access and Use of Health Services and Prevention Programmes
Here we encounter two different situations (FSG, 2009 ${ }^{1034}$ ):

1. Universal health care has meant an improvement in Roma population access to general medical services, hospitals, emergency rooms and access to medicines. The comparatively worse health sta- tus of this sector of the population sometimes implies

[^179]more frequent use of these services in com- parison with the general population.

- The public health system absorbs the bulk of medical visits and hospitalisations of the Roma population.
- The percentage of cases where the Roma population needed medical attention and did not re- ceive it is very similar to that of the general population.
- General medical check-ups, however, are less frequent among the Roma population, the latter more frequently turning to physicians for the diagnosis or treatment of more acute pathologies.

2. Access of the Roma population is lower in the case of services not covered by the National Health System or prevention (as opposed to direct treatment of ailments): dental health, prevention prac- tices among women, access to hearing aids or eyeglasses.

Access to the health system. General medicine, hospitalisation, emergency room and medicines. Some noteworthy results:

## General medicine

$26.3 \%$ of Roma men had been to their general practitioner within the previous two weeks com- pared with $25 \%$ of social class V and $19 \%$ of social class I from the general population. In the case of women these percentages were 33.5\% (Roma population), 39.6\% (social class V) and 26.2\% (social class I).

## Hospitalisation

$11.6 \%$ of the Roma men had been hospitalised during the previous year compared with $10.4 \%$ of the men from social class V and $8.3 \%$ from social class I.

For women (with the exception of births): Roma population (12.2\%), 10.9\% (class V) and 5.4\% (class I).
For older sectors of the population, hospitalisations of the Roma population double those of the general population.

The percentage of hospitalisations grows very swiftly with age in the case of the Roma population.

## Emergency room

Of the Roma population under age 16, 29.8\% of the boys and $40.4 \%$ of the girls had used emer- gency room services during the previous year.

Use by Roma boys is lower than that of boys from the general population (38.6\%)

## Use of medicines

The Roma population consumes more medicines than the general population: for example, $28 \%$ of Roma men and $42.9 \%$ of Roma women report having consumed medicines for pain and/or to reduce fever in the previous two weeks (compared to $14.7 \%$ and $24.9 \%$ for men and women respectively of the general population).

The Roma population takes more prescription medicines than the general population.

Self-mediation is a problem shared by the Roma population and the general population, especially when it comes to medicines for cough, flu, sore throat and bronchitis and those for pain or fever.

Access to the health system: prevention practices among women, dental health, and access to hearing aids or eyeglasses. Some noteworthy results:

## Prevention practices among women

$25.3 \%$ of Roma women over the age of 16 have never gone to the gynaecologist compared with
$17.6 \%$ of the general population ( $25.2 \%$ class V and $9.2 \%$ class I).
A higher proportion of Roma women see the gynaecologist for some gynaecological problem.
The percentage of women reporting that their last visit to the gynaecologist was due to some gynaecological problem is $30 \%$ in the case of Roma women, $20.8 \%$ for class V dropping to $10.2 \%$ for class I.

However, a lower percentage of Roma women see their gynaecologist for regular checkups, this being the reason for the most recent visit to the gynaecologist in $44.2 \%$ of the cases of Roma women, $69 \%$ for class V and $84.2 \%$ in the case of class I .

Mammography's are recommended between the ages of 50 and 64. Of Roma women over the age of $55,59.2 \%$ had had a mammography compared with $72.1 \%$ of women from the general population.

As for pap smears, 47\% of Roma women had undergone the test compared with $52.4 \%$ of the women from social class V and $81.1 \%$ from social class I.

## Dental health

$49.5 \%$ of Roma boys and $51.4 \%$ of Roma girls have never gone to the dentist compared with $39 \%$ and $38.4 \%$ respectively among the general population.

Dental work such as extractions, fillings, caps, bridges or false teeth are less frequent among the Roma population in the case of women and men and children and adults. For example, $42 \%$ of Roma men report having fillings compared with $43.8 \%$ in class V and $71.6 \%$ in class I.

Sight problems, with correction (glasses or contact lenses) if applicable
$14.2 \%$ of Roma men report vision impairment compared to $3.7 \%$ of the general population (4.5\% of class V and $2.4 \%$ of class I).

The figures for women are 19.7\% (Roma population) compared to 6.6\% (general population). In the general population, the percentage varies from $9.4 \%$ for women from class V to $3.7 \%$ for class I.

## Hearing impairment, with correction (hearing aid), if applicable

$42.8 \%$ of Roma men over the age of 55 reported hearing problems as opposed to $24.4 \%$ of the general population. The figures for women are $34.4 \%$ for the Roma population and $20.5 \%$ for the general population.

## New situation due to the economic crisis 2009-2013:

In general there is not a significant deterioration of health of the Roma population, but there are obvious problems associated with certain health cuts: more red tape to get the health card, pharmaceutical co-payment, etc... However, and most worringly, we can see very direct effects on health-related habits in the most vulnerable families, especially children and the elderly and / or disabled, mainly affecting the diet in
children and lack of monitoring chronic disease in the latter. There are more cases of the deterioration of the mental health of Roma, especially women, for depression, anxiety, etc... arising from economic and social experiences very stressful and desperate.

The Roma of Eastern Europe have been severely restricted in their right to health care, due to the new law on health in 2012: lack of health card, barriers for vaccination, overuse of emergency, confusion in processing rules, etc... This limitation is even affecting children and pregnant women.

According to information collected in 54 cities of Spain in 2013 by Fundación Secretariado Gitano, the report concludes that the economic crisis and cuts measures that are being implemented in Spain are very 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 already had precarious situations in many social and labor aspects, and other families who once had a stable situation.

The consequence of the austerity measures is that many Roma families are caught in a complex circle of interactions between the barriers in access to health, employment, education and housing, which ultimately produces greater social exclusion, which means a serious social decline compared to the situation a few years ago in this community.

The measures that have been taken recently, tightening the conditions for payment of the basic income and social assistance, are severely affecting many Roma families; there are cases of people who were independent but now have to return to the social protection system. The social protection system is not meeting the basic needs of the most vulnerable and excluded in our society. Moreover, reducing aid dependency affects many Roma families who have disabled people in their care, giving 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 also has long-term effects on carers because it is limiting their educational and employment promotion.

## Prevalence of Major Chronic Diseases

There is a prevalence of chronic illnesses or disabilities: high blood pressure, diabetes, cholesterol, allergies, respiratory problems among the elderly, and asthma among children.

Psychological troubles: depression or chronic pain (particularly bones and head and migraines).

According to the survey (2009). 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. Madrid, regarding the perception of health, only $10.5 \%$ of Roma women over age 55 describe their health as good or very good compared to $38.2 \%$ in the general population.

Differences in health problems can also be observed depending on the type of housing or level of education: Roma women who live in sub-standard housing or shanty towns 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 (loose teeth), accidents and use of tobacco.

They also show a greater tendency to have had to curtail their main activity or to have used emergency room services more frequently.

Differences are also observed among Roma men depending on their type of housing. Those living in sub-standard housing or shanty towns report a greater number of hernias, hearing problems, accidents, depression and other mental illnesses.

The Roma population with a higher level of academic studies has a better perception of their health status and are less inclined to hypertension, asthma, eye problems and tobacco consumption (the latter only applying to men).

In the case of women, higher academic level is also associated with less obesity and fewer cavities and more frequent preventive practices (mammography's and smear tests).

Of the wide range of health problems studied in the survey (cholesterol, depression, stomach ulcers, migraine headaches, etc.), Roma over the age of 35 (both men and women) suffer these in greater proportions than the general population. In some cases this is also true of younger age groups as well. Examples: $13.6 \%$ of Roma men report having high cholesterol levels compared to $9.6 \%$ from among the general population.

Migraines are more prevalent among Roma women and men (37.1\% and 20.7\% respectively) than among their counterparts in the general population ( $9 \%$ and $3.9 \%$ respectively).
$16.4 \%$ of the Roma women reported allergy problems compared with $10.9 \%$ of the rest of the population.

The depression rate for Roma women stands at $17.6 \%$ compared to $7.7 \%$ of women of the general population.

The asthma rate for Roma children is $13.3 \%$ compared to $5.4 \%$ in the general population.

## Health Factors Related to the Role of Women in the Roma Community

Roma women develop a key role within their community. The play a role as educators, caregivers of children and elderly, and are the transmitters of the norms and values of Roma Culture (García, 2006).

Today many women have shifted from exclusively performing household tasks and childcare to work in the labor market or to play other roles formerly assigned to men. However an FRA study reported that in $201171 \%$ of Roma women are still unemployed or fulltime home makers ${ }^{1035}$. The impact of education, demographic changes, the information technology and urban life have prompted processes of intense and ambivalent cultural transformation, reflected particularly in the younger Roma, but also in women.

At the same time, a reducing birth rate means smaller families, a new position of children and the value of education, and a new relationship between the sexes, as many women do not live dedicated to motherhood and their potential increases because they have more time and better health.

[^180]Nevertheless they suffer more health problems in comparison to Roma men and when compared to women of the general population. The data show problems associated with early and late pregnancy, lower gynecological prevention habits and health problems caused by work overload. It is also important to note, with due suspicion, that regarding self-declared general health Roma women stated less incidents of bad health (19\% for Roma v. 23\% for non-Roma) ${ }^{1036}$.

## Prevention practices among women:

$25.3 \%$ of Roma women over the age of 16 have never gone to the gynaecologist compared with
$17.6 \%$ of the general population.
A higher proportion of Roma women see the gynaecologist for some gynaecological problem.

The percentage of women reporting that their last visit to the gynaecologist was due to some gynaecological problem is $30 \%$ in the case of Roma women, However, a lower percentage of Roma women see their gynaecologist for regular checkups, this being the reason for the most recent visit to the gynaecologist in $44.2 \%$ of the cases of Roma women.

Mammographies are recommended between the ages of 50 and 64. Of Roma women over the age of $55,59.2 \%$ had had a mammography compared with $72.1 \%$ of women from the general population.

## Environmental and other Socio-Economic Factors

The main causes of the worst health of Roma are socioeconomic and related to habitat, in a physical sense and also symbolic. Being segregated or less citizens is in itself a serious health problem. But, as we have seen, the cultural factor in relation to one's health has also a major impact (Ayala Rubio, 2008).

Again, we must distinguish traditional elements of the culture of the body with elements of the transition to a consumer society and with the features of a culture in crisis.

As for the elements coming from the transition to a consumer society, for example, adopting unhealthy habits like smoking or eating industrial cakes is not a traditional activity, but rather an adaptive response to a consumer society whose disciplines must be learned.

Comparative studies show that tobacco is a gateway to modern consumption and its patterns: individualistic, compulsive, but also perfectly compatible with the production, is proof of status and social integration. In countries in transition, as was Spain in the 60s, mainly men of professional elites used to smoke. The rest of society has incorporated these habits later, even if their harmful effects have been proven.

A sedentary lifestyle and the automobile, easy access to cheap and satisfactory goods or the need to be integrated into the consumer society (even in its most popular strata) influences lifestyles and prevalence. In this regard, several studies have found

[^181]that Roma made little or no physical activity in their free time, especially after age 25 (Arza Pozas, 2008).

There are other aspects in which this transition fails or becomes darker. Consumption can be more compulsive, the sense of loss or failure can lead to increased risk behaviors in adults or youth. In many older women this situation is manifested in depression when facing problems of one's life. People more vulnerable such as young women and men can become drug addicts.

## Traditional aspects of Roma Culture related to health

Importance given to health, coupled with the importance of family and the health of others. This fact explains the mutual support between relatives, which in the case of women becomes forgetting one's health and for men to reject the weakness and care. The importance of the elderly and the sense of vulnerability means that disease and death are very present in Roma culture, even young.

Health as absence of disease and as something disabling linked to the death. The Roma community, as almost all traditional populations, only go to the doctor when they are very sick. When a person (and family) perceives that the disease has appeared, the action must be immediate and decisive, given the relationship they feel between illness and death.
Fear of disease is linked to the problems of access to health services in some places. So it is logical to use emergency services instead of the regular (or preventive) and there is a tendency to self-medicate and informal advice from relatives or neighbors.

Health and physical illness. The relationship established between health and the absence of physical sickness means that they do not take into account aspects of behavior related to psychology.

The link of the idea of health with morality, making certain diseases, as HIV, a disgrace and a dishonor, so often lived in secret and with a great sense of guilt, greater in women.

Invisibility of prevention. The fear of death and denial of illness hinder the preventive work, and because Roma, as already mentioned, just go to the doctor when they are very sick. Furthermore, in environments where life is long and with uncertain future, the idea of planning and care makes little sense, while caring for others and securing the future of the group usually does. For this reason many of the behaviors of the Roma have a cultural sense that does not always coincide with the dominant culture of health.

Other distinctive features of the culture that hinder prevention:

- Immediate life (daily living), which on one hand encourages the development of guidelines for daily life, but on the other hand difficult to plan.
- The prevalence of the emotional over the rational, where the action is very present and reflection often serves to fix or remedy, but not to anticipate or prevent.


