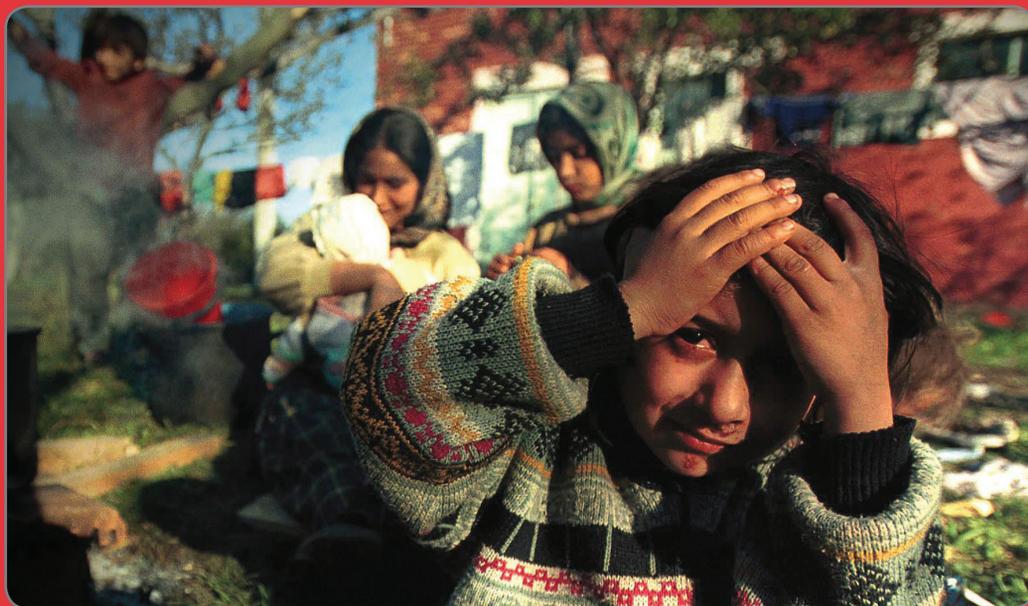


# HIDDEN HEALTH CRISIS

A REPORT BY THE EUROPEAN ROMA RIGHTS CENTRE



## Health Inequalities and Disaggregated Data

OCTOBER 2013

CHALLENGING DISCRIMINATION PROMOTING EQUALITY



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# Table of Contents

<b>1 Introduction</b>	<b>3</b>
1.1 Data and Health; the Connection	3
<b>2 Executive Summary</b>	<b>5</b>
2.1 Health Inequalities	5
2.2 The Need for Data	7
<b>3 Methodology</b>	<b>11</b>
<b>4 Previous Research on Health Inequalities Among Roma</b>	<b>13</b>
<b>5 Our Survey Results – Health Inequalities in Romania 2013</b>	<b>15</b>
5.1 Health Inequalities – an Overview	15
5.2 Age Structure and Life Expectancy	15
5.3 Self Assessment of Health Status	16
5.4 Mortality	17
5.5 Access to Medical Care	19
5.6 Screening and Vaccination Programmes	20
5.7 Children’s Health Issues	23
5.8 Incidence of Particular Medical Conditions	25
<b>6 Making the Case for a Legal Duty to Collect Disaggregated Data</b>	<b>37</b>
6.1 Why is a Legal Duty Necessary?	37
6.2 European Law Enabling Ethnic Data Collection	40
<b>7 Making Data Collection a Reality Through a Legal Duty in Romania</b>	<b>43</b>
7.1 The Connection Between Health and Human Rights	43
7.2 Public Health and Roma Health in Romania	43
7.3 Protection Against Discrimination in the Enjoyment of the Right to Health	45
<b>8 The Legal Framework on Disaggregated Data Collection in Romania</b>	<b>47</b>
8.1 Law and Policy	47
8.2 Institutional Framework	48
8.3 The Collection of Disaggregated Data in Romania	49
<b>9 Good Practice in Disaggregated Data Collection</b>	<b>51</b>
9.1 Collection of Data Disaggregated by Ethnicity in the UK	51
9.2 Collection of Data Disaggregated Based on Ethnicity in the Health Sector	53
<b>10 Conclusions and Recommendations</b>	<b>55</b>
<b>11 Annex 1: What are Health Inequalities and what are their Causes?</b>	<b>57</b>
<b>12 Annex 2: Survey Details</b>	<b>59</b>



# 1 Introduction

This report identifies differences between Roma and non-Roma in access to health and in health outcomes, through the collection of disaggregated data in households across Romania in 2013. Some of the differences which emerge are extreme – Roma live on average 16 years less, are more susceptible to serious medical conditions, and are less likely to have access to medical attention or be able to afford the costs of medicines when compared with the rest of Romania’s population.

The European Roma Rights Centre has undertaken this research to highlight a key problem in health initiatives for Roma across Europe – a lack of data. Through the lens of health inequality, the report highlights the need for all states to collect and publish disaggregated data in order to measure all inequalities between groups within the state and the effectiveness of any measures taken to address existing inequalities. There is a clear need for disaggregated data in order to demonstrate the scope of discrimination Roma face and to develop and implement targeted policy measures to address this situation.

While some States argue that they are prevented from collecting and publishing disaggregated data on ethnicity due to EU legislation on data protection, this is not the case. In fact, examples of good practice in disaggregated data collection can be found within the EU, including in the UK,<sup>1</sup> where legislation not only allows the collection of sensitive ethnic data, but makes it a legal requirement.<sup>2</sup> In the UK ethnic data collection is routine and uncontroversial.<sup>3</sup> At the same time, there are safeguards in place to protect the privacy of individuals, and ensure that data is collected and used only for legitimate purposes.

## 1.1 Data and Health; the Connection

The right to the highest attainable standard of physical and mental health is guaranteed in the International Covenant on Economic, Social and Cultural Rights.<sup>4</sup> The right to health should be provided for without discrimination on grounds such as race or ethnicity.

Where discrimination is direct and written into legislation it can be challenged more easily through courts and through advocacy for change. However, while related legislation may not on the face of it be discriminatory in character, access to or enjoyment of public services, including

1 Open Society Foundations, *No Data-No Progress: Data Collection in Countries Participating in the Decade of Roma Inclusion 2005-2015* (2010), 17.

2 Patrick Simon, “Ethnic” statistics and data protection in the Council of Europe countries: Study report, European Commission against Racism and Intolerance, (Strasbourg, 2007), 60.

3 European Commission, *Comparative Study on the Collection of data to Measure the Extent and Impact of Discrimination in a selection of countries: Final Report on England*, Measurement of discriminations Projects (2004), 3.

4 Article 12, *International Covenant on Economic, Social and Cultural Rights*, 1966.

social services, may be uneven. One group may find that it is at a disadvantage in relation to particular services, as the conditions of access, which appear to be neutral, have a negative impact. In this case, evidence is needed in order to show that indirect discrimination is taking place.

**The best way to ensure that inequalities are addressed is through the collection and publication of disaggregated data, disaggregated by factors which can be grounds for discrimination, such as ethnicity and sex.** This report examines whether health inequalities exist between Roma and other groups in Romania, and the extent of any such health inequalities, based on primary statistical research disaggregated by ethnicity.

The report consists of two interrelated sections:

- **The first section** highlights existing health inequalities between Roma and non-Roma in Romania, and the obligations on the state to provide for the health of all without discrimination. The health inequalities which are revealed here can only be shown and highlighted through the collection and publication of data disaggregated by ethnicity. For this report, Roma and non-Roma households across Romania were surveyed to provide a representative sample.
- **The second section** outlines the legal framework around data collection, including the safeguards that exist to protect individuals, and the good practice of States which collect and publish such data in order to inform public policy, address the needs of vulnerable minorities, and ensure that the State strives to provide for the rights of all, without discrimination. The legal framework in Romania is also analysed.

The interaction between these sections may not be immediately apparent. However, successful public policy planning must take into account the particular impact that policy may have on different parts of society. It must also take into account the disadvantages that certain groups may face due to historical discrimination and exclusion. In order to measure the impact of policy, data is needed, and this data needs to be disaggregated. Individuals may be vulnerable or have particular needs due to ethnicity, age, sex, sexual identity, and other characteristics, or due to a combination of these characteristics. This applies not only in the area of health, but also in education, social protection and other areas. Ongoing collection and publication of disaggregated data is also necessary in order to measure changes in health inequalities, and to assess whether and to what degree public health policies are successfully reducing and eliminating inequalities

## 2 Executive Summary

This report ties together two interrelated issues – health inequalities in Roma communities, and the duty on states to collect and publish disaggregated data in order to monitor these health inequalities. **The information on health inequalities in this report could only be revealed through the collection and analysis of disaggregated data, in this case disaggregated by ethnicity**, and also by age and sex. Without data, inequality remains hidden and the most vulnerable continue to face exclusion and discrimination.

While the report specifically focuses on health in Romania, disaggregated data is vital to measure inequality over many areas, and in all states. Such data is necessary in order to assess inequalities in accessing housing and employment, to assess the extent to which Roma are overrepresented in special education institutions, or to measure the effects of poverty on vulnerable communities. All of these issues involve positive obligations on the State to protect the rights of all people and effective monitoring through data collection is an essential tool for fulfilling such obligations.

### 2.1 Health Inequalities

The results of the Gallup survey on health in Roma and non-Roma communities reveal many health inequalities and a stark difference in the life expectancy and the quality of life of Roma and non-Roma, with Roma at a significant disadvantage. Some of the key results follow.

Mortality:

- A **16-year difference in the age at death** underlines the dramatic disparity between Roma and the general population in Romania in relation to health status and health outcomes.
- 21 deaths were recorded in the Roma population under the age of ten, compared with three in the general population. This corresponds to 47 deaths per 1000 people under the age of 10 in the Roma population and 14 per one thousand in the general population – **the mortality rate in those aged under 10 is over three times higher in the Roma population.**
- **The average time between first diagnosis of a condition and death is 3.9 years in the Roma population, while it is 6.8 years in the general population.**

One aspect of health inequality relates to access to doctors, medicines, preventive treatments and vaccinations. Roma face more obstacles in these areas, see doctors less frequently, are less able to afford medication, and are less likely to have knowledge of or access to screening and vaccination programmes.

Access to healthcare:

- Roma face greater obstacles and difficulties in accessing healthcare and paying for medication. 11% of Roma respondents reported that in the last year they had needed healthcare but did not get it, in comparison with 5% of the general population.
- **The number of Romani women who report never having had a gynaecological examination is twice as high as in the general population:** 32% of Romani women compared to 16% of women from the general population.
- 62% of Romani women responding to the survey had never heard of mammography, while only 20% of women in the general population reported the same. 39% of women from the general population reported high awareness of mammography compared to only 6% of Romani women.
- In relation to vaccinations and other preventive measures for children, clear health inequalities are revealed. The survey revealed that **almost four times as many Romani children had never been vaccinated when compared with the general population** (6.4% compared with 1.7%).
- The difference in the number of children who have not been vaccinated is very visible when looking at data disaggregated by gender – there are 11 times the number of Romani girls who have never been vaccinated than girls in general population households (6.6% of Romani girls have never been vaccinated compared with 0.6% in the general population).

There are many health conditions which are more likely to be diagnosed among Roma, and in particular, these conditions are more likely to be diagnosed at a younger age. However, it is worth noting that there is no one health condition which stands out as a main cause of health inequalities. Rather it appears that the cumulative effect of susceptibility to a variety of conditions leads to the outcome that Roma die 16 years younger and live less healthy lives overall. As explained in an annex to this report, health inequalities arise due to a variety of factors including poverty, poor living conditions, poor diet, lower levels of education, and higher unemployment. These factors are all interrelated and lead to a cycle of inequality which continues from one generation to the next.

Specific health conditions:

- Results of the survey show that the **rate of diagnosis of TB among Roma respondents is more than double that of the general population**, while in the 55 to 64 age bracket diagnosis is four times higher among Roma respondents.
- In the 35 to 44 age group 2.7% of the Roma population have been diagnosed with some form of heart disease while for the general population the figure is 0.3%.
- **Diagnosis of pneumonia is higher among Roma respondents across all age groups** and to a significant degree between the ages of 45 and 54 and in those aged 65 and over.
- Results for chronic bronchitis or emphysema also show statistically significant results in the 55 to 64 age group.

## 2.2 The Need for Data

Having examined health inequality, the report outlines the need for States to collect and publish disaggregated data with a view to adequately redressing such inequalities through tailor-made governmental policies. It has been argued that **when data is disaggregated based on factors such as gender, region, religion and ethnicity, policy makers are able to discern the relative enjoyment of rights among members of different social groups and identify “de facto discrimination and exclusion.”**<sup>5</sup> This report highlights the fact that international human rights bodies have repeatedly called on states to use disaggregated data, and the Council of Europe has stated that due to the lack of collected statistics based on ethnicity and gender, the outcome of government policies and programmes could not be accurately monitored, assessed and improved.<sup>6</sup>

The report outlines the necessity to collect disaggregated data and **the European legal framework which allows for such data to be collected and published**, with appropriate safeguards. It also provides an overview of the current legal and political framework in Romania. The report also highlights a good practice example in relation to the United Kingdom, where data has long been collected and disaggregated in order to improve efforts at tackling discrimination.

<sup>5</sup> Todd Landman and Edzia Carvalho, *Measuring Human Rights*, (London and Oxford: Routledge, 2007) p 116.

<sup>6</sup> Council of Europe, Parliamentary Assembly, Resolution 1740 (2010), *The Situation of Roma in Europe and relevant activities of the Council of Europe*, paragraph 15.7.



# **Section One**

**Health Inequalities Faced by Roma  
in Romania, and the Right to Health**



### 3 Methodology

This report is based on a survey carried out by Gallup Romania, from February to April 2013, on health inequalities between Roma and non-Roma in Romania. The survey was carried out in 1119 Roma households and 800 non-Roma households, in Romania's eight development regions.<sup>7</sup> The survey focused on the most common health conditions in Romania and provides disaggregated data on the rate of diagnosis in both Roma and non-Roma communities. It also examined access to primary medical services and access to preventative measures such as screening programmes. The survey builds a picture of common medical conditions<sup>8</sup> and how widespread they are in both Roma and non-Roma communities, and also of access to the medical services which are essential for the prevention or treatment of such conditions. A fuller description of the survey methodology is contained in an annex to this report (see page 59). The report is also based on research carried out by the ERRC and by the Essex Human Rights Clinic in the University of Essex, examining the duty to collect and publish disaggregated data, and also the health situation of Roma communities in Romania.

Survey respondents were asked whether they had received an official diagnosis for a variety of medical conditions. Therefore, the possibility of non-diagnosis is not addressed and it is clear that non-diagnosis or under-diagnosis of conditions may have an impact on the overall results. This issue is particularly relevant for Roma respondents as Roma report more obstacles in accessing medical care and medical services, and also shorter survival periods following diagnosis. Both of these factors suggest that under-diagnosis may have a significant impact on the Roma population sample.

The survey questioned respondents about a broad range of common health conditions in Romania. The list of health conditions was drawn from Romanian health statistics, which are available for the entire country but are not available disaggregated by ethnicity. Questions on specific conditions included the following three questions:

- Have you ever been diagnosed by a physician or a health professional with X condition?
- Were you diagnosed in the last 5 years with X condition?
- Are you currently suffering from X condition?