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## Country Profile: Sweden

| Main Characteristics of the Roma in Sweden |  |  |
| :--- | :---: | :---: |
| Demography |  |  |

According to official government documents ${ }^{1037}$, approximately 50,000 Romas are currently living in Sweden and a similar estimate is provided by the Council of Europe: $35,000-50,000^{1038}$. Although it is stressed in the government documents that the figures are rough estimates, none of them provide an actual source (e.g. a survey or an expert or stakeholder consultation). The 50,000 estimate may originate from a government inquiry from 1997 in relation to the Swedish ratification of the European Council's Framework Convention for the Protection of National Minorities. The 1997 estimate was based on information obtained from various sources including the national minority organisations and state agencies ${ }^{1039}$. According to an interview with a Roma organisation carried out as part of a RAXEN study on Roma housing (2009) the 50,000 estimate was nevertheless still seen as realistic in $2008^{1040} 1041$.

There are five Roma groups in Sweden. The estimated size of the different groups varies only slightly. The following figures are quoted (although not referenced) in a study from the Swedish National Institute of Public Health from $2010^{1042}$. Where other estimates are identified, these are provided with references. The description of each Roma group is drawn from a government document from 2006 ${ }^{1043}$ :

- Swedish Roma people $(2,500)$

This group came to Sweden from Russia around the turn of the last century.

- Finnish Roma people $(3,200)$

The Finnish Roma, or Kale, arrived in Sweden in the 16th century and were deported to what was then the eastern part of the kingdom (Finland). Many Kale Roma moved to Sweden in the 1960s on account of the introduction of Nordic passport exemption in 1954.

- Travellers $(20,000-25,000)^{1044}$

According to certain sources ${ }^{1045}$ the Travellers originate from the first Roma migration

[^182]to Sweden in the 16th century. Others think that they originate from German and French soldiers from the wars of the 17th century that the then King brought with him to Sweden.

- Roma people from outside Nordic countries (10,000-15,000)

Many of them belong to the Lovari-speaking Roma who came to Sweden from Poland and other countries in the 1960s and 1970s.

- Newly arrived Roma people $(5,000)$.

Roma asylum seekers and refugees who have come to Sweden from former Yugoslavia and Kosovo that are classed as new arrivals.

## Geographical distribution

No information has been identified on the geographical distribution of Swedish Roma.

## Other Information (including highlights of data gaps)

Pursuant to the Swedish Personal Data Act it is "prohibited to process personal data that reveals race or ethnic origin" ${ }^{1046}$. There are hence no official register statistics available on the health of Roma.

The most important recent study mapping the health situation of national minorities in Sweden (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 ${ }^{1047}$. 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. Consequently, the quantitative survey approach was abandoned in favour of individual qualitative interviews combined with focus group meetings ${ }^{1048}$ reaching a total 334 individual Roma ${ }^{1049}$.

The remainder of this country report is based on this study along with available international publications on the subject.

Mortality and Life Expectancy
The study team has found no quantifications of this indicator.
Prevalence of Major Infectious Diseases

The study team has found no quantifications of this indicator.

[^183]However, the role of low vaccination rates within the Roma population and its effect on the health status of Roma was mentioned a study by The National Institute of Public Health ${ }^{1050}$.

## Healthy Life Styles and Related Behaviours

The study team has found no quantifications of this indicator.
In a study from 2010 by the Swedish National Institute of Public Health, it was found that physical inactivity and a high fat diet were more common among Roma than the majority of the population. High alcohol consumption was found to be particularly problematic for young males. Additionally, problems with abuse of drugs and medical problems were seen to be widespread. Gambling alongside tablet and drug abuse was also earmarked as a growing problem in this study. ${ }^{1051}$.

## Access and Use of Health Services and Prevention Programmes

The study team has found no quantifications of this indicator.
In a recent Study by the Fundamental Rights Agency, the Swedish Social Insurance Agency (Försäkringskassan) that administers medical insurance, confirmed that no data were collected in the area. A desk review of studies carried out in the context of the same study showed that in the 2006-2012 period no reports or studies providing insight into the medical insurance coverage among Roma had been published ${ }^{1052}$.

A study by the Swedish National Institute of Public Health found that Roma generally wait long before seeking healthcare due to distrust of medical personnel in part out of fear of discrimination ${ }^{1053}$.

Prevalence of Major Chronic Diseases
The study team has found no quantifications of this indicator.
A study by the Swedish National Institute of Public Health found cardiovascular diseases to be a particular problem among Swedish Roma ${ }^{1054}$.

Health Factors Related to the Role of Women in the Roma Community
The study team has found no quantifications of this indicator.
In a study by the Swedish National Institute of Public Health, Roma women reported stress due to the overwhelming burden in their families ${ }^{1055}$.

[^184]The government has commissioned the Swedish National Institute of Public Health to assess the health of Roma girls and women. The study will be carried out by prof. Maria Emmelin of Lund University in collaboration with Roma representatives and experts. Conclusions will be presented in March $2014{ }^{1056}$.

A report, Lyssna, förklara och förstå (2011) collected data on Roma migrants' in the Swedish health care system. This study reported that Roma women generally do not want to be examined by male doctors or use a male interpreter ${ }^{1057}$.

## Environmental and other Socio-Economic Factors

## - Housing

A main source of data for housing is the 2009 study commissioned by Fundamental Rights Agency of the EU - the Raxen National Focal Point for Sweden ${ }^{1058}$. No public data are collected in this area so findings were based on interviews with various stakeholders. The key points are summarised below:

- Municipalities are responsible for the housing supply that is regulated in the Housing Supply Act (2000:1383). This act provides a universal right to housing. However, the Act does not give the residents any individual right that can be determined by the courts.
- According to the Swedish ombudsman, the dominant type of housing for Roma in Sweden is rental housing.
- Roma are according to an activist interviewed often referred to segregated and socially disadvantaged residential areas and their possibilities of choosing housing based on their own needs are very limited.


## - Employment

In the above mentioned 2009 Raxen Study, interviews with Roma organisations and the Swedish ombudsman confirm that landlords' requirements of permanent or lasting employment are difficult for Roma to meet with illiteracy widespread and many unemployed. Landlords do not count social welfare allowance as an income, and Roma who cannot show a clean financial record have difficulties in finding housing ${ }^{1059}$.

## - Education

A key source for education is a Raxen report from 2004 on education of Roma relying mainly on reports from local authorities and to a minor extent interviews with Roma representatives ${ }^{1060}$. The study found that Roma children despite 30 years of active policies were still leaving school in large numbers without completed compulsory education. It also found that discriminatory mechanisms in Swedish society to be an

[^185]important barrier as most Roma had been subject to some form of ethnic discrimination ${ }^{1061}$.

In a study by the Swedish National Institute of Public Health better education is identified as a key factor in improving health of Roma ${ }^{1062}$.

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[^186]
## Country Profile: United Kingdom

| Main Characteristics of the Roma in United Kingdom |
| :--- |
| Demography |
| No Official Data |
| Estimated population 300,000; however there are no official records. See discussion |
| below |

## Geographical distribution

No official data

## Other Information (including highlights of data gaps):

The Roma population in the UK is diverse and made up of a number of different groups, which whilst categorised under a broad definition have distinct and often quite different cultural identities and lifestyles ${ }^{1063}$. Understanding the health status of Roma in the UK is therefore immediately complicated by the demographic and social complexity of the groups designated by that term. Definitions of Gypsy Roma Travellers (GRT) are the subject of much political debate and are often highly contested. They are underpinned by discussions around what Clark and Greenfields ${ }^{1064}$ describe as 'self ascriptive' definitions: Roma Travellers use the term to talk about their own people and communities, and those which are 'imposed' by non Gypsy Traveller Roma who wish to make laws and policies about people they perceive as such. This report adopts the Council of Europe's categorisation of Roma which includes UK Gypsies and Travellers as well as Central and Eastern European Roma who have predominantly migrated to the UK since the fall of the Eastern Bloc in 1989 and in greater numbers since the accession of European States from 2004 onwards.

## UK Gypsies and Travellers

Broadly speaking, UK Gypsies and Travellers are defined and define themselves as: English Romany Gypsies (UK Roma) Scottish Gypsy/ Travellers, Welsh Gypsies, Irish Travellers and New Travellers. While Irish Travellers are not from the same ethnic group or origin as UK Roma they are often brought together in policy documents due to similarities in experience, particularly with regards to the barriers they confront in accessing health, education, welfare, the discrimination and prejudice they face, as well as their cultural accommodation needs.

## Central and Eastern European Roma

Roma from Central and Eastern Europe living as migrants in the UK also represent a diverse range of communities and identities but predominantly come from Poland, Czech Republic and Romania, Lithuania, Slovakia and the former Yugoslavia ${ }^{1065} 1066$.

[^187]Many came to the UK initially to seek asylum and then as migrants under EU accession from A8 countries in 2004 and A2 countries in 2007. Whilst it can be argued that Central and Eastern European Migrant Roma experience similar forms of social exclusion, prejudice and discrimination to UK Gypsies and Travellers, it is also clear from the available literature that their experiences in the UK differ and that their health status, and their ability to access health care and services is shaped by experiences in their countries of origin, and by their status as migrants in the UK.

Given their distinct experiences, and in light of the available literature, UK Gypsies and Travellers (GT) and Central and Eastern European Roma are referred to separately in this report.

## Population Estimates

In contrast to many EU Member States, the UK collects data on the ethnicity of its population. However in spite of this, quantitative data on the number of UK Gypsies and Travellers and Central and Eastern European Roma in the UK is both sparse and unreliable, due in part to the fact that there are almost no official records. Census data for example, did not include UK Gypsies and Travellers as a separate ethnic category until 2011. Other official data collection consists of Gypsy Caravan counts carried out twice-yearly by Local Authorities (LAs) and assessments of accommodation need, known as Gypsy and Traveller Accommodation Assessments (GTAAs). However as Staniewicz ${ }^{1067}$ states with regards to caravan counts, there are likely to be significant inaccuracies due to the fact that LAs may not be aware of all sites. Similarly Niner ${ }^{1068}$ has noted that the Caravan Count numerates caravans not households or individuals. Furthermore an estimated two thirds of Gypsy and Travellers live at least some (if not all) of the time in 'bricks and mortar' housing and the count is done without inclusion or verification of the figures from Gypsies and Travellers. Estimates of the Gypsy Traveller population range from 200,000 to 300,000 ( $0.6 \%$ of the UK population) ${ }^{1069}$. A mapping exercise undertaken by European Dialogue for the Department for Children, Schools and Families in 2009 estimated the minimum number of Central and Eastern European Migrant Roma in the UK to be 50,000. Community estimates range however from 400,000 to 1 million ${ }^{1070}$. 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 Central and Eastern European Roma in the UK. Anecdotal information is currently putting the population of Central and Eastern European Roma in the UK at around 200,000 as of 2012. There are strong suggestions from practitioners working with Central and Eastern European Roma that this figure is increasing.

## Health Data

Similarly, both quantitative and qualitative data on the health status of GRT are largely unavailable. There are no official health records which focus on GRT as an ethnic group and a recent report by the Irish Traveller Movement in Britain (2012), 'Inclusion and Ethnic Monitoring of Gypsies and Travellers in the National Health Service' highlights that despite a commitment from the Department of Health and the National Health Service (NHS) to address health inequalities, there is a lack of ethnic data collection and commitment to such a process at the local level.

Given the lack of official and systematic data collection on Roma health, this report draws on academic research, local, qualitative studies, project evaluations, grey

[^188]literature and data collected by advocacy organisations to provide an assessment of the situation. Data has been assessed under the following categories: Mortality and life expectancy, prevalence of major infectious diseases, healthy life styles and behaviours, access and use of health services and prevention programmes, prevalence of major chronic diseases, health factors related to the role of women and environmental and socio-economic factors. When combined, they aim to sketch a picture of Roma health in the UK as is currently understood.

Existing research, both qualitative and quantitative, is consistent in drawing attention to the striking health inequalities between GRT and the rest of the UK population. Parry et al's (2007) ${ }^{1071}$ study 'Health Status of Gypsies and Travellers in England' for example was the first epidemiological study of its kind to attempt to produce reliable data on the health status of this group. It highlights the significant health inequalities that exist between Gypsies and Travellers (excluding Central and Eastern European Roma) and non Gypsies, even when compared with other socially excluded and deprived groups. Other research identified in this report reinforces the link between health status and wider social determinants such as social exclusion, discrimination, access to suitable accommodation and welfare as well as cultural practices and understandings of health as being significant factors in the health of both UK Gypsies and Travellers and Central and Eastern European Roma.

## Conclusion

Research which uses appropriate methodologies that combine qualitative and quantitative approaches and which pay close attention to specific indices of health is needed in order to begin to paint a more detailed picture of Roma health in the UK. In addition to this there is a need to further investigate the impact of social exclusion, discrimination, and low socio economic status on the impact of health status and to explore Roma experiences as compared to other socially disadvantaged groups. The diversity of Roma in the UK, the differing experiences of UK Gypsies and Travellers as compared to Central and Eastern European Roma and the diversity within these two categories suggests that there is also scope to explore differing experiences within the category of Roma as well as how cultural factors influence health.

A greater commitment to more effective data gathering, for example ethnic data at the local NHS level, could also contribute to a broader understanding of the health issues at stake for this group.

More detailed and effective data on health status and health barriers for UK Gypsies and Travellers also needs to be met with policy change and a commitment to address health inequalities through innovative practice. There is also some evidence of commitment from the NHS and the Department of Health to tackle health inequalities at a community level through initiatives such as the Pacesetters Programme. This has had some positive effects, at least on a local level. Cleemput (2010) et al's evaluation of the Health Ambassadors project in the Midlands, for example, suggests that attempts to create dialogue between Gypsies and Travellers and health professionals has facilitated enhanced cultural awareness on the part of health professionals and a better understanding of the health system and approaches to health care for Gypsies and Travellers. However, the report suggests that deeply embedded negative assumptions of Gypsy Traveller, culture, values and lifestyle means that there is still a long way to go.