The results were further disaggregated by age categories; 15 to 34; 35 to 64; and 65 and over.

Information on public health in Romania is collected by state bodies and in particular by the National Institute for Statistics and by the Ministry of Health. It is believed that a large

<sup>7</sup> These regions are North-East, North-West, South, South-East, South-West, West, Centre, and Bucharest.

<sup>8</sup> General information on the prevalence and rate of occurrence of these conditions was taken from official Romanian health data. *Ministerul Sănătății Institutul Național de Sănătate Publică, Centrul Național de Statistică și Informatică în Sănătate Publică Buletin Informativ*, No 13, 2011.

## METHODOLOGY

amount of information is readily available, and can be used by the relevant bodies to assess the health status of various groups in Romania, including ethnic minorities.<sup>9</sup> However, this information is not being used to investigate health inequalities. This survey did not have access to medical institutions or services or the records kept by them. Research was carried out with members of households, and relies on personal understanding and knowledge of health status. State bodies have the capacity to facilitate the collection and disaggregation of such information by medical experts and professionals, and through medical institutions.

<sup>9</sup> ERRC interview with Romanian NGO, July 2013.

## 4 Previous Research on Health Inequalities Among Roma

The 2009 report *Health and the Roma Community: analysis of the situation in Europe* surveyed 759 Roma households in Romania, asking participants about self-perception of health status and disease; accidents; limitations on everyday activities due to health problems; medicines used; visits to the doctor's office; visits to the dentist; hospitalisation; use of emergency healthcare services; preventive health measures taken by women; social support; amount of physical activity and rest; and nutrition.<sup>10</sup>

79% of respondents in the 2009 survey gave a positive assessment of their health status, and such a positive assessment is typical of Roma health surveys. However, studies which include indicators on life expectancy and infant mortality contradict the positive assessment.<sup>11</sup> The study showed that 'a large percentage of Roma conceive of health as the absence of disease, and disease as an incapacitating phenomenon linked to death'.<sup>12</sup> The World Health Organization describes health as follows: 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' While this sets an international standard for the definition of health, the understanding of health may differ between states, and between communities within states; therefore, self-assessment of health may vary greatly.

The 2009 health survey showed that among the Roma population in Romania over half of those over 45 suffered from disabilities or chronic disease, over 60% suffered from cavities, and over half of all adults were overweight or obese.<sup>13</sup> 47.5% of minors had not received all of the vaccines available in the National Immunisation Programme, even though these vaccines were free and mandatory.<sup>14</sup> The study showed that diet is calorically unbalanced, with an overuse of cereals and a low consumption of protein-rich foods.<sup>15</sup>

A 2011 UNDP and Fundamental Rights Agency survey showed that while 81% of non-Roma have access to health insurance, this figure falls to 52% for Roma. 73% of Romani individuals have no access to essential drugs. For non-Roma this figure is 33%.<sup>16</sup> In relation to incidence of four different types of medical check which were included in this survey, the figure was higher in every case for non-Roma; 25% of Roma reported having had a heart check-up but

<sup>10</sup> Fundación Secretariado Gitano Health Area, *Health and the Roma Community: analysis of the situation in Europe*, (2009), 148.

<sup>11</sup> *Ibid*, 148.

<sup>12</sup> *Ibid*, 148.

<sup>13</sup> *Ibid*, 148.

<sup>14</sup> *Ibid*, 149.

<sup>15</sup> *Ibid*, 150.

<sup>16</sup> UNDP, *Data on Roma: Romania, 2011*, available at: <http://europeandcis.undp.org/ourwork/roma/show/D69F01FE-F203-1EE9-B45121B12A557E1B>.

for non-Roma this figure was 40%.<sup>17</sup> These figures indicate that there are inequalities in access to health services which leave Roma at greater risk of ill health.

### Roma in Romania

Although it is not known exactly how many Roma are living in Romania, unofficial estimates put the Roma population of Romania at about 1.7 million, or 9%. In February 2012, the National Statistics Institute published the preliminary results of the 2011 Census, finding that the total population had dropped from 21.68 million inhabitants in 2002<sup>18</sup> to 19 million, while the number of persons self-identifying as Roma had increased to 619,007 (3.2% of the total population, an increase from 2.46% in the 2002 census).<sup>19</sup>

Roma in Romania are subjected to discrimination, exclusion, social marginalisation and poverty. While many organisations, including Romani NGOs, are working to improve this situation, the challenges are significant and obstacles remain in accessing employment, education, housing and healthcare.

<sup>17</sup> *Ibid.* The other figures were as follows; Dental check - Roma 12%, non-Roma 26%; X-ray, ultrasound or other scan – Roma 14%, non-Roma 21%; Cholesterol test – Roma 21%, non-Roma 36%.

<sup>18</sup> Romania pe Regiuni de Dezvoltare si Judete, available at: [www.insse.ro/cms/files/rpl2002rezgen1/14.pdf](http://www.insse.ro/cms/files/rpl2002rezgen1/14.pdf).

<sup>19</sup> National Statistics Institute, *Central Commission for the Census of the Population and Households, Press release concerning the preliminary results of the Census of the Population and Households*, 2011, 2 February 2012, [www.insse.ro/cms/files/5Cstatistici%5Ccommunicate%5Calte%5C2012%5CComunicat%20DATE%20PROVIZORII%20RPL%202011.pdf](http://www.insse.ro/cms/files/5Cstatistici%5Ccommunicate%5Calte%5C2012%5CComunicat%20DATE%20PROVIZORII%20RPL%202011.pdf).

## 5 Our Survey Results – Health Inequalities in Romania 2013

### 5.1 Health Inequalities – an Overview

The overall picture of health status in Romania in 2013 shows that there are significant differences in access to doctors and medical care, and that Roma also face many obstacles in accessing preventive treatments. The lack of equality in this regard, combined with poor living conditions and other obstacles, means that Roma are at a severe disadvantage, and do not enjoy the highest attainable standard of health.

**For Roma in Romania 16 years are missing;** that is the difference in the age at mortality which the survey revealed. Roma are more likely to be diagnosed with various serious conditions at a younger age, and live three years less following diagnosis.

There is no one condition or factor which explains this discrepancy; there is no one medical condition or factor which can explain such a difference in health outcomes between Roma and non-Roma in Romania. Rather, the discrepancy is due to the interaction of multiple factors which lie at the root of health inequalities (see annex I) including poverty, poor living conditions, lower levels of employment and education, and social exclusion.

It is only through the collection and publication of data disaggregated by ethnicity that these health inequalities can be quantified, and such data is also essential in order to monitor and measure any changes or improvements which might be brought about by public health policy, as well as to highlight any necessary adjustments. The survey has taken a representative national sample in both the Roma and general population to assess the extent of health inequalities. It has shown that statistically significant differences exist across many areas of health and that the Roma population in Romania does not enjoy equal access to health care or equality in health outcomes.

Any state which aims to guarantee the access to rights such as health on an equal basis has a duty to monitor that access, taking particular account of groups which may be vulnerable to discrimination or exclusion, whether on the basis of ethnicity or nationality, religion, sex, or any other factor.

The survey for this research was carried out by Gallup Romania in March and April 2013. In total, 1119 Roma households and 800 non-Roma households were surveyed. A full description of the survey methodology is found in an annex to this report.

### 5.2 Age Structure and Life Expectancy

The survey showed that there are considerable differences between the structure and age profile of the Roma population and the general population. The general population sample shows a

much older age profile, while the situation in Roma households is reversed. In Romani families there is a dramatic decrease in the proportion of people over 65 and a much higher proportion of children and young people.

**Distribution of age groups in each sample surveyed (by percentage). Source: Gallup, 2013.**

	Roma Population Survey Sample	General Population Survey Sample
Under 15	36.6	15.4
15-34	28.2	18.2
35-64	30	44.2
65 and over	5.2	22.2

The very different age structure of the two populations has a direct impact on the results of the survey. Due to the higher birth rate and shorter life expectancy, the Roma population has a much younger profile than the general population. This should be borne in mind when examining the results. Many health conditions naturally show an increased occurrence with age, and therefore may be expected to have a higher occurrence in those aged 65 and over. This creates a potential bias towards the general population. Therefore, results are further disaggregated by age, and the occurrence of conditions within younger age brackets is examined. The survey shows that Romani respondents are more likely to be diagnosed with medical conditions at a younger age.

The age profile has a significant impact on mortality statistics. At first glance, the survey shows a higher overall mortality rate in the general population. However, this is misleading as the general population sample is on average much older. On further examination the survey reveals that among Roma deaths occur more frequently at younger ages and the age of death is much lower; **the average age at death in surveyed households is 52 years old in the Roma sample, and 68 years old in the general population sample.**

**This 16-year difference in life expectancy underlines the dramatic disparity between Roma and the general population in Romania, in relation to health status and health outcomes.**

### **5.3 Self Assessment of Health Status**

Interviewees were asked to self-assess their health status. Although self assessment cannot be considered to be an accurate tool, it gives a useful indication of how respondents feel about their overall health.<sup>20</sup> As with previous studies, the survey showed that individuals in Roma households generally gave a more favourable health assessment than non-Roma, with 25%

<sup>20</sup> The question was ‘In general, how would you rate your health today?’ with six possible answers as follows; very good, good, moderate, bad, very bad, N/A.

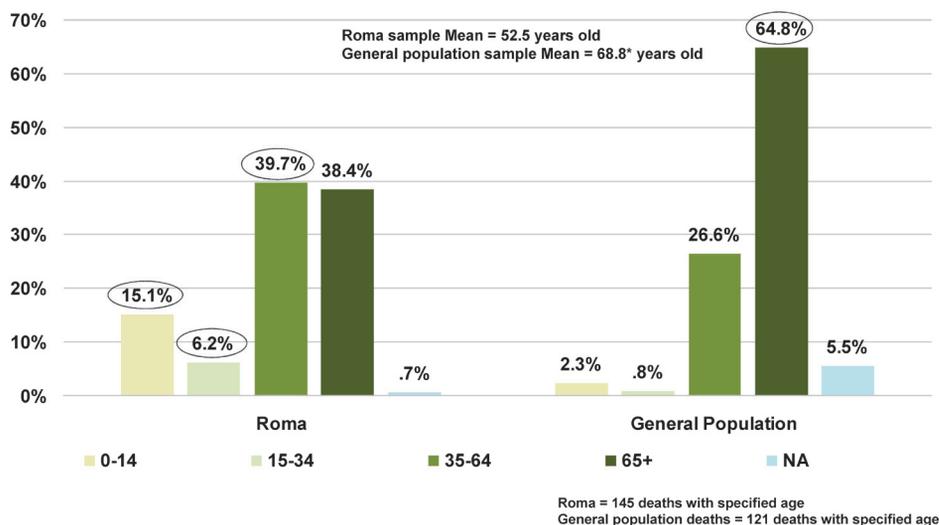
of Roma assessing their health as very good compared with 17% of the general population. However, when the two categories of very good and good are taken together the difference is not as noticeable, with 63% of Roma respondents and 60% of the general population declaring their health to be in one of these two categories.

When disaggregated by age, the self-assessment results show that in the 35 to 64 age group the self assessment of Roma becomes less positive, and the number of respondents who assess their health as bad is 21% for Roma compared to 14% for the general population. This trend continues in the over-65 age group, which shows a disparity of 41% for Roma and 31% for non-Roma. In a related question on difficulty with performing work or household activities, in the 35 to 64 category 16% of Roma reported severe difficulty and 6% answered extreme/cannot do; the corresponding figures in the general population are 10% and 3%. It is noteworthy that negative self assessment increases more rapidly for Roma respondents with age, and suggests that Roma are encountering health problems at a younger age than the general population.

## 5.4 Mortality

In relation to age distribution of deaths in the last five years the survey found statistically significant results across all age groups. In all of the age categories 0 to 14, 15 to 34 and 35 to 64, the figures for Roma were significantly higher than for the general population. This situation is reversed only in the oldest age category of 65 and older; while 64.8% of deaths in the general population occur in this age group, in the Roma population this figure falls to 38.4%.

**Chart 1: Age distribution of deaths in the last 5 years. Source: Gallup, 2013.<sup>21</sup>**



<sup>21</sup> In the survey results, all figures which are circled are considered to be statistically significant by Gallup.

**The mean age at death in the Roma sample is 52.5 years, while for the general population it is 68.8 years.**

Further analysis of mortality rates is provided through a life table analysis for all deaths reported over the last five years, which calculates the probability of surviving or dying within separate age groups. Age categories are divided in ten-year intervals.

The table below illustrates the fact that the number of deaths per one thousand people remains higher in Roma populations. Roma are dying more frequently at younger ages.

Between the ages of 20 and 39, 13 deaths were recorded in the Roma households surveyed, compared to one death in the general population.

21 deaths were recorded in the Roma population under the age of ten compared with three in the general population. **This corresponds to 47 deaths per 1000 people under the age of 10 in the Roma population and 14 per one thousand in the general population, and so is over three times higher in the Roma population.**

**Number of deaths occurring in different age categories. Source: Gallup, 2013.**

Age category	Roma number of deaths	Roma proportion of deaths (out of 1000 people)	General population number of deaths	General population proportion of deaths (out of 1000 people)
0 - 9	21	0.0047	3	0.0014
10 - 19	2	0.0006	0	0
20 - 29	5	0.0020	0	0
30 - 39	8	0.0045	1	0.0007
40 - 49	12	0.0101	8	0.0064
50 - 59	20	0.0290	14	0.0151
60 - 69	32	0.0920	21	0.0361
70 - 79	29	0.2021	41	0.1411
80 - 89	14	0.3733	30	0.3279
90 and over	2	0.400	3	0.3750

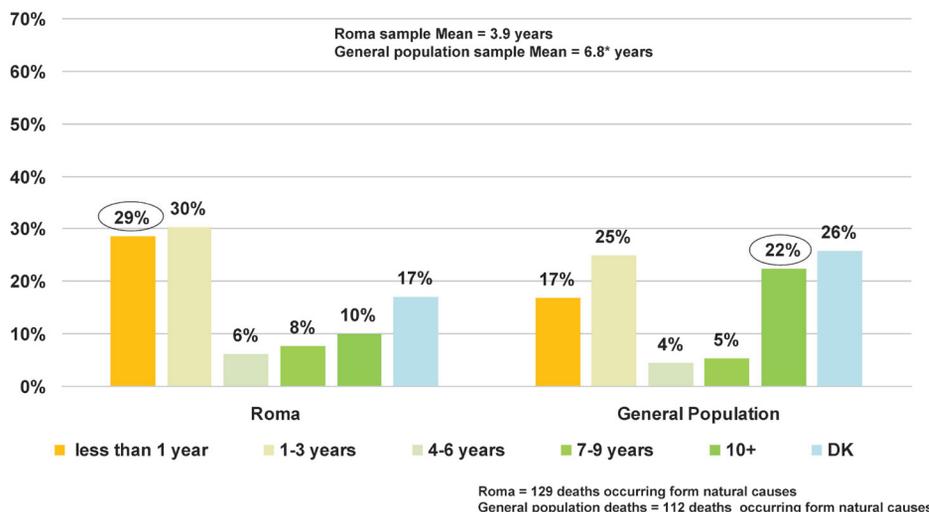
One clear trend has emerged in the survey. While the mortality rate in the first year is similar across both groups, **from one to five years of age ten deaths were recorded in the Roma population, while no such deaths were recorded in the general population.** A much larger survey would be required to investigate this worrying trend further. Such a survey is beyond the scope of

this research project, but within the scope of national agencies. Nonetheless, the results suggest that there is a clear difference in the childhood mortality rate between the two populations.