[^189]
## Mortality and Life Expectancy

Research into life expectancy and cause of death amongst UK Gypsy and Traveller populations is extremely limited and appears to be non-existent for Central and Eastern European Roma migrants in the UK. However, small scale, localised studies consistently state that the life expectancy of Gypsy and Traveller and Central and Eastern European Roma is lower than the general population ${ }^{1072}$.

Clark and Greenfield ${ }^{1073}$ for example report that a study from Ireland demonstrates that Irish Traveller women and men are estimated to live 12 years less and 10 years less respectively, on average, than the sedentary population. In the UK an example is the average life expectancy in Leeds. An overall average life expectancy of 78 years was reported yet only $3 \%$ of Gypsies and Travellers were over 60 years of age ${ }^{1074}$.

Data on infant mortality rates also show higher rates of infant mortality amongst UK Gypsies and Travellers as compared with the non Gypsy Traveller population. For example, in Parry et al's ${ }^{1075}$ study 26 Gypsy Traveller women out of 172 interviewed had lost a child (excluding miscarriages) as compared to no women from the non Gypsy Traveller control group.

Higher levels of infant mortality amongst Gypsy Traveller populations are also emphasised by a study carried out by Pahl and Vaile (1988): 'Health and Health Care Among Travellers ${ }^{1076}$. This study focused on Traveller mothers and their children under five living in Kent. Data was collected by health visitors among all known Traveller sites in the area. The study found that infant mortality amongst Traveller communities in Kent stood at 17.5 deaths per 1,000 births, whereas the figure for the non Gypsy and Traveller population across England and Wales was 11.9 deaths per 1,000 births.

Clark and Greenfield ${ }^{1077}$ highlight further disparities between Gypsy Traveller populations and the general population by drawing on findings from the 'Confidential enquiries in to maternal deaths in the UK 1997-1999'. This report specifically asserts that Traveller women from 'traditional communities' (rather than New Travellers who are also at increased risk), are statistically at greater risk of maternal mortality than any other community in the UK.

## Prevalence of Major Infectious Diseases

There are no data regarding the prevalence of major infectious diseases amongst UK Gypsies and Travellers and Central and Eastern European Roma in the UK. Lower levels of childhood immunisation amongst UK Gypsies and Travellers are however highlighted in two studies by Feder (1993) and Pahl and Vaile (1988).

Feder's (1993) ${ }^{1078}$ research 'Traveller Gypsies and Childhood Immunisation: a study in East London', focused on the immunisation status of Gypsy Traveller children recorded

[^190]at two GP surgeries and a paediatric Accident and Emergency in East London between July 1988 and Feb 1990. A study of records for 72 Gypsy Traveller children and 106 control children aged between 10 months and 6 years was also conducted. The study found that Gypsy Traveller children had a significantly lower completion rate of vaccines for Pertussis, Measles, Diphtheria, Tetanus and Polio compared to the control group. Only 20\% of Gypsy Traveller children had had their MMR vaccine, as compared with 71\% of the control group.

Similarly, Pahl and Vaile (1988) found from their study of Traveller sites in Kent that $14 \%$ of Traveller children had had their MMR vaccination, as compared to $55 \%$ of the children from the general population.

Health needs assessments were also carried out by Cumbria National Health Service (2009), NHS West Sussex (2010), Cambridge PCT (2010), Surrey NHS (2011) and NHS Luton (2009). These studies also reported lower levels of immunisation amongst Gypsy and Traveller children (e.g. $42 \%$ as opposed to $95 \%$ in Cumbria) ${ }^{1079}$.

These studies are both small scale and local in their focus and therefore cannot necessarily claim to be representative of the Gypsy Traveller population as a whole. However Feder (1993) argues that the low levels of immunisation amongst Gypsy Traveller children are indicative of a range of factors shaped by their culture and lifestyle. Key factors are: Involuntary mobility as a result of eviction from sites, difficulties in registering and accessing GPs and a lack of information regarding community health. Parental choice is the main reason for non-completion of childhood vaccinations for the non Gypsy Traveller population.

Hepatitis B has been found in endemic levels within the Romanian Roma community and particular Roma communities show higher rates of contagious diseases. These include tuberculosis, hepatitis, scabies and pediculosis ${ }^{1080}$.

## Healthy Life Styles and Related Behaviours

Local studies as well as anecdotal evidence from Gypsy Traveller communities, point to high levels of cardiovascular disease, cancer, asthma diabetes, arthritis, chronic renal and urinary tract infections as well as smoking related diseases such as respiratory tract infections and emphysema. These conditions are, strongly linked to life style, low socioeconomic status and poor environmental conditions ${ }^{1081}$.

## Smoking

Parry et al's (2007) ${ }^{1082}$ research shows higher rates of smoking amongst Gypsy Traveller populations as compared to the control group. From a sample of $260,64 \%$ of $16-35$ year old Gypsy Traveller are current smokers as compared to $26 \%$ of the control group.

Tobi et al (2010) also stated that smoking rates were highest among the Roma (74\%) when assessing the health and social care needs of Eastern Europeans living in Barking and Dagenham ${ }^{1083}$. Another paper on the drug habits of Roma migrants in Tower Hamlets in London (Winyard and Felja 2010) also suggests that there are also high levels

[^191]
## of smoking amongst the Central and Eastern European migrant Roma population.

Moore's (2010) ${ }^{1084}$ study of Slovak Roma in Tinsley, Sheffield is small scale and local in its focus. It highlights a range of cultural factors within this community which contribute to ill health and which have shown 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.

Moore ${ }^{1085}$ also highlights an overall poor awareness of how to maintain a healthy lifestyle amongst Slovak Roma, while Mahoney (2006) ${ }^{1086}$ attributes poor diet amongst Central and Eastern European Roma in Leeds to poverty and a lack of money to buy fresh fruit and vegetables.

Anecdotal evidence from a project working with Central and Eastern European Roma at the Black Health Agency in Manchester also points to high levels of dental decay amongst Central and Eastern European Roma children due to lack of awareness of the food and drinks which contribute to decay, as well as lack of access to dentists.

## Drugs

A six month piece of research carried out by Tower Hamlets (London) Substance Misuse Service and the Roma Support Group ${ }^{1087}$ draws attention to the rising numbers of Central and Eastern European Roma young men who require intervention for heroin and cocaine dependency. Indeed, $10 \%$ of referrals to the specialist drug treatment centre for heroin dependency in the past two years have been young people from the Roma community and non Roma from Eastern European Countries.

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 in 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.

## Access and Use of Health Services and Prevention Programmes

Language and literacy barriers profoundly affect the ability of Central and Eastern European Migrant Roma to access health services in the UK. Reports ${ }^{1088}$ highlight difficulties in accessing appropriate interpreters for GP and hospital appointments and a lack of simply written and translated materials regarding health services. In addition Central and Eastern European Roma, particularly those who have recently arrived in the UK, have very little knowledge of how the health system works and the services available to them.

Such barriers are further cemented by distrust of health professionals ${ }^{1089}$ and a lack of culturally appropriate services (Toby and Sheridan 2010). A health and social care needs

[^192]assessment of Eastern Europeans in Barking and Dagenham notes that taboos within Roma culture around issues such as sexual health, drug and alcohol abuse, disability and mental health mean that such issues may not be brought to health professionals or conversely that discussion of the issues in a culturally inappropriate way can deter Roma from seeking help in the future ${ }^{1090}$. This study noted that only $57 \%$ of Roma had registered with a GP citing various reasons; ignorance of the process, never tried/bothered, and language barriers.

Moore ${ }^{1091}$ and others also draw attention to the lack of social networks, representation and advocacy available to support Central and Eastern European Roma in accessing health services. Health professionals also lack knowledge about organisations such as the Roma Support Group who advocate for the community, therefore overlooking the opportunity to increase the reach of their services.

The Roma Support Group's evaluation of its three year Mental Health Advocacy Project (2012) ${ }^{1092}$ with the Central and Eastern European Roma Community in London highlights some recurring themes with regards to barriers to mental health services:

- A lack of trust in mental health professionals
- Lack of knowledge of the existence of mental health services
- Communication, language and literacy barriers
- Stigma of mental health issues.

More has been written about the barriers that UK Gypsy Traveller communities face in accessing health services. Similar to Central and Eastern European Migrant Roma, 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. Gypsy and Traveller cultural understandings of ill health are also significant. In her analysis of Gypsy and Traveller Social exclusion and its impact on health status, Cleemput (2010) highlights the following points with regards to the reticence of Gypsies and Travellers to access health care:

- A sense of fatalism regarding ill health particularly in relation to cancer
- A need to identify and present as 'strong, tough and healthy' as way of maintaining control in the face of exclusion and discrimination
- A lack of trust in health professionals diagnoses
- Anticipated discrimination and lack of confidence in being taken seriously
- A lack of knowledge about the body, medical conditions and prevention

Research by Feder (1989) highlights the discrimination faced by Gypsies and Travellers when attempting to access primary care. This study shows that 10 percent of GPs in East London refused to accept travellers on their list. There is also further anecdotal evidence of Travellers being refused GP registration ${ }^{1093}$.

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

[^193]travel long distances to visit their GP and evictions due to a lack of authorised sites are all relevant ${ }^{1094}$.

## Prevalence of Major Chronic Diseases

Data on the prevalence of major chronic diseases are limited to small scale, local, qualitative research and anecdotal evidence. Studies have pointed to the following issues:

- Moore ${ }^{1095}$ highlights that 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 Roma presenting with undiagnosed health conditions is also common
- Nearly half of Roma respondents in Leeds reported that someone in their house was suffering from a long term health condition (Mahoney 2006, p.19).


## Mental Health

Very little research has been done into GRT and mental health. However, small studies and anecdotal evidence suggests that Gypsies and Travellers suffer from high levels of mental illness ${ }^{1096}$. This section of the report draws primarily on grey literature.

## Central and Eastern European Roma

Data gathered from reports and the Roma Support Group's own statistics demonstrate poor mental health amongst high numbers of service users accessing their health project. For example $50 \%$ of 300 clients suffered from mental health problems ranging from depression, personality disorders, dementia, learning disabilities, suicidal tendencies, self-abuse and drug abuse ${ }^{1097}$.

These findings are reinforced by the report from Tobi and Sheridan ${ }^{1098}$ which highlights high levels of stress, anxiety and depression amongst Roma which is influenced by the impact of migration, traumatic experiences in their country of origin and the challenges of negotiating and adapting to a new culture. Moreover the impact of consistently experiencing, racism, discrimination and social exclusion should not be underestimated.

## UK Gypsies and Travellers

Yin Har Lau and Ridge ${ }^{1099}$ also highlight social exclusion and experiences of racism and discrimination as significant factors contributing to mental health problems in Gypsy and Traveller communities. They also cite a report undertaken by Cemlyn et al (2009) for the Equalities and Human Rights Commission which found strong evidence to suggest that a high proportion of Gypsy Traveller families are affected by suicide and that this is anecdotally linked to depression influenced by 'social exclusion, experiences of racism, and unresolved grief following the death of close family members ${ }^{11100}$.

[^194]Yin Har Lau and Ridge (2011) ${ }^{1101}$ also suggest strong links between the lack of site provision and culturally sensitive accommodation and mental health issues amongst UK Gypsies and Travellers, underlining a 'psychological aversion to housing' (p.130)

## Health Factors Related to the Role of Women in the Roma Community

Yin Har Lau and Ridge ${ }^{1102}$ make the general statement that there is significant pressure within GRT communities to conform to traditional gender roles, that domestic violence is relatively common and that this has obvious effects on mental health such as low selfesteem and depression. Findings from a $2007^{1103}$ report on the health of Gypsies and Travellers in Wrexham are consistent with this statement. It reports that 61\% of married English Gypsy women and 81\% of married Irish Traveller women interviewed for the study had experienced direct domestic abuse. However as Yin Har Lau and Ridge point out, there is no further information regarding how the sample was obtained and how this might influence the findings, nor do they underline any concrete evidence of the health impacts of domestic violence.Parry et al (2004) also noted that anxiety was twice as prevalent in women than men in the Roma community ${ }^{1104}$.

Staniewicz's ${ }^{1105}$ assessment of Gypsy and Traveller housing and accommodation also suggests that gender roles within these communities have an impact on health, stating that Gypsy and Traveller women accommodated in 'bricks and mortar' experience intense isolation due to the fact that they often become disconnected from their communities and are less likely to go out to work than men. Pahl and Vaile's (1988) study of Traveller women and their children under 5 living on sites in Kent, suggests that poor conditions on sites have a disproportionate effect on women and children due to the fact that they spend more time there.

Mahoney's study ${ }^{1106}$ of Central and Eastern European Roma in Leeds raises concerns regarding women's knowledge of health services suggesting that women may be unaware of their entitlement to maternity services and to free contraception.

Discussions with the Black Health Agency in Manchester have also highlighted strict moral codes for Central and Eastern European Roma women regarding contraception. However due to the limits of this report we have been unable to explore this further.

## Environmental and other Socio-Economic Factors

The impact of housing, accommodation and related environmental factors on the health status of GRT is discussed in a number of different studies. There are distinct differences between the housing and accommodation needs of UK Gypsies and Travellers and Central and Eastern European Roma. While the preference amongst Gypsies and Travellers is to live on caravan sites - by contrast Central and Eastern European Roma who have been sedentary for generations ${ }^{1107}$ live predominantly in overcrowded, privately rented housing in the UK.

[^195]
## UK Gypsies and Travellers

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 ${ }^{1108}$. 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 ${ }^{1109}$.

The occupation of 'bricks and mortar' housing by Gypsies and Travellers has been linked to mental health problems ${ }^{1110}$. 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 (Felder and Hussy 1990, Pahl and Vaile 1988)

## Central and Eastern European Roma

Roma access to accommodation in the UK is shaped by their status as EU migrants and their access to employment but is also mediated through their experiences as a socially excluded ethnic minority ${ }^{1111}$. Since EU accession in 2004, Roma have entered the UK as economic migrants. Studies of Roma in Leeds ${ }^{1112}$, Glasgow (Poole and Adamson 2008) and Thameside, Greater Manchester ${ }^{1113}$, 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 with high rents ${ }^{1114}$. There are two key reasons for this: first, Roma people are often badly paid and in 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 (Poole and Adamson 2008). 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.

Poverty and in some cases destitution is therefore a persistent problem for Central and Eastern European Roma. Moore's (2010) study of Slovak Roma in Sheffield notes how a lack of resources impacts on families' abilities to access healthy food and exercise and that the stress associated with poverty often means that health is not prioritised. Health

[^196]workers in Leeds have identified lack of clothing and fresh food, and lack of money to buy milk formula amongst Central and Eastern European Roma ${ }^{1115}$.

All the evidence suggests that socio economic factors fundamentally impact on health. Cleemput (2010) argues that medical interventions are far less significant than socioeconomic factors in determining the health of GRT, a position which is reinforced by Cemlyn et al's (2009) report for the Equality and Human Rights Commission

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## Appendix C Glossary

| Abbreviation | Full name | Explanation if applicable |
| :---: | :---: | :---: |
| A\&E | Accidents and Emergency | Emergency department of a Hospital |
| BCG | Bacillus Calmette-Guérin | Vaccine against Tuberculosis |
| CAHROM | Ad Hoc Committee of Experts on Roma Issues | Committee under the Council of Europe |
| CEE | Central and Eastern Europe |  |
| CHD | Coronary heart disease | The narrowing or blockage of the coronary arteries |
| CoE | Council of Europe | International Organisation |
| CSD | Centre for the Study of Democracy | Research institute contributing to this study |
| DET | Data Extraction Tool |  |
| DG REGIO | Directorate General for Regional and Urban Policy | Directorate General under the European Commission |
| DG SANCO | Directorate General for Health and Consumers | Directorate General under the European Commission |
| EC | European Commission | Institution under the European Union |
| ECDC | European Centre for Disease Prevention and Control | European Union body |
| ECHI | European Core Health Indicators | Health indicators are sets of data (tables, graphs, maps) on health status, determinants and care in EU member countries |
| ECRI | European Commission against Racism and Intolerance | NGO |
| EEA/EFTA | European Economic Area /European Free Trade Area | An Area covering Norway, Iceland and Liechtenstein as well as the European Union excluding Croatia |
| EHES | European Health Examination Survey | The European Health Examination Survey is a collaboration to collect nationally representative, high quality health data which are comparable between countries and over time |
| EMCDDA | European Monitoring Centre for Drugs and Drug Addiction | European Union body |
| EP | European Parliament | Institution under the European Union |
| EPHA | European Public Health Alliance | Research institute contributing to this study |
| ERDF | European Regional Development Fund | The Fund aims to promote economic and social cohesion by correcting the main regional imbalances and participating in the development and |


| Abbreviation | Full name | Explanation if applicable |
| :---: | :---: | :---: |
|  |  | conversion of regions, while ensuring synergy with assistance from the other Structural Funds |
| ESF | European Social Funds | The ESF is Europe's main instrument for supporting jobs, helping people get better jobs and ensuring fairer job opportunities for all EU citizens |
| EU2020 |  | Europe 2020 is the EU's growth strategy for the coming decade |
| EUROFOUND | European Foundation for the Improvement of Living and Working Conditions | European Union body |
| FRA | European Union Agency for Fundamental Rights | European Union body |
| GP | General Practitioner |  |
| HLE | High Level Events |  |
| IOM | International Organisation for Migration | International Organisation |
| IVDU / IDU | Intravenous Drug User |  |
| LIBE | Committee on Civil Liberties, Justice and Home Affairs | Committee in the European Parliament |
| MdM | Médecins du Monde | NGO |
| MDRTB | Multi-drug-resistant tuberculosis |  |
| NRIS | National Roma Integration Strategy |  |
| OECD | Organisation of Economic Cooperation and Development | International Organisation |
| PROGRESS | Programme for Employment and Social Solidarity | The PROGRESS programme is a financial instrument supporting the development and coordination of EU policy |
| RAXEN | Racism and Xenophobia European Network | Research Network |
| Social OMC | the Open Method of Coordination for Social Protection and Social Inclusion |  |
| SRSG | the Special Representative of the Secretary General for Roma issues | European Union body |
| TB | Tuberculosis |  |
| UK GRT | United Kingdom Gypsies and Travellers |  |
| UNDP | United Nations Development | International Organisation |


| Abbreviation | Full name | Explanation if applicable |
| :---: | :---: | :---: |
|  | Programme |  |
| UNICEF | The United Nations Children's <br> Fund | International Organisation |
| WHO | World Health Organisation | International Organisation |
| WB | The World Bank | International Organisation |

## Appendix D Interview Respondents

## Irina Dinca

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## Gregor Burkhart

Senior Scientific Analyst - Prevention
European Monitoring Centre for Drugs and Drug Abuse

## Agnieszka Gajewska

Ministry of Administration and Digitization of Poland

## Livia Otal

Roma Mission Coordinator
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Ronnie Fay
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Pavee Point Ireland

Henry Scicluna
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## Jaroslav Kling

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## Maja Saitovic

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## Part 2

## Data Collection

## in the Member States

## Appendices

## Appendix A Country Reports (Providing a 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 National Roma Integration Strategies in the area of health)

## Country Report Austria

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed 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 outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or <br> future) projects on <br> Roma that might <br> produce data on <br> health   | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes (integrated packages of policy measures in social inclusion policy) | No | Indirect objectives: -Inclusion in the healthcare system -Overcome language barriers | No | There is a proposed research project which will use expert interviews, focus groups and database analysis as part of a mixedmethods approach to better understand Roma health. | Breast screening project in Vienna (for socially disadvantaged/migrants) | Yes (funds allocation is not specified) | $\begin{aligned} & \text { Yes (not } \\ & \text { specifically } \\ & \text { addressing } \\ & \text { Roma } \\ & \text { health } \\ & \text { issues) } \end{aligned}$ |

Although the Austrian strategy document recognises the Roma community as a separate and heterogeneous group, the welfare and social inclusion policy is not Roma-specific. Austria has prepared a set of integrated measures targeting Roma issues within the context of a broader social inclusion policy, whose objectives more generally include increasing inclusion and reducing language barriers in the health service. In the past this has included the introduction of mother tongue experts, seminars on intercultural skills, intercultural training courses and foreign language brochures aimed at patients.

In the healthcare system itself Austria provides services regardless of demographics and does not take special account of the Roma community. The only current project which provides some information on Roma health (indirectly) is a general screening project
aimed at the socially disadvantaged and migrants. There is no current quantitative information regarding the current health status of the Roma community according to recognised health indicators, although there are plans for a mixed-methods exploratory study into Roma health. The strategy document however does refer to specific funding ( 23,500 EUR in 2009) for the activity of the Ketani Association (NGO) which offers therapy to the Roma community (among others). There is also reference to access to European funds, but no mention of specific projects or precise budgetary values. At present there is mention of a framework for monitoring the health of the Roma community via a working group, but no specific logistical explanations.

## Country Report Belgium

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed 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 outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | Access to healthcare Encouraging the collection of data | No | No <br> (however two surveys are planned: (i) a survey on the push and pull factors associated with intraEuropean migration, and (ii) a survey of factors that attract people to migrate) | Intercultural mediators, Accessible health care for Roma patients, Networking between healthcare providers | No | Yes (not specifically addressing Roma health issues) |

The Belgian strategy document distinguishes the Roma population as a separate disadvantaged group. There is also description of sub-categories according to waves of immigration over time. However where health policy is concerned the Roma community is not considered separately. There are no distinct quantitative targets with respect to the health status of the Roma community, but there is acknowledgement of reduced health access and current status. Monitoring activities are largely unspecified despite the fact that the Federal Government, in conjunction with the associations of Social Welfare Offices, will consider how data on the various target groups (including Roma) that approach Social Welfare Offices for help could be recorded. Two surveys will be carried out, but they will not focus on Roma Health. The national respondent to our survey confirmed that plans to fund activities to collect data on Roma health are unknown; reiterating that in Belgium data cannot be collected on the basis of ethnicity ${ }^{1116}$.

It must be noted however that Belgium does deploy cultural mediators to improve Roma community relations with healthcare providers. Cultural mediators might be a means to collect data on Roma health status, but again there is no quantitative explanation of the extent or future plans for this activity.
${ }^{1116}$ Source: Second round Delphi Survey

## Country Report Bulgaria

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed 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 outputs and impacts on Roma Health | NRIS <br> (current or future) specific projects on monitoring Roma health | NRIS <br> (current or future) <br> projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | Ensuring equal access to healthcare and preventive programmes, <br> Preventive healthcare for mothers and children, Equal access for minorities, Increase Roma health specialists and mediation, Raise awareness and access to information, Increase health insurance in ethnic minorities | Unconfirmed | Unconfirmed | Unconfirmed | Yes (fund allocation is not specified) | Yes <br> (not <br> specifically <br> addressing <br> Roma health issues) |

Bulgaria distinguishes the Roma population as a separate disadvantaged group. The strategy document outlines a number of objectives under the broad aim to ensure equal access to healthcare and preventive services. There is mention of future monitoring activities in the strategy by using the monitoring system from the implementation of the National Action Plan for the Decade of Roma Inclusion initiatives 2005-2015. The national respondent to our survey confirmed that data on Roma health will be collected through the monitoring of the implementation of projects and through the assessment of their results, as well as specific surveys. The main institutions responsible for implementing such activities are public authorities, general practitioners, hospitals and health care centres. The respondent also observed that the planned activities in the context of the NRIS have been set in a way that can be measured against the SMART approach, which is able to measure the NRIS short, medium and long term impacts on Roma health. In addition, the activities set are judged to be sustainable beyond the timeframe of the NRIS itself.

These findings are slightly different to the review of the strategy documentation, which does not show quantitative values provided with respect to objectives, health outcomes/impacts, monitoring or a proposed budget. Further clarifications are needed to understand the actual situation in Bulgaria.

## Country Report Croatia

The table below gives an overview of the current and future activities to collect da'3wta to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health issues <br> subject to specific positive actions | NRIS priorities for Roma health | NRIS specific indicators/benchmarks to evaluate NRIS outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS <br> (current or future) <br> projects on <br> Roma that might <br> produce <br> data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of <br> structural  <br> funds for <br> projects to <br> monitor or to <br> improve  <br> Roma health  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | Increase health insurance coverage, Increase healthcare availability, <br> Improve <br> personal responsibility for health, Improve women's health (especially sexual), <br> Improve relationship with healthcare professionals, Reduce sanitary preventable disease, Reduce consumption of addictive substances | Inclusion rate in health insurance, <br> 100\% access by Roma population by 2020, <br> Rate of contraction of lifestyle related disease, Reduce mortality rate of children, <br> Survey on satisfaction from both sides, <br> Rate of contraction of sanitary disease or disease w/vaccinations, Rate of addictive substance use | Planned actions/surveys to monitor: <br> Health - Mortality (\& infant mortality) rates, Vaccination rates, Extent of health insurance coverage, Underage pregnancy rates | Roma Inclusion Action Plan (pre-NRIS) | Yes (funds allocation is not specified) | Yes (not specifically addressing Roma health issues) |

Croatia's strategy document does define the Roma population separately, but there are no Roma-specific health policies. The document provides an extensive statistical account of the current state of health in the Roma community, including current health perception, insurance use, financial restrictions on doctor attendance, life expectancy and others. Croatia clearly defines strategy goals and specific indicators for measurement. However there are no set targets, but rather a measured improvement over time. There is evidence of a pre-NRIS program which would collect some health data on the Roma community, however there are no budgetary or spending references to it. In addition actions are in place to measure: (i) mortality and infant mortality rates, (ii) vaccination rates, (iii) extent of health insurance coverage; and (iv) underage pregnancy rates. Data collection via annual surveys is 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 to be extracted from forms provided by the Central

Health Information System. Notwithstanding the intention of carrying out studies on Roma health issues there is a lack of up to date information about the outcomes/ impacts of the suggested interventions or objectives implemented so far.

## Country Report Cyprus

The table below gives an overview of the current and future activities to collect da'3wta to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed 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 outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| No | No | No | No | No | No | No | No |

The term "Roma" is not in the traditional Cypriot vocabulary, which instead uses various terms to characterise Cypriot gypsies (some of whom may be ethnically Roma). The strategy document outlines the country's inclusive healthcare provisions regardless of demographics. Therefore there is no specific mention of Roma as a subgroup and by extension no policy measures, programmes or objectives.