*Mortality following diagnosis of an illness*

The survey showed further significant results in relation to the survival time following diagnoses of an illness. **While 29% of respondents in the Roma sample survive less than one year, in the general population that figure falls to 17%.** The situation is reversed in relation to those surviving ten years or more; in the Roma sample just 10% survive this long while in the general population 22% survive this long. **It is also shown that the average time between first diagnosis of a condition and death is 3.9 years in the Roma population while it is 6.8 years in the general population.**

**Chart 2: Distribution of deaths by survival time (years between first diagnosis and death). Source: Gallup, 2013.**



These figures indicate clearly that Roma are more likely to suffer more serious consequences and poorer health outcomes, including increased mortality, once diagnosed with an illness. This can be explained either by a later diagnosis of serious conditions which gives the patient a lower chance of survival or by poorer treatment once diagnosed.

## 5.5 Access to Medical Care

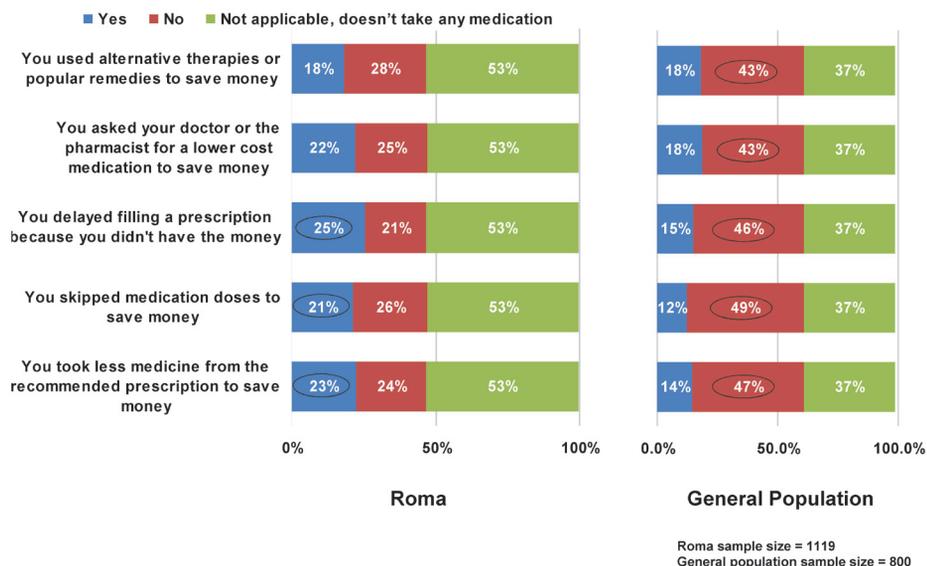
The survey questioned participants about access to healthcare and also to screening and prevention programmes. Participants were also asked about barriers and obstacles to healthcare such as associated costs, including travel and medication, and lack of health insurance.

The results clearly indicate that Roma face greater obstacles and difficulties in accessing healthcare and paying for medication. **11% of Roma respondents reported that in the last year they had needed healthcare but did not get it, in comparison with 5% of the general population.**

As for reasons given, 72% of Roma stated that they could not afford the cost of the visit (compared with 56% of respondents in the general population), while 48% also stated that they could not afford the cost of transport (compared with 31% of the general population). 41% did not have medical insurance (compared with 33% of the general population).

For those who had visited a doctor and received a diagnosis, further obstacles arose in accessing treatment and medication. Here many significant differences were revealed between Roma and non-Roma, showing **that Roma are more likely to delay filling in a prescription, or take less of the prescription, in order to save money.** In relation to specific medical conditions, while 100% of the general population who had been diagnosed with either TB or pneumonia reported receiving treatment, these figures fell to 89% of Roma diagnosed with pneumonia and 95% of those diagnosed with TB. Furthermore, diagnosis of both conditions is higher among Roma.

**Chart 3: During the past 12 months, are any of the following true for you?**  
**Source: Gallup, 2013.**



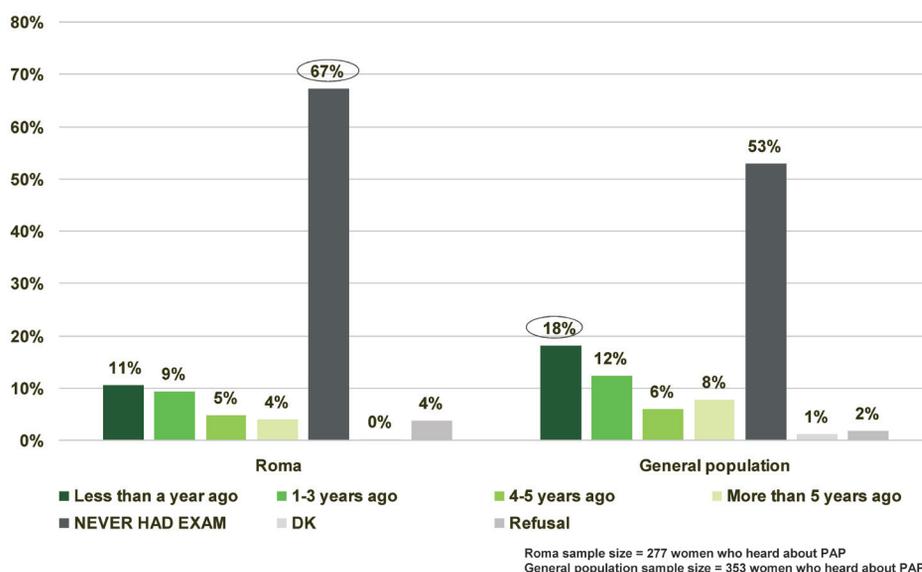
## 5.6 Screening and Vaccination Programmes

Information on access to screening programmes for tuberculosis (TB), cervical cancer and breast cancer, and vaccination programmes also show significant differences and reveal that Roma in Romania are much less likely to have access to these health services.

In relation to x-ray screening for tuberculosis (TB), over half of all Roma surveyed had never had access to such screening (54%) while the figure drops to approximately one-third (34%) in the non-Roma population.

Figures in relation to gynaecological examinations and to PAP smear tests also showed significant differences in access to tests. **The number of Romani women who report never having had a gynaecological examination<sup>22</sup> is twice as high as in the general population:** 32% of Romani women compared to 16% of women from the general population. The figures for the PAP test are shown below.