## Country Report Czech Republic

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed 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 outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| No | Yes | Increase awareness of healthy lifestyles, <br> Strengthen public education activities in excluded localities, Reduce prejudice toward health workers, <br> Improve awareness of cultural and social differences which affect diagnosis | No | Yes | Programme for: health mediators (pre- NRIS), social assistants | No | Yes <br> (ESF to be used to extend the training programme for social assistants who coordinate with the Roma population) |

The strategy document provided by the Czech Republic addresses the Roma population as a distinct group. Recent research uncovered problems which are reflected in the NRIS current objectives. There is an overarching focus on the cultural and social nuances the Roma community demonstrate and which contribute to sub-optimal healthcare provision and uptake. The objectives include awareness raising activities within the community and action on behalf of healthcare professionals to reduce the cultural or social distance and/or misunderstanding. A program of health mediators in the country has produced some data on the health status of the Roma population, however the information is not comprehensive nor does it refer to accepted health indicators. Similarly the programme for social assistants funded through ESF does not make reference to outcome/impact indicators for Roma health. In practice there are no quantitative measures included in the objectives, future projects or fund allocation, nor planned studies to collect data on Roma health. The national respondents to our survey reported that some activities to collect data on Roma health are planned, but they are still under scrutiny of anti-discrimination law. It is suggested that a possible solution to investigate Roma
health is undertaking ad hoc surveys among the Roma and non-Roma population living in similar environmental and socio-economic circumstances. ${ }^{1117}$
${ }^{1117}$ Source: Second round Delphi Survey

## Country Report Denmark

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the Framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed 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 outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes <br> (integrated set of policy measures) | No | No | No | No | No | $\begin{aligned} & \text { €2.7m for } \\ & 2012-2016 \\ & \text { for anti- } \\ & \text { discrimination } \\ & \text { actions as } \\ & \text { whole. } \end{aligned}$ | Yes |

Denmark addresses the Roma population separately in its strategy document, but in practice the country adheres to a horizontal approach in which the general social inclusion policies aim to promote Roma inclusion in the social system. Health and social programmes in the country do not differentiate individuals on the basis of ethnicity. As such the Roma community will not be subject to specific policies or objectives, and neither will it be possible to monitor the NRIS specific actions and impacts as a result. The responsibility for healthcare resides at the municipal level with no overarching Roma-specific goals or policies in place. Healthcare provision is offered equally to all with permanent or temporary residence in Denmark.

The total funds allocation in the period between 2012 and 2016 for anti-discrimination actions is equal to $€ 2.7$ million. Structural Funds are also employed to combat discrimination, but in both cases it is not possible to, from the documents examined, understand the share of funds aimed at improving the health of Roma in Denmark. Overall there is no quantified information regarding the budget, the timeline or the impacts of health actions targeting the Roma population in the country.

## Country Report Estonia

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health <br> issues subject <br> to specific <br> positive actions  | NRIS priorities for Roma health | NRIS specific indicators/benchmarks to evaluate NRIS outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| No | Yes | No | No | No | No (Census data collected on the basis of ethnicity) | No | No |

The Estonian strategy document does not address the Roma population separately. Although the current health status of the Roma population is described, the Strategic Action Plan does not separate actions for this group, as provision is offered regardless of ethnicity. Therefore there is also no Roma-specific mention of monitoring, objectives, outcomes, budget spend or priorities. This is in line with the response obtained through our survey.

The Estonian National Contact Point stated that Roma in the country account for less than $0.05 \%$ of the population. Therefore data collection and assessment of Roma health are not priorities ${ }^{1118}$. Moreover the Census in Estonia collected data on the basis of ethnicity and some data are available on health self-assessment, the presence of a long-term illness or health problems and healthrelated limitations in daily activities.

[^198]
## Country Report France

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health <br> issues subject <br> to specific <br> positive actions  | NRIS priorities for Roma health | NRIS specific indicators/benchmarks to evaluate NRIS outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes (PRAPS programme to target minorities and disadvantaged groups) | No | Yes <br> (PRAPS <br> health programme to target minorities and disadvantaged groups) | No | No | Project: <br> Recruitment of local mediators to promote: <br> Facilitate accesses to health care, <br> Reduce the gaps between specific groups' needs and medical offer, <br> Encourage access to prevention and health education of specific groups | Yes (fund allocation is not specified) | Yes (not specifically addressing Roma health issues) |

In the French strategy document the Roma population is seen as being part of marginalised populations. Public health programmes aimed at the Roma community will operate via the "programme régional d'accès à la prévention et aux soins" (PRAPS - Regional Programme to access to prevention and healthcare) which is a regional prevention and healthcare programme for the most disadvantaged people. Vaccination uptake, treatment promotion and support for teenage mothers will all be promoted via PRAPS which is financed by the Ministry of Health. Whilst there appear to be programmes in place, they are non-specific to the Roma community and at present none of these programmes are actively seeking to monitor Roma health on the basis of determined indicators.

Local associations have been supported by the Ministry of Health since 2009 to train and employ mediators with the focus on improving healthcare access and uptake in Roma communities. The Ministry of Health has also supported the production of a specific guide to travellers entitled 'Understanding and working for the health of travellers', within the partnership with the WHO's French Network of Healthy Towns and Cities (2009).

Data produced from the aforementioned initiatives (if any) might be used to monitor Roma health status, however no additional information is provided.

Overall there is no quantified information regarding the budget, the timeline or the impacts of the NRIS health actions targeting the Roma population in the country. This is confirmed by the EC assessment carried out in June 2013, according to which France has not put in place actions able to monitor the NRIS outputs, outcomes and results in the field of Roma health ${ }^{1119}$.

[^199]
## Country Report Finland

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma $\quad$ health issues mainstreamed in the $\quad$ general domestic and $\quad$ solfare inclusion | Roma health issues subject to specific positive actions | NRIS priorities for Roma health | NRIS Indicators/benchmarks to evaluate to NRIS impacts on Roma | NRIS (current or future) specific projects on monitoring Roma health | NRIS <br> (current or future) <br> project on <br> Roma that might <br> produce data on health | Allocation of NRIS funds for project to monitor or to improve Roma health | Use of <br> structural <br> funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| No | Yes | Promoting the welfare of the Roma population and enhancing the allocation of social welfare and health services: <br> Charting living conditions and assessing healthcare demand and uptake, Reducing marginalisation and promoting services, Enhance preventive information targeted at Roma community | No | The Ministry of Social Affairs and Health has commissioned a pilot study where the National Institute for Health and Welfare runs a study on the health and welfare of Roma in Finland. | Mediators programme | $\begin{aligned} & \text { Yes (fund } \\ & \text { allocation is } \\ & \text { not specified) } \end{aligned}$ | Yes (not specifically addressing Roma health issues) |

The strategy document of Finland addresses the Roma population as a separate group. Broadly speaking the health objectives fall into three categories, referring to improved monitoring of demand and uptake, service promotion and discrimination reduction and enhanced preventive awareness. There are extensive plans for future research projects as well as more tangible interventions such as community mediators. This is confirmed by the national respondent to our survey. The Ministry of Social Affairs and Health has commissioned a pilot study for which the National Institute for Health and Welfare runs a study on the health and welfare of Roma in Finland. The study contains an extensive interview programme and health checks. In 2013 the methods were tested and the study will be carried out in 2014 if enough resources are available (the funding allocation is not yet specified). The respondent also claimed that the planned activities will aid the monitoring of the NRIS, but will not benefit its long term impacts. The review of the existing documentation has indeed shown that there are no quantitative targets at present against which the NRIS impacts on Roma
health can be benchmarked. Finally it is not clear whether the planned data collection activities are compatible with the European Core Health Indicators to ensure comparability with HIS/HES data across the EU ${ }^{1120}$.

[^200]
## Country Report Germany

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health issues subject to specific positive actions | NRIS priorities for Roma health | NRIS Specific  <br> Indicators/benchmarks to <br> evaluate NRIS impacts on  <br> Roma Health  | ```NRIS (current or future) specific projects on monitoring Roma health``` | NRIS (current  <br> or future)  <br> or  <br> project on  <br> Roma that <br> might  <br> producer data  <br> on health  | Allocation of NRIS funds for project to monitor or to improve Roma health | Use of <br> structural  <br> funds for <br> projects to  <br> monitor or to <br> improve  <br> Roma health  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | No | No | No | Advice Centres for Roma and Sinti populations | Yes | Yes (ESF and Youth in Action programme to fund advice centres and NGOs) |

The German document does not distinguish the Roma community as a separate group and consequently no specific policies exist. Healthcare in Germany is provided regardless of demographics and moreover ethnicity is not a criterion for provision. As such there is little ethnicity-specific data available. Specific advice centres (NGOs) are available specifically to Roma and Sinti populations, but again there is no quantitative information with respect to budget, impact or coverage. Channels of funding are briefly explained. The national respondent to our survey confirms our findings stating that Sinti and Roma that have been living in Germany for a long time belong to a national minority and are not counted as a population with a migration background. Therefore it is not possible to distinguish them in statistics. In this regard no specific action is planned to fill data gaps on Roma health ${ }^{1121}$.

[^201]
## Country Report Greece

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health <br> issues subject <br> to specific <br> positive actions  | NRIS priorities for Roma health | NRIS specific indicators/benchmarks to evaluate NRIS outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| No | Yes | Measure 1: <br> Access to primary health care (women and children) health education and field research for epidemiological data Measure 2: <br> Support centres for Roma and other vulnerable groups Measure 3: <br> Development of actions to empower Roma women | Measure 1 : <br> $0 \rightarrow 110$ primary health programmes in Roma settlements <br> $0 \rightarrow 110$ health education programmes <br> Measure 2: <br> $33 \rightarrow 44$ support centres Measure 3: $0 \rightarrow 35$ programmes to empower Roma women | Yes | Yes | Measure 1: $€ 1 \mathrm{~m}$ <br> Measure <br> €15m <br> Measure 3: <br> €100,000 <br> Total: $€ 16,1 \mathrm{~m}$ | Yes (not specifically addressing Roma health issues) |

## Country Report Hungary

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health <br> issues subject <br> to specific <br> positive actions  | NRIS priorities for Roma health | NRIS Specific indicators/benchmarks to evaluate NRIS outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | Promote access to health care, Incentivise health professionals to work in disadvantaged areas, <br> Support a prevention and screening programme, Provide health education, Encourage <br> sport activities | Screening tests for 150,000 Roma 150,000 Roma <br> Involve 30,000 Roma in sport activities | No, but a NRIS monitoring system will be set segregated communities at territorial level | No | No | Yes (not specifically addressing Roma health issues) |

Hungary's strategy document identifies the Roma community as an ethnic group. There are no specific policies in place targeting this community as the government wishes to consider any issues as part of national policy rather than a poverty policy issue. Whilst this is the case, there are some clearly defined numerical objectives as part of health care policy in general. However it is unclear if they are to be followed up via monitoring or assessment of health status indicators.

The NRIS monitoring system has not been put in place yet, but the national authorities responsible for the implementation of the strategy are aware of the data needed and of the existing surveys (such as the European population health survey) required to assess the progress of the NRIS towards Roma health needs.

The national authorities also point out the necessity of carrying out targeted sociological studies with large sample sizes to follow-up on the attainment of the goals set forth in the strategy. They refer in a detailed manner to the preparation and development of the map of segregation at territorial level.

In line with the above, the national authorities claim to be interested in improving the coordination of the use of development funds (e.g. European Cohesion policy and its Structural Funds) to enable the implementation of complex interventions in the field of social inclusion in the context of EU 2020 and social inclusion. In practice, there is a need to create the pre-conditions of an effective and target-oriented funding policy, including results-oriented follow-up and evaluation based on professional criteria.

According to the Commission Communication 'Step Forward in implementing Roma integrating strategies'1122, Hungary has been able to map the baseline situation of Roma, while evaluation and regular reporting are planned to be carried out. Notwithstanding this, there is no quantitative information regarding budgets and timeline.

[^202]
## Country Report Italy

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed 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 outputs and impacts on Roma Health | ```NRIS (current or future) specific projects on monitoring Roma health``` | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Roma health issues mainstreamed in the general domestic welfare and social inclusion policy |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | Promoting the analysis and how to access quality health and social services for Roma and Sinti, with a specific focus on women, children, adolescents, the elderly and disabled", "Promoting access to preventive health services, with specific regard to reproductive health and maternal- child health", Involving trained Roma and Sinti people in social services and medical care programs, such as, for instance, cultural mediators" | Vaccination 30\% $\rightarrow$ 50\% | Preliminary feasibility study and promote experimentation in local plans for inclusion of Roma and Sinti persons. | Pre-NRIS: <br> "Health promotion among immigrant workers in Italy", <br> The heath of the immigrant population analysis methodology. <br> Post NRIS: <br> "A model for the integration of disadvantaged socio-health", project, "Health without exclusion", project Vaccination campaign in Roma areas, Training courses for mediators, Territorial network for antidiscrimination, <br> The establishment at the NCP of an ad hoc working group, aimed at closing the information and statistical gaps, by involving the central administrations concerned, including ISTAT (The National Statistics Institute) | Yes (fund allocation is not specified) | ```Yes (not specifically addressing Roma health issues)``` |

The strategy document of Italy considers the Roma population separately. Actions targeting Roma however are framed in the context of support for vulnerable groups. The document outlines extensive objectives for Roma health and details projects pre-NRIS and future projects to be initiated, however only one metric is given (for increased vaccination from $30 \%-50 \%$ of the Roma population). Moreover, the document also makes reference to a preliminary feasibility study and promotes experimentation through
local programmes for the inclusion of Roma and Sinti persons. Generally regional coordinators are consulted by the Ministry of Health to provide some insight on Roma health. There is a methodology in place for analysing the health of the immigrant population involving collaboration between regions. Therefore there are as yet no projects or programmes designed to specifically and directly monitor Roma health. However some projects on access to health services are likely to indirectly produce data in this field.