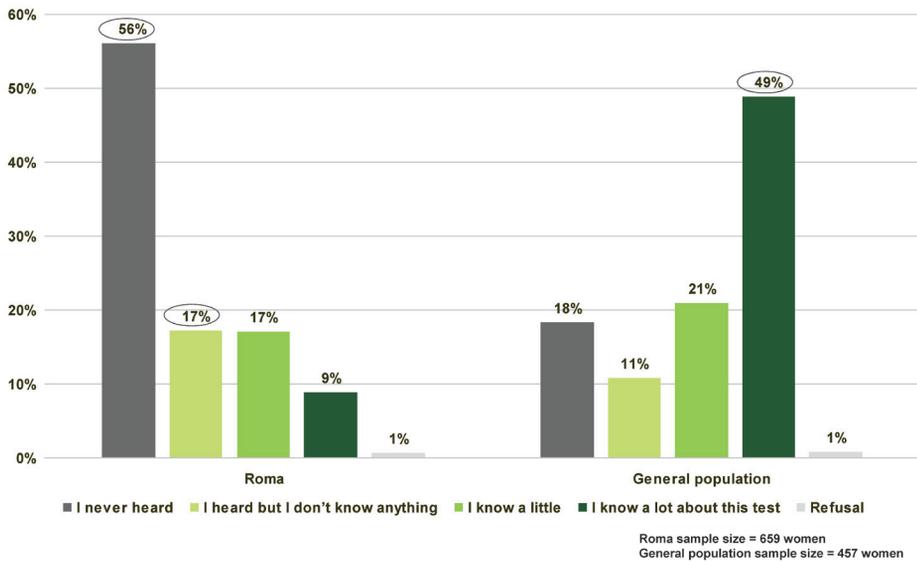
**Chart 4: When was the last time you had a PAP smear test? Source: Gallup, 2013.**



The difference remains significant when the figure is broken down by age group, and 74% of Romani women in the 15 to 34 age group have never had the test, compared with 61% in the general population sample. Worryingly, knowledge of this test remains much lower among Romani women when compared with the general population. Overall, 56% of Romani women who responded to the survey had never heard of the test compared to 18% of the general population, while only 9% of Romani women knew a lot compared to 49% of women from the general population.

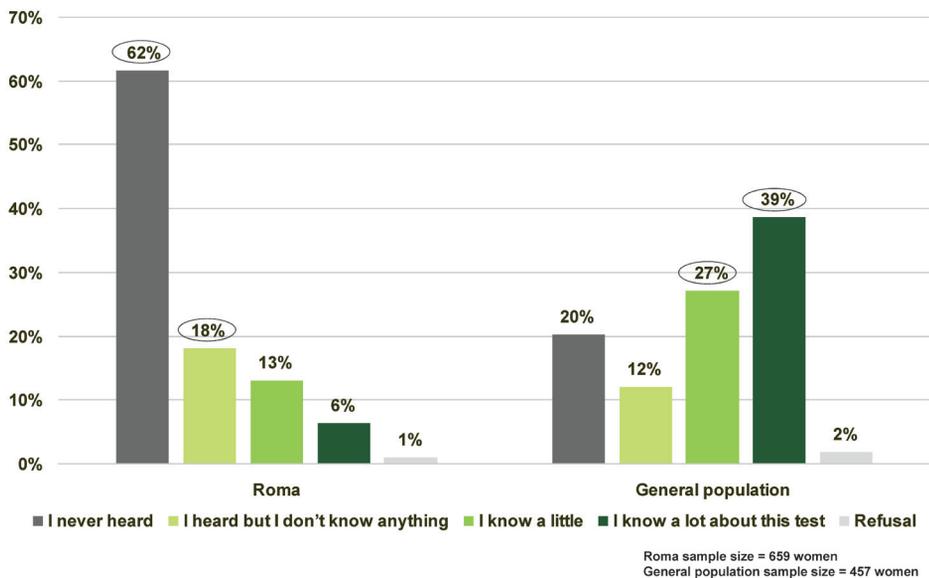
22 This question excluded such examinations carried out during childbirth or pregnancy.

**Chart 5: Please tell me how much you know about PAP smear test? Source: Gallup, 2013.**



A similar situation arises in relation to awareness of, and access to, mammography as a means of detecting breast cancer. 62% of Romani women responding to the survey had never heard of mammography, while only 20% of women in the general population reported the same. 39% of women from the general population reported high awareness of mammography, compared to only 6% of Romani women.

**Chart 6: Please tell me how much you know about mammography? Source: Gallup, 2013.**



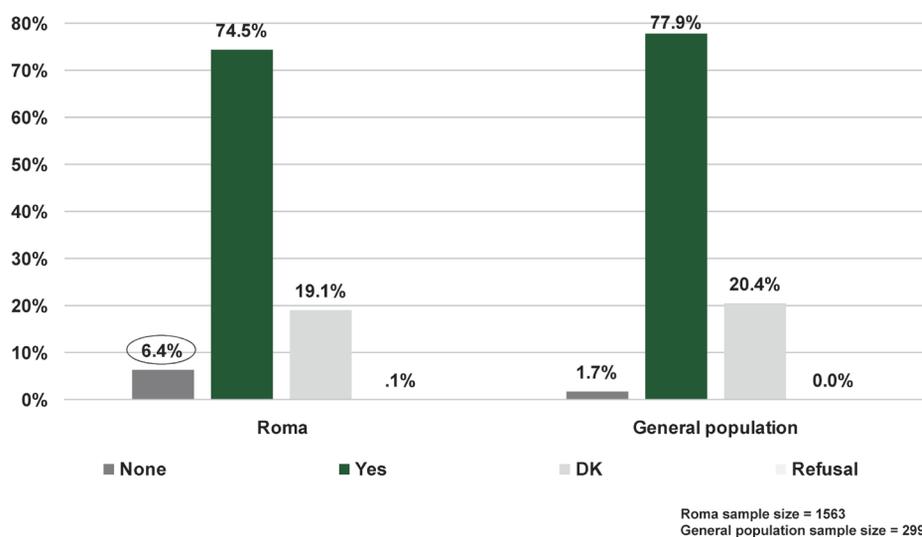
Of the women who had heard of mammography, 88% of Romani women reported that they had never had a mammogram compared to 79% of the women from the general population.

## 5.7 Children’s Health Issues

Access to medical care, and also to prevention and treatment programmes are essential for ensuring the healthy development of children.

In relation to vaccinations and other preventive measures for children, clear health inequalities are revealed. The survey revealed that almost four times as many Romani children had never been vaccinated when compared with the general population (6.4% compared with 1.7%).

**Chart 7: Do you remember how many vaccinations your child had until now?**  
Source: Gallup, 2013.

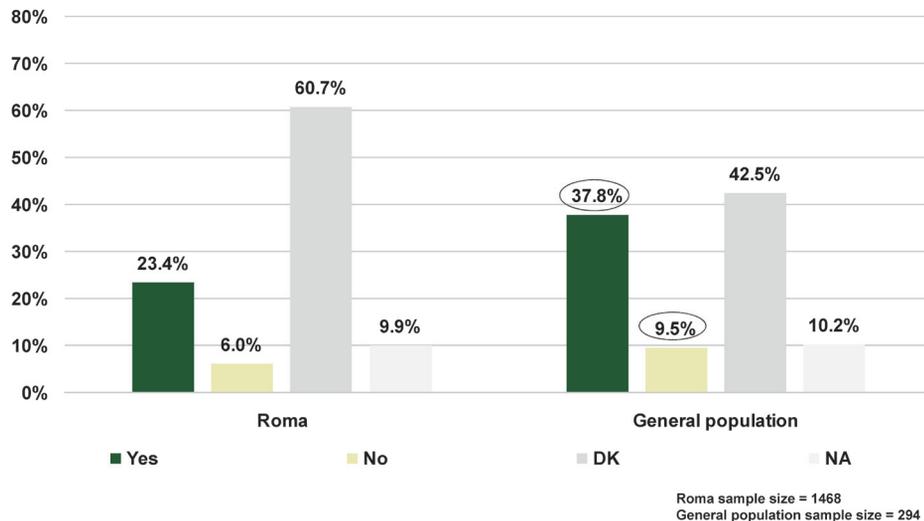


The difference in the number of children who have not been vaccinated is very visible when looking at data disaggregated by gender – there are 11 times the number of Romani girls who have never been vaccinated than girls in general population households (6.6% of Romani girls have never been vaccinated compared with 0.6% in the general population).

Romani children are much less likely to receive particular vaccinations. This can be seen with various vaccinations, including Hepatitis B and the Diphtheria, Tetanus and Pertussis (DTP) vaccine below. It is also evident with the TB IDR test.