The relevance of the local and territorial dimensions in collecting data is confirmed by the national respondent to our survey; data are indeed collected through administrative registers at local level and also through the monitoring and the implementation of social inclusion projects and their results. The planned activities are judged to be able to evaluate the medium and long term impacts of the NRIS. However they are only partly able to fill a gap of comparable data between the general population and Roma and they are not aligned with the European Core Health Indicators to ensure comparability with HIS/HES data across the EU ${ }^{1123}$.

Projects are funded through domestic and European resources; however there is no specification of the financial amount targeting Roma health.

[^203]
## Country Report Ireland

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

|  | Roma health <br> issues  <br> subject to <br> specific  <br> positive  <br> actions  | NRIS priorities for Roma health | NRIS specific indicators/benchmarks to evaluate NRIS outputs and impacts on Roma Health | ```NRIS (current or future) specific projects on monitoring Roma health``` | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes  <br>   <br> (National  <br> Intercultural Health <br> Strategy by the  <br> Health Service <br> Executive since <br> 2012)  | No | Mental health, Suicide, Men's Health, Addiction, Domestic Violence, Diabetes, Cardiac health, (Results of All Ireland Traveller Health Study) | No | Health Key performance indicators (KPI) to measure improvement in the access to health services | Primary Health Care Projects, Improve access to services, Traveller Health Units, Health Services ExecutiveTraveller health | $\begin{array}{lr} \hline € 9.5 m & \text { per } \\ \text { year } \\ 2010) \end{array}$ | No |

Unlike other member states, in Ireland the Roma community are identified as indigenous Irish Travellers. There are no policy measures targeting the Roma community as distinct from other minority groups. Rather a National Intercultural Health Strategy exists, managed by the Health Service Executive since 2012. At present there are nationally funded health services in place which seek to employ 'travellers' to work as Community Health Workers. These projects do not report on key health indicators for the traveller community. Future plans to improve access to services and develop Health Key Performance Indicators (KPIs) are in place, although there are no strict timelines on its implementation. There are no current NRIS projects dedicated to monitoring the health status of the Roma community. Data are available up to 2010 resulting from the study All Ireland Traveller Health Study, however the only quantitative information is from 2008-2010 funding allocations.

## Country Report Latvia

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed 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 outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes (actions to target minorities and disadvantaged groups) | No | Involvement of representatives from Roma NGOs, <br> Awareness on sanitary conditions, <br> Research on the homeless <br> Roma population, <br> Train social workers about <br> Roma, <br> Study of healthcare access | No | Yes (2013 <br> system to collect  <br> and collate <br> statistical data <br> on Roma socio- <br> economic  <br> conditions  <br> including  <br> healthcare)  | Project on socialexclusionProject <br> discrimination. on | Yes (fund allocation is not specified) | Yes (not specifically addressing Roma health issues) |

The Latvian strategy document defines the Roma population as a distinct group, but interventions are framed in the general context of actions for disadvantaged groups. Latvia sets out a number of objectives for improving the health status of the Roma population, however these include provisional research topics rather than quantifiable health indicators. There are no clear benchmarks or targets, simply overall aims. Future projects are defined to directly and indirectly monitor Roma health, so future healthcare provision is likely to be better informed. There is mention of funding at national and EU levels, but the quantities are unspecified. The national respondent to our survey was not aware of specific projects to monitor and analyse Roma health status. Rather they stated that there is the statistical collection of data, on health care and public health indicators in the country (out-patient and inpatient medical care, emergency medical aid, oncology, mental health, maternal and child health, population mortality and other topics) but information related to ethnicity is available only in the Register of Patients with Particular Diseases, Patients with Drug Use Disorders ${ }^{1124}$.

[^204]
## Country Report Lithuania

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health <br> issues subject <br> to specific <br> positive actions  | NRIS priorities for Roma health | NRIS Specific <br> Indicators/benchmarks  <br> to evaluate NRIS <br> impacts on Roma <br> 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 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | No | No | No | No | No | No |

The Lithuanian strategy document does not mention Roma health specifically. The national respondent to our survey stated that the monitoring and research activities will fill a gap of comparable data between the general population and Roma in the health status and access to health care ${ }^{1125}$, but the document reviewed only mentions benchmarks and indicators to measure the impacts of the NRIS in the fields of education and employment.

[^205]
## Country Report Luxembourg

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health <br> issues subject to <br> specific positive <br> actions  | NRIS priorities for Roma health | NRIS Specific <br> Indicators/benchmarks  <br> to evaluate NRIS <br> impacts on Roma <br> 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 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | No | No | No | No | No | No |

Luxembourg differentiates the Roma population according to their strategy document. Healthcare provision is accessed via the social security system. There is no further information regarding funds, monitoring, policy, programmes or objectives (quantitative or qualitative). The NCP responsible for the implementation of the strategy confirmed that because the Roma population in the country is very small there was no need to develop a monitoring system that would have administrative and financial burdens.

## Country Report Malta

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health <br> issues subject <br> to specific <br> positive actions  | NRIS priorities for Roma health | NRIS specific indicators/benchmarks to evaluate NRIS outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | No | No | No | No | No | No |

Although Malta differentiates Roma as an ethnic group or separate population, they report no Roma population. Therefore there is no information on NRIS from Malta with respect to Roma.

## Country Report the Netherlands

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health <br> issues subject <br> to specific <br> positive actions  | NRIS priorities for Roma health | NRIS specific indicators/benchmarks to evaluate NRIS outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | No | No | No | No | No | No |

The strategy document from the Netherlands does distinguish the Roma population as a separate community. The Dutch healthcare system provides services to all its legal citizens. However as it is conditional care it may make services less available to nomadic populations. There are no Roma-specific policy measures in place at present, nor are there monitoring programmes or estimates of the current health status of the Roma community. There is description of dialogue between municipalities and the Roma community, but no explanation of how this translates to health care provision, access or impact.

## Country Report Poland

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health <br> issues subject to <br> specific positive <br> actions  | NRIS priorities for Roma health | NRIS specific indicators/benchmarks to evaluate NRIS outputs and impacts on Roma Health | ```NRIS (current or future) specific projects on monitoring Roma health``` | NRIS (current or future) projects on Roma that might produce data on health | Allocation of $\quad$ NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| No | Yes | Improve Roma health status by improving access to healthcare provision and the state of hygiene at community level | Rate of Roma covered by preventive medical examinations and vaccinations from $13 \%$ to 21\% from 2014-2020. | No | Programme for the Roma community in Poland <br> Community nurses and vaccination programmes | $\begin{aligned} & \text { €2.5m } \\ & \text { (national } \\ & \text { quota) } \\ & \text { €0.2m is } \\ & \text { described in } \\ & \text { relation to } 52 \\ & \text { tasks for } \\ & 2011-2013 \text {, } \\ & \text { but the } \\ & \text { source is not } \\ & \text { stated } \end{aligned}$ | $\begin{aligned} & \text { Yes - €22m } \\ & 2007-2013 \\ & \text { (community } \\ & \text { quota ESF) } \end{aligned}$ |

The strategy document from Poland addresses the Roma population separately as an ethnic minority. There is some description of the current health status of the Roma community; however there is little quantitative data. Poland employed 39 community nurses and completed 3901 vaccinations in 2011-2012. The ongoing Programme for the Roma community in Poland which has indirect implications with regards to the group's health lays out some objectives and sub-objectives. The main objectives refer to improved access and state of hygiene at community level; and this is linked to stated targets with reference to access to medical examinations and vaccinations. There are a number of measures stipulated in general terms, but are described without specific reference to policy instruments or actions to achieve them. Data collection on this metric is not specified and is calculated in part via an algorithm. The
impacts of measures remain therefore unknown. Current funding is sourced nationally and via the European Social Fund and precise figures are discussed; however they are not always presented in separate and distinct terms.

## Country Report Portugal

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health <br> issues subject <br> to specific <br> positive actions  | NRIS priorities for Roma health | NRIS Specific Indicators/benchmarks to evaluate NRIS 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 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | Promoting training / information actions on health education and services. <br> Contributing to improve Roma health by focusing on prevention. <br> Training health professionals on cultural diversity. <br> Creating and / or enhancing relations between services for health and Roma communities, by building bridges and streamlining partnerships. | Number of campaigns (10 by 2020) and evaluation of their impacts. <br> Number of information / awareness sessions about healthy eating habits and early motherhood and assessment of their impacts. (5 sessions per year) <br> No. of trainings conducted in each group of health centres and number of health professionals involved (5 by 2020) <br> Number of awareness sessions on health and access to health resources for Roma held annually (1 per year); Number of Roma mediators placed in health services ( 20 mediators). | Cross sectional study to understand the socio economic conditions of Roma | Pre NRIS Mobile units for health care services <br> NRIS: <br> Mediators programme | Yes <br> (fund allocation is not specified) | Yes <br> (not <br> specifically addressing Roma health issues) |

Portugal addresses the Roma population separately in its strategy document. In practice however the country adheres to a horizontal approach where the general social inclusion policies aim to promote Roma inclusion in the social system. The right to
access to healthcare is universal, regardless of individual characteristics, ethnicity, religion, socioeconomic status or any other differentiating factor in various social groups. Roma communities have still benefited from initiatives of positive discrimination, namely the operation of different mobile units of the National Health Service. The objective of these services is to reach the neediest populations, particularly for households in social neighbourhoods, resettlement areas or underserved communities, where Roma very often reside ${ }^{1126}$. The Portuguese National Roma Integration Strategy refers to the implementation of a national study about the social, economic and cultural situation of the Roma communities, including health conditions. The strategy also sets several outcome indicators regarding the amount of training, information campaigns and cultural mediators that should be supported in the health centres in order to target the Roma Community. The analysis of the impact of such actions is also mentioned, but impact indicators are missing as well as the specification of the funds available for the strategy's actions.

[^206]
## Country Report Romania

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstrea med in the general domestic welfare and social inclusion policy | Roma health issues subjec t to specifi c positiv e action s | NRIS priorities for Roma health | NRIS specific indicators/benchmark $s$ to evaluate NRIS outputs and impacts on Roma Health | NRIS <br> (curre nt or future ) <br> specifi c projec ts on monito ring Roma health | NRIS <br> (current <br> or <br> future) <br> projects <br> on <br> Roma <br> that <br> might <br> produce <br> data on <br> Roma <br> health | Allocati on of NRIS <br> funds <br> for <br> projects to monitor or to improve Roma health | Use of structura I funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| No | Yes | Attracting medical staff to economically disadvantaged areas (in the case of major Roma communities); <br> Allocating separate amounts for uninsured people and for social cases (Roma people match this profile); <br> Establishing national health programs to address the public health issues and the needs of vulnerable groups; <br> Reducing the impact of diseases and the impact of chronic diseases, especially in the case of vulnerable groups; <br> Vaccinate children in Roma communities; <br> Health education campaigns for TB prevention in Roma communities; <br> Preventive awareness campaigns; <br> Improved access via mediators; <br> Employ Roma medical graduates in Roma community areas; <br> Inclusion solutions; <br> Information programmes in various medical areas; <br> Analyse mediator activity and extend training; <br> Assess Roma access levels; <br> Develop local health links | Establish 1 technical assistance unit to coordinate, monitor and assess health mediators' activities; <br> Number of employed health mediators (25\% increase in health mediators $450 \rightarrow 560$ ); <br> Number of communities assisted by a health mediator; <br> Number of functional medical facilities in isolated communities; Number of health information, education and communication (IEC) campaigns | No | Health <br> Mediator <br> s <br> Program <br> (prior to- <br> NIRS) $\rightarrow$ <br> 450 <br> health <br> mediator <br> s actively <br> involved <br> from <br> 2002- <br> 2011 | Yes <br> (fund allocation is not specified) | Yes (not specificall y addressin g Roma health issues) |

## Country Report Slovakia

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health <br> issues <br> mainstreame <br> d in the <br> general <br> domestic <br> welfare and <br> social <br> inclusion <br> policy | Roma <br> health <br> issues <br> subject to specific positive actions | NRIS priorities for Roma health | NRIS specific indicators/benchmarks to evaluate NRIS outputs and impacts on Roma Health | NRIS <br> (current or future) specific projects on monitorin g Roma health | NRIS (current <br> or future) <br> projects on <br> Roma that <br> might <br> produce data <br> on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes (stratified as minority, communities and marginalised communities. Program of Health Support for Disadvantaged Communities $2007-2015$ (pre-NRIS)) | No | - Bridge health status gap <br> - Improve communal hygiene <br> - Assess environmental safety of settlements <br> - Improve access to quality drinking water <br> - Improve healthcare access <br> - Reduce infection rates \& vaccinate <br> - Educate on family planning \& related <br> - Educate on drug use <br> - Improve network of community workers | - Increase \% of households where waste is removed every 2 weeks ( $79 \%$ in 2011) <br> - Increase drinkable water use (68-82\% in 2011) <br> - Increase \% of households visiting doctors (18\% shortage of funds in 2011) <br> - Reduce \% with infectious disease <br> - Increase average mothering age <br> - Increase from 30 community workers (2011) | National <br> Centre for Medical Informatio n <br> Atlas of Roma Communiti es in Slovakia (2004). | Program of Health Support for Disadvantaged Communities 2007-2015 (pre-NRIS) | 2012 - <br> $€ 1.7 \mathrm{~m}$  <br> 2013 - <br> $€ 1.8 \mathrm{~m}$  <br> 2014 - <br> $€ 2.1 \mathrm{~m}$  <br> 2015 - <br> $€ 2.4 \mathrm{~m}$  | Yes (not specifically addressing Roma health issues) |

Slovakia is extremely specific in its approach to the health status of the Roma community. Their strategy document outlines the Roma community as a separate group and also includes sub-categories to account for its heterogeneous nature. Whilst there are presently no Roma-specific policy instruments, Slovakia details numerous health objectives coupled with quantifiable health indicators and budgetary timeframes. There is extensive use of statistical information in the objective setting which reflect recognised potential positive health impacts. The approach is detailed, precise and extensive, with budgets determined in advance.