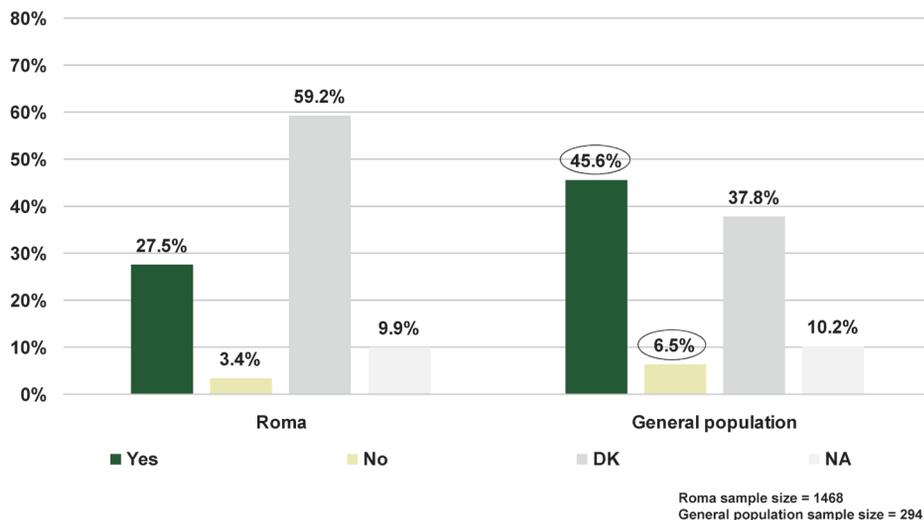
**Chart 8: Can you please tell me which types of vaccines were administered to your child? Source: Gallup, 2013.**

Hepatitis B vaccine

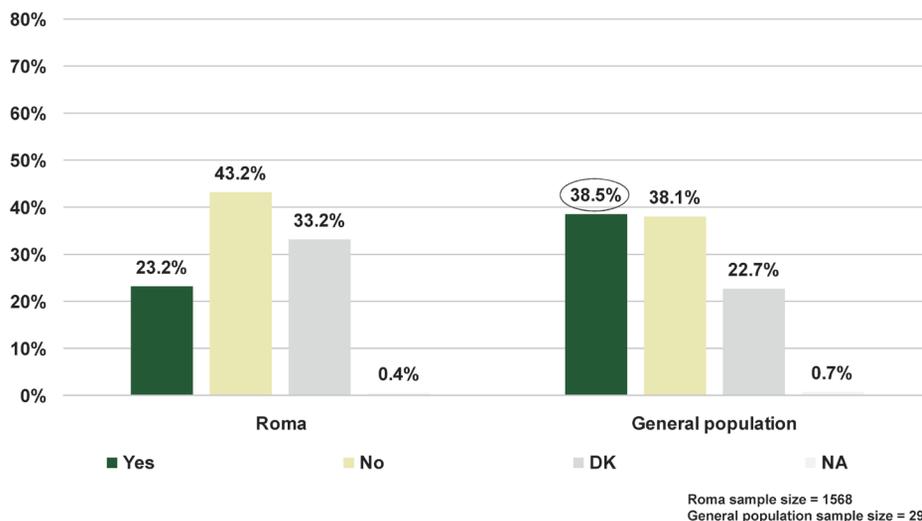


**Chart 9: Can you please tell me which types of vaccines were administered to your child? Source: Gallup, 2013.**

Diphtheria, Tetanus and Pertussis vaccine



**Chart 10: Has your child ever been tested for tuberculosis with IDR test?**  
 (when an injection is administered in the forearm and the body reaction as skin redness is measured in 2-3 days) Source: Gallup, 2013.



## 5.8 Incidence of Particular Medical Conditions

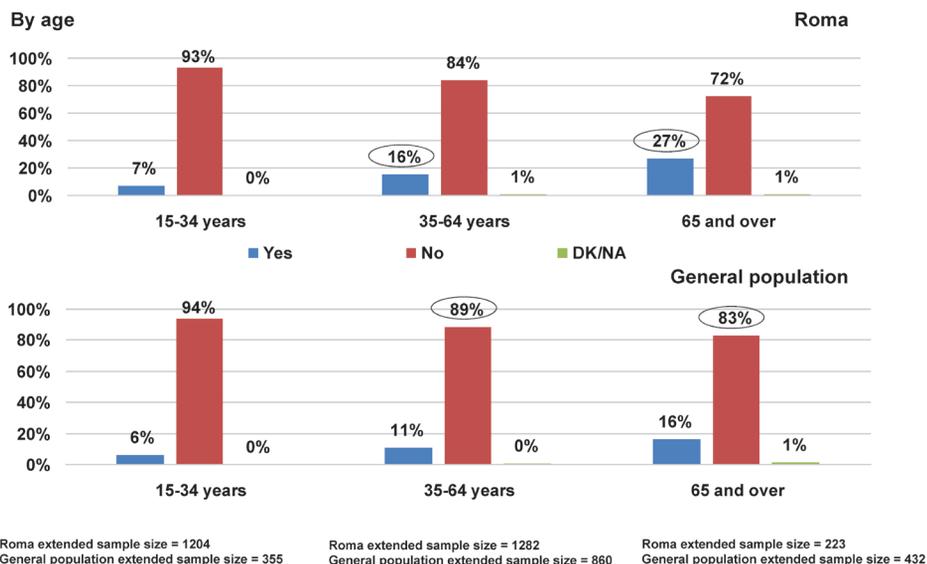
Across the overall sample for many serious issues and conditions diagnosis among non-Roma respondents is higher. These conditions include hypertension (7.7% higher), heart or vascular diseases (7%), liver disease (3%) and cancers (0.8%). All of these disparities are considered statistically significant.<sup>23</sup> However, the older age profile of the general population leads to a potential bias in the overall results, as older respondents are more likely to be diagnosed with such conditions. Indeed, when the results are disaggregated by age groups, they show that Roma are more likely to be diagnosed with many conditions at a younger age.

Moreover, the absence of a diagnosis does not necessarily confirm the absence of a condition. Diagnosis depends on having access to a doctor or medical professional, which a greater number of Roma reported to be a problem, compared with the general population (see Section 5.5). Obstacles which prevent or reduce access to healthcare, and therefore reduce the chances of a timely diagnosis, include associated costs (the cost of transport to a healthcare facility, the cost of medication, and also unofficial payments to medical professionals), and discrimination.

**Respiratory diseases:** The survey shows that Roma are significantly more likely to be diagnosed with various respiratory diseases, affecting the respiratory system and lungs.

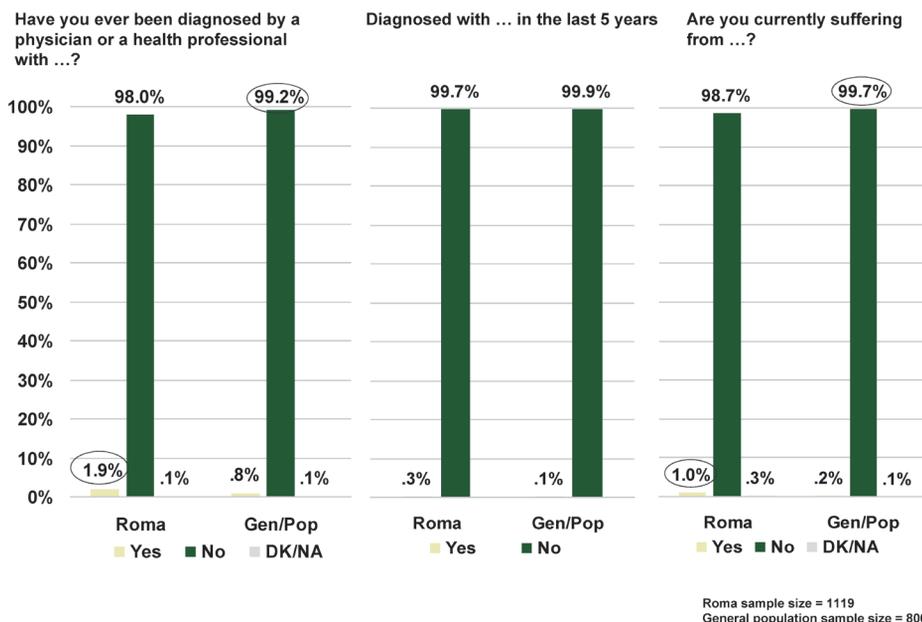
<sup>23</sup> With rarer conditions, such as cancers, a difference of 0.8% is considered statistically significant.