## Country Report Slovenia

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health <br> issues subject to <br> specific positive <br> actions  | NRIS priorities for Roma health | NRIS specific indicators/benchmarks to evaluate NRIS outputs and impacts on Roma Health | ```NRIS (current or future) specific projects on monitoring health``` | NRIS (current or future) projects on Roma that might produce data on Roma health | Allocation of $\quad$ NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | - Promote health in Roma population especially women and children <br> - Conferences and consultation on Roma health (cross-border) | - Improved health status indicators <br> - Conferences \& meetings held | No | No | $€ 120,000$ pa. for health promotion <br> Unspecified amount for conferences | No |

The Slovenian strategy document identifies the Roma population as a separate group, but there are no current policy instruments which are Roma-specific. The two objectives include promotion of health in the Roma community and cooperative cross-border conferences and consultations. In addition, the document outlines health indicators to be monitored and assessed, but does not name any specific health programmes to implement the changes. The budget for health promotion is stated in numerical terms, but is undisclosed with regards to conferences. At present there are no statistics given which outline the current health status of the Roma community or targets for improvement (other than general improvement). However, in the future reporting and evaluation activities are planned to be carried out by the state authorities and self-governing local communities ${ }^{1127}$.

[^207]
## Country Report Spain

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed 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 outputs and impacts on Roma Health | NRIS (current or future) specific projects on monitoring Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | Improve health and reduce social inequalities in healthcare | - Improve perception of health as "good" by 10\% <br> - Reduce traffic accidents by 15-20\% <br> - Reduce smoking by $30 \%$ <br> - Reduce obesity by $10 \%$ <br> - Increase gynaecological consults by $10 \%$ <br> - Reduce home accidents by 15-30\% <br> - Increase dentist attendance 10-15\% | No | No | No | Yes <br> (not <br> specifically <br> addressing <br> Roma health issues) |

The Spanish strategy document addresses the Roma population separately, but the actions targeting them are framed in the general framework for the support of disadvantaged groups. The document states the objective to generally improve health and social aspects in this community, but also includes specific targets based on current health indicators or benchmarks. However, whilst the objective indicators are extremely specific, there is no explanation of practical methods to achieve change, nor is there any indication of current budgets or spend, or projects to monitor health status in the Roma community. The EC assessment on the status of the implementation of the NRIS reports that Spain has not yet planned regular reporting or evaluation activities on the progresses of the strategy ${ }^{1128}$. In addition, there is limited quantitative information available apart from background information on the health status and health indicator targets. Finally it has to be observed that the document details future plans which include the use of Structural Funds to support Roma inclusion projects. Such projects might generate data on the socio-economic status of Roma.

[^208]
## Country Report Sweden

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed in the general domestic welfare and social inclusion policy | Roma health issues subject to specific positive actions | NRIS priorities for Roma health | NRIS Specific <br> Indicators/benchmarks  <br> to evaluate NRIS  <br> impacts on Roma  <br> 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 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | - Reduced incidence of illness <br> - Improved life expectancy <br> - Improved perception of medical care in the Roma community <br> - Improved treatment of this group by medical professionals | No | National Institute of Public Health and National Board of Health and Welfare are to produce a health status report (particularly on Roma women). Likely to be mostly qualitative. | Stockholm County Administrative Board to conduct telephone consultations with Roma women and girls regarding reproductive health. | 500,000 EUR per year will be allocated for Roma mediators from mid2013 onward. | Yes (not specifically addressing Roma health issues) |

Sweden's strategy document addresses the Roma population separately, stating that their health status is to be improved via the Swedish National Health Service. The broad goals set out dictate that the Roma community should not experience ill health above the national average, particularly with respect to incidence of illness and life expectancy. There are also other objectives concerning the treatment of or attitude towards this population by health care professionals. Future health projects include nationalised initiatives collecting qualitative data on the (particularly female) Roma population and their health status and local authority initiatives regarding reproductive health. Half a million Euros per annum is the funding expected for the Roma population (excluding spending on employment or housing for the Roma community). According to the Swedish authorities the actions and the monitoring system put in place under the NRIS will be able to measure its results and impacts on Roma and in particular Roma women and girls ${ }^{1129}$.

[^209]
## Country Report United Kingdom

The table below gives an overview of the current and future activities to collect data to monitor Roma health within the framework of the National Roma Integration Strategy.

| Roma health issues mainstreamed 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 outputs and impacts on Roma Health | NRIS (current <br> or future) <br> specific <br> projects on <br> monitoring <br> Roma health | NRIS (current or future) projects on Roma that might produce data on health | Allocation of NRIS funds for projects to monitor or to improve Roma health | Use of structural funds for projects to monitor or to improve Roma health |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Yes | No | Wales - tackle infant mortality, accidents, illness \& life expectancy | No | NI - An Munia Tober (AMT traveller support group) <br> NI - Travellers' Health Advocacy Project |   <br> Scotland -pre- <br> NRIS <br> Minority  <br> Ethnic Carers' <br> Older People's <br> Project (MECOPP)  | MECOPP <br> £57,570 <br> AMT - £83,000 <br> £60m budget for <br> accommodation sites and housing | No |

The UK strategy document addresses the Roma population separately. The document reports background information on Roma taken from the 2011 Census. According to the EC assessment there is cooperation between the authorities in charge of implementing the strategy and the National Statistical Office in order to put in place a robust monitoring and evaluation system ${ }^{1130}$. However, NRIS actions or projects to specifically monitor Roma health do not seem planned. There is little to no quantitative or qualitative information from England other than acknowledgement of the Roma community being disadvantaged with respect to health. In Wales there are some objectives in place but no policy measures, monitoring programmes or impact assessments. Northern Ireland has support groups and projects already in place which receive defined national funding, but no quantitative information with respect to changes in health status. Scotland runs a funded general project which reaches the Roma community, but again there are no quantitative reports forthcoming. Overall there is little evidence for quantitative assessments of health status in the UK documentation.

[^210]
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## Appendix C Interview Respondents

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Written input also received from Belgium, Cyprus, Poland and Sweden.

# Appendix D Questionnaire for monitoring health and implementing NRIS 

Data collection issues for monitoring Roma health status and progresses in the implementation of National Roma Integration Strategies

The present survey is an important part of the study "Reports on 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". This is a project which is currently being carried out by Matrix Knowledge on behalf of the European Executive Agency for Health and Consumers. Its aim is to highlight relevant indicators and reliable data on Roma health in order to (i) assess the health status of Roma at local level (ii) identify priority areas and how to best implement these and (iii) inform the allocation of resources. However it is also apparent that such indicators and data are not available in a significant number of Member States and the systematic collation and assessment of such data appears to be limited and fragmented across Europe.

The European Fundamental Rights Agency (FRA) is also currently investigating the situation of Roma in the European Union (EU) and has distributed a questionnaire to the National Roma Contact Points able to provide information on Roma conditions in different areas: housing, health, education and employment.

This survey has been designed to complement that of FRA, as it has a specific focus on Roma health status. For this reason the targets of the survey are: public health authorities, health professionals and non-governmental organisations (NGOs) operating at EU, national and regional as well as grassroots (local) level. The respondents are asked: (i) to evaluate the overall strengths and weaknesses of current data collection on Roma health status, (ii) to assess the use that they made of the existing data and (iii) to consider how the situation could be improved.

Data collection is essential to verify the achievements in health of the National Roma Integration Strategy (NRIS). The NRIS aims to promote and achieve the inclusion of Roma. They have been developed by the Member States and presented to the European Commission as a concrete response to the European Framework for National Roma Integration Strategy by 2020.

The goals of the present survey are therefore:

1. To map existing official quantitative and statistical data set currently used (data availability)
2. To identify the main good practices and challenges of the current health data collection and related use in the context of the National Roma Integration Strategy (NRIS)
3. To propose potential solutions and policy options for improvement.

This survey does collect personal data to allow the research team to contact a respondent to follow up on their experience in the context of the study. Anonymity will
be granted as individual responses will not be shared or used in the study report. Nor will the Research Team share respondents' names.

If you have any questions or difficulties with the survey or would like to provide further input to this study, please contact Malin Carlberg at Matrix Knowledge at malin.carlberg@Matrix Knowledgeknowledge.com or on +44 (0)20 75534819

Please click 'Next' to begin the survey.
Thank you for your input.

## Introductory Part

Information about the respondents and their organisations

- Respondent's name and surname:
- Respondent's phone number:
- Respondent's email:

1. What is the name of the organisation/office you work for?
2. What is your role in your organisation?
a. Director
b. Service Manager
c. Health Care Professional
d. Analyst/ Researcher
e. Expert
f. Beneficiary of Roma interventions
g. Other (please specify)
3. What is the relationship between your organisation and Roma health?
a. My organisation provides health care services
b. My organisation provides service delivery
c. My organisation provides advocacy services
d. My organisation is a think tank
e. Other (please specify)
4. Does your organisation:
a. Gather data on Roma health status?
b. Analyse data on Roma health status?
c. Use data on Roma health status?
d. None of the above
e. Other (please specify)
5. Does your organisation/office operate at:
a. Local level
b. Regional level
c. National level
d. European level
6. Is your organisation engaged in the design, implementation, monitoring or evaluation of the National Roma Integration Strategy?
a. No
b. Do not know
c. Yes If yes please specify how?

Mapping existing official quantitative and statistical data sets currently used (data availability)
7. From the list of Roma health status sources presented below, please choose those to which you have access
a. Census
b. Micro census
c. Administrative records
d. Data survey
e. Community-based data collection
f. Do not know
g. Other (please specify)
8. Which of the sources listed below on Roma health status do you or your organisation use? Please choose all that apply.
a. Census
b. Micro census
c. Administrative records
d. Data survey
e. Community-based data collection
f. Others (please specify)
9. Are the data on population health status that you use ethnically disaggregated?
a. Yes
b. No
c. Do not know
d. Partly Please explain
10. At which level is the Roma data your organisation works with collected?
a. Local level
b. Regional level
c. National level
d. Other (please specify)
11. Which of the institutions listed below are the ones responsible for collecting the Roma health data that you or your organisation use? Please choose all that apply.
a. My organisation's own research / data gathering
b. Public authorities responsible for Health (health conditions and health insurance)
c. General Practitioners (common illnesses and primary care)
d. Hospitals (hospitalisations and secondary care)
e. Health Care Centres (screening surveys, regular check-up and tertiary care)
f. Education institutions (primary and secondary schools and related immunisation programmes' registries)
g. Job Centres (social assistance coverage)
h. Private employees (labour contracts)
i. Social housing institutions (house assignment criteria, including health conditions)
j. Civil Society organisations
k. Other (please specify)
12. If any of the institutions listed below collect data on Roma health status, how often does this happen? (Please choose one option per row)

|  | Regularly | Occasionally | Rarely | Never | Do not know |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Ministry or <br> Public <br> Authorities <br> responsible for <br> Health      <br> General <br> Practitioners      <br> Hospitals Care      <br> Health <br> Centres      <br> Education <br> institutions      <br> Job Centres      <br> Private <br> employees      <br> Social housing <br> institutions      |  |  |  |  |  |

13. For each of the sources listed below, how frequently are data on Roma health collected? Please choose one option per row.

|  | Only <br> once | Monthly | Annually | Every <br> 5 <br> years | Every <br> 10 <br> years | Continuously | Other <br> (please <br> specify) |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Census |  |  |  |  |  |  |  |
| Micro Census |  |  |  |  |  |  |  |
| Administrative <br> Records |  |  |  |  |  |  |  |
| Data survey |  |  |  |  |  |  |  |
| Community <br> based data <br> collection |  |  |  |  |  |  |  |
| Other Sources <br> (please <br> specify) |  |  |  |  |  |  |  |
| Additional comments |  |  |  |  |  |  |  |

14. If data are not collected on a regular basis, why is this the case? (Please provide explanations)
15. Once data are collected, at which level are they analysed?
a. Local
b. Regional
c. National
d. Supranational
e. Other (please specify)
16. Once data are analysed, are they publicly available?
a. Yes
b. No
c. Partly Please explain
17. If data are not publicly available, why is this the case? (Please provide an explanation)

Identifying the main challenges and good practices of the current health data collection and related use in the context of the National Roma Integration Strategy (NRIS)
18. Overall, how would you rate the data system collection on Roma health status?

| Very poor | Poor | Satisfactory | Good | Very Good |
| :--- | :--- | :--- | :--- | :--- |

19. How would you rate the following aspects of data collection of Roma health status?

|  | Very poor | Poor | Satisfactory | Good | Very Good |
| :---: | :---: | :---: | :---: | :---: | :---: |
| The data collection system on Roma Health |  |  |  |  |  |
| The existing methods and techniques involved in ensuring data quality |  |  |  |  |  |
| The level of cooperation among the institutions/offices responsible collecting data on Roma health status (To e.g. avoid overlapping and promoting complementarity data) |  |  |  |  |  |
| The level of accessibility of the existing data set on Roma health |  |  |  |  |  |
| The quality of the existing data on Roma health |  |  |  |  |  |
| The timeliness of the existing data on Roma health |  |  |  |  |  |
| The comparability of existing data on Roma health |  |  |  |  |  |
| Comparability between indigenous and migrant Roma groups |  |  |  |  |  |

20. How would you rate the comparability of the existing data on Roma health vis-à-vis the European Community Health Indicators (ECHI)

| Very poor | Poor | Satisfactory | Good | Very good |
| :--- | :--- | :--- | :--- | :--- |

21. How would you rate the level of involvement of Roma civil society and Roma communities in data collection on Roma health

| Very poor | Poor | Satisfactory | Good | Very good |
| :---: | :---: | :---: | :---: | :---: |

22. Please rate the extent to which existing data has helped you to shape your intervention in the field of Roma health

| Not helpful at all | Somewhat helpful | Helpful | Very helpful |
| :--- | :--- | :--- | :--- |

23. Please could you give one or two examples of existing data which has been useful to you? This could be examples of useful sources or types of data.
24. The National Roma Integration Strategy (NRIS) is a tool for the EU Member States to improve the Roma population's life conditions, including health. Please rate to what extent health is a relevant driver in shaping the NRIS?

| Don't know | Not relevant | Somewhat <br> relevant | Relevant | Very relevant |
| :---: | :---: | :---: | :---: | :---: |

25. Is the current data collection system aligned with the objectives of the NRIS in the field of Roma health status
a. Yes
b. Know
c. Do not know
d. Partly (Please explain)
26. If yes, how would you rate the extent to which data collection is appropriate to verify the outcomes produced by the NRIS on Roma health

| Don't know | Not appropriate | Somewhat <br> appropriate | Appropriate | Very <br> appropriate |
| :---: | :---: | :---: | :---: | :---: |

27. How would you rate the level of involvement of Roma civil society and Roma communities in data collection on Roma health? (Please tick one box)

|  | Regularly | Occasionally | Rarely | Never | Do not know | $\begin{gathered} \text { Not } \\ \text { collected } \end{gathered}$ |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Mortality |  |  |  |  |  |  |
| Prevalence of major infectious diseases |  |  |  |  |  |  |
| Healthy life <br> styles and <br> related  <br> behaviours  |  |  |  |  |  |  |
| Access and use of health services and prevention programmes |  |  |  |  |  |  |
| Prevalence of major chronic disease |  |  |  |  |  |  |
| Health factors related to the role of women |  |  |  |  |  |  |
| Environmental and other socioeconomic factors (i.e. education, employment and housing) |  |  |  |  |  |  |

28. Please rate to what extent you agree or disagree with the following statements about the collection data system to monitor the implementation of the NRIS

|  | Completely Agree | Somewhat Agree | Not sure | Somewhat Disagree | Completely Disagree |
| :---: | :---: | :---: | :---: | :---: | :---: |
| The existing data collection system is able to detect whether the NRIS is improving the data gap between the general population and Roma health |  |  |  |  |  |
| The existing data collection system is able to detect the impacts of the NRIS on disadvantaged micro-regions or segregated neighbourhoods |  |  |  |  |  |
| The $r$ funds <br> allocated for the <br> data collection <br> system $r$ are <br> enough to monitor  <br> NRIS progress on  <br> Roma health  |  |  |  |  |  |
| The existing data collection system ensures that civil society organisations working with Roma, Roma NGOs and Roma community representatives are involved in the design, implementation and assessment of data collection. |  |  |  |  |  |

29. Could you give an example of good/best practices of Roma health data collection
a. No
b. Yes (please specify)

Proposing potential solutions and policy responses
30. If data on population health status are not collected on an ethnic basis, how feasible would you rate the implementation of a data collection system based on ethnicity in the future? (Please select one option)

| High | Medium | Low |
| :---: | :---: | :---: |

31. If a data collection system based on ethnicity will be implemented in the future, which safeguards should be in place to protect the privacy of the respondents?
32. In order to collect data on Roma health status, what would be the best option for the identification of ethnicity? (Please select one option)
a. Self-identification
b. Hetero identification (Roma identified by a third person)
c. Combination of both
d. Do not know
33. Do you think that other indicators (i.e. proxies) would be valid means to approximate for Roma health status? (Please select one option)
a. Yes
b. No
c. Partly
d. Do not know
34. If yes, which are the most appropriate indicators and information (i.e. proxies) to be cross-referenced to indirectly obtain data on the Roma health status? (Please select up to three options)
a. Language
b. Territorial information (residential area tag)
c. Life style
d. Disadvantage or vulnerable group status
e. Educational status
f. Employment status
g. Living conditions
h. Other (please specify)
35. Considering the following list of indicators on Roma health status, which are the most suitable institution/actors to collect these data?

|  | G | Hospit als | Healt <br> h <br> Care <br> Centr <br> es | Educatio <br> n <br> instituti <br> ons | Employm ent agencies | Private employ ee | Social Housing instituti ons | Other instituti ons |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Mortality |  |  |  |  |  |  |  |  |
| Prevalence of major infectious diseases |  |  |  |  |  |  |  |  |
| Health life styles and related behaviours |  |  |  |  |  |  |  |  |
| Access and use of prevention programm es |  |  |  |  |  |  |  |  |
| Prevalence of major chronic disease |  |  |  |  |  |  |  |  |
| Health factors related to the role of women |  |  |  |  |  |  |  |  |
| Environme ntal and other factors (i.e. education, employme nt and housing) |  |  |  |  |  |  |  |  |
| Other (please specify) |  |  |  |  |  |  |  |  |

36. Considering the following list of indicators on Roma Health Status, at which jurisdictional level might they be better collected and analysed?

|  | Supranational | National | Regional | Local |
| :--- | :--- | :--- | :--- | :--- |
| Mortality <br> Prevalence of <br> major <br> infectious <br> diseases |  |  |  |  |
| Health life <br> styles and <br> related <br> behaviours and |  |  |  |  |
| Access and <br> use <br> prevention <br> programmes |  |  |  |  |
| Prevalence of <br> major chronic <br> disease |  |  |  |  |
| Health factors <br> related to the <br> role of women |  |  |  |  |
| Environmental <br> and other <br> factors (i.e. <br> education, <br> employment <br> and housing) |  |  |  |  |

37. How frequently should data be collected in order to improve their comparability across time?

|  | Only <br> once | Monthly | Annually | Every 5 <br> years | Every <br> 10 <br> years | Continuously |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Mortality |  |  |  |  |  |  |
| Prevalence of major infectious <br> diseases |  |  |  |  |  |  |
| Health life styles and related <br> behaviours |  |  |  |  |  |  |
| Access and use of prevention <br> programmes |  |  |  |  |  |  |
| Prevalence of major chronic <br> disease |  |  |  |  |  |  |
| Health factors related to the <br> role of women |  |  |  |  |  |  |
| Environmental and other <br> factors (i.e. education, <br> employment and housing) |  |  |  |  |  |  |

38. Please rate in the order of importance the following issues that have could be improved for Roma health data (1 is most important, 8 is least important)
a. Existing methods and techniques for data collection
b. Level of cooperation among institutions responsible for data collection
c. Comparability of the existing data among different Roma age groups
d. Comparability of the existing data among Roma and the general population
e. Compatibility with ECHI indicators
f. Alignment with the NRIS objectives
g. Involvement of Roma communities and Roma civil society in data collection
h. Comparability of existing data among indigenous and migrant Roma
39. The list below encompasses potential solutions to improve data collection on Roma health status. Please rate these in order of importance. (1 is most important, 8 is least important)
a. Administrative data collected through administrative registers
b. Data and information collected through anonymous surveys conducted on the spot (i.e. hospitals or employment agencies)by private service providers
c. Data collected by the National Statistic Institutes (including censuses)
d. Data collected through grass-root community monitoring of the implementation of projects and through assessment of project results by the final beneficiaries
e. Data collected through surveys among social services recipients
f. Data collected through surveys of specific ministerial agencies
g. Data collected through qualitative and quantitative studies following a specific population group over a long time period (i.e. Iongitudinal studies)
h. Data collected through a specific focus on a small sample of the population (i.e. specific Roma focus in sample surveys)
40. In what other ways could data collection be improved to help support policy interventions in Roma health?
41. In what ways could data collection be improved to monitor the progress, outcomes and impacts of the NRIS on Roma health?
42. Do you have any further comments that you would like to add?

## Thank you!

We sincerely appreciate your input and would like to say thank you for taking the time to help us with our study.

## Appendix E Questionnaire on future health activities

Roma health: future activities in the EU member states

## Introduction

This survey is undertaken as part of the Executive Agency for Health and Consumers (EAHC / DG General for Health and Consumers (Sanco) project "Reports on 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 study, carried out by Matrix Knowledge, aims to i) prepare a report assessing the health status and health-related lifestyle attributes of the Roma population, ii) provide a 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 National Roma Inclusion Strategies in the area of health.

The study has been gathering information on how European countries collect healthrelated data on the Roma population and to what extent the existing activities in data collection align to the National Roma Integration Strategies (NRIS).

The evidence indicate that data are not available in a significant number of Member States and the systematic collation and assessment of Roma health data appear to be limited.

Therefore the present survey aims to understand whether and to what extent European countries are planning data collection activities on Roma health and development of specific surveys aiming to monitor the progress under the framework of the National Roma Integration Strategy.

Questions

- Respondent's name
- Respondent's organisation

1. In your country are there currently plans to fund activities to collect data and assess the Roma health status?
a. Yes
b. No (please skip to question number 7)
c. Do not know (please skip to question number 7)
2. What type of activity is / activities are currently planned?
a. Administrative data collected through administrative registers
b. Data and information collected through anonymous surveys conducted on the spot
c. Census data collected by the National Statistic Institutes
d. Data collected through monitoring of the implementation of projects or through assessment of project results
e. Data collected through qualitative and quantitative studies following a specific population group over a longer time period (i.e. longitudinal studies)
f. Data collected through a specific focus on a sample of the population (e.g. specific Roma focus in sample surveys)
g. Other activities [Please specify]
3. Which institution(s) are tasked with the main responsibility of implementing the activities?
a. Public authorities
b. Universities
c. General Practitioners (primary care)
d. Hospitals (secondary care)
e. Health Care Centres (screening surveys, regular check-up and tertiary care)
f. Educational institutions (primary and secondary schools and related immunisation programmes' registries)
g. Job Centres (social assistance coverage)
h. Social housing institutions (house assignment criteria, including health conditions)
i. Private service provider [Please specify]
j. Other [Please specify]
4. Please rate to what extent you agree or disagree with the following statements about the planned data collection and monitoring activities.
(Please tick one box for each statement)

| Completely <br> Agree | Somewhat <br> Agree | Not sure | Somewhat <br> Disagree | Completely <br> Disagree |
| :--- | :--- | :--- | :--- | :--- |


| The planned activities have been developed with SMART ${ }^{1131}$ objectives in mind |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: |
| The planned activities are compatible with the European Core Health Indicators ${ }^{1132}$ |  |  |  |  |  |
| The planned activities will aid the monitoring and evaluation of the NRIS |  |  |  |  |  |
| The planned activities have sufficient (financial and human) resources |  |  |  |  |  |
| The planned activities will fill a gap of comparable data between the general population and Roma in the health status and access to health care |  |  |  |  |  |
| The planned activities encompass geographically segregated micro regions, segregated neighbourhoods and settlements following the DG REGIO (NUTS) ${ }^{1133}$ |  |  |  |  |  |
| The activities will be able to measure impacts of the NRIS at short, medium of long term depending on the |  |  |  |  |  |

[^211]| NRIS timeline for the monitoring and evaluation |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: |
| The planned activities will build on already existing programmes (e.g. national budget, use of EU, ERDF, Structural Funds, etc) |  |  |  |  |  |
| The activities will ensure the involvement of civil society organisations working with Roma, Roma NGOs and Roma community representatives |  |  |  |  |  |

5. How would you rate the sustainability of the planned activities at short, medium of long term depending on the NRIS timeline for the monitoring and evaluation?

|  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- |
| Very High | High | Do not know | Low | Very Low |

6. Please use this comment box to provide any further details of the planned activities.
$\square$
7. If no activities are planned please describe why this is the case. This may include suggestions to improve the current scenario.
$\square$

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[^211]:    ${ }^{1131}$ S.M.A.R.T. is an acronym that is used to guide the development of measurable goals. Each objective should be: Specific, Measurable, Achievable, Relevant and Time-Oriented.
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    http://epp.eurostat.ec.europa.eu/portal/page/portal/nuts_nomenclature/introduction or for a visual map: http://ec.europa.eu/regional_policy/atlas2007/index_en.htm