**Chart 11: Have you ever been diagnosed by a physician or a health professional with a respiratory disease, meaning any disease related to the respiratory airways or lungs? Source: Gallup, 2013.**

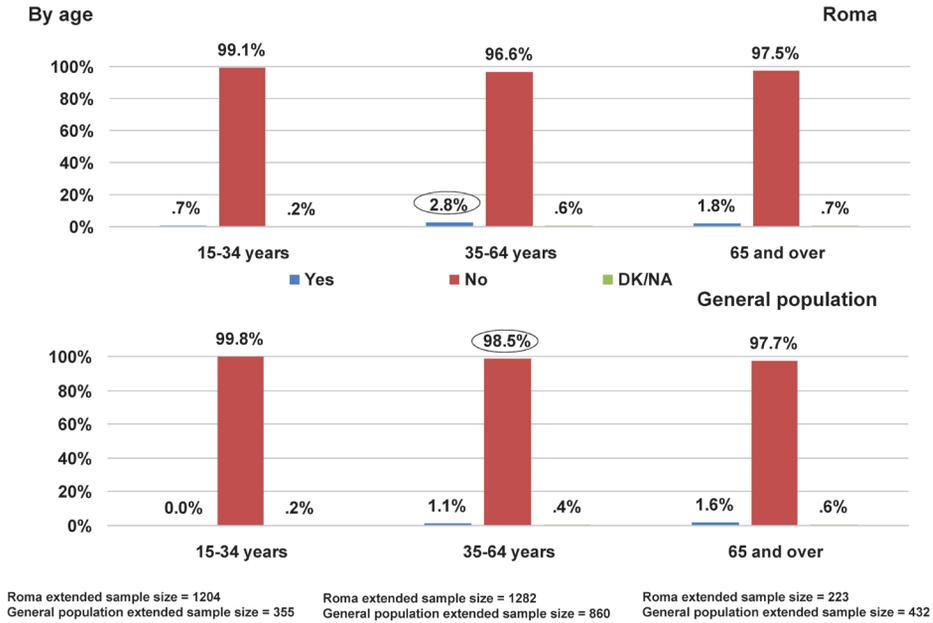


**Tuberculosis:** Results of the survey have shown that the rate of diagnosis of TB among Roma respondents is more than double that of the general population.

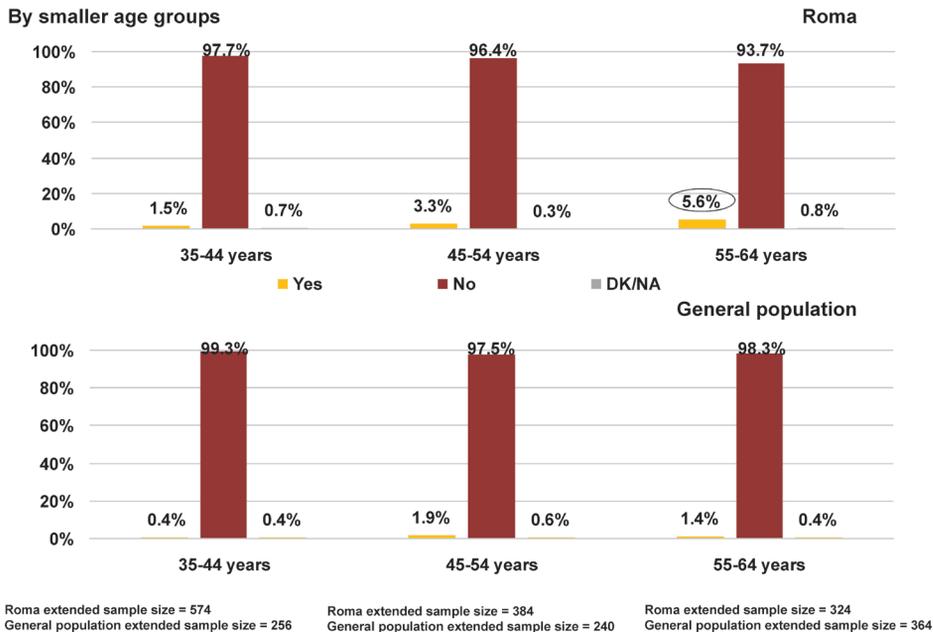
**Chart 12: Tuberculosis (TB). Source: Gallup, 2013.**



**Chart 13: Have you ever been diagnosed by a physician or a health professional with tuberculosis (TB)? Disaggregated by age. Source: Gallup, 2013.**



**Chart 14: Have you ever been diagnosed by a physician or a health professional with tuberculosis (TB)? By smaller age groups. Source: Gallup, 2013.**



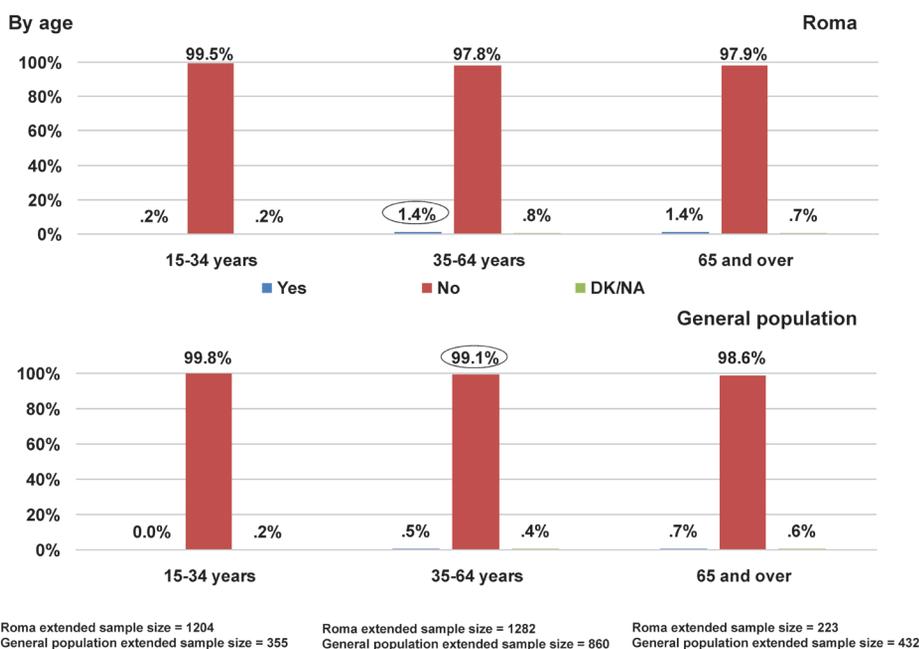
As shown above (Section 5.7), vaccination rates for TB are also lower among Roma.

When results are further disaggregated by age, the results show that the occurrence remains higher among all age groups in Roma populations, and to a statistically significant degree in the 35 to 64 age category.

**In the 55 to 64 age bracket, diagnosis is four times higher among Roma respondents.**

Of those currently suffering from the condition the results are also significant, with 1.0% of Roma currently suffering from TB, compared with 0.2% of the general population. Again, when disaggregated by age group, the results are higher for all age groups, and significantly higher in the 35 to 64 age category.

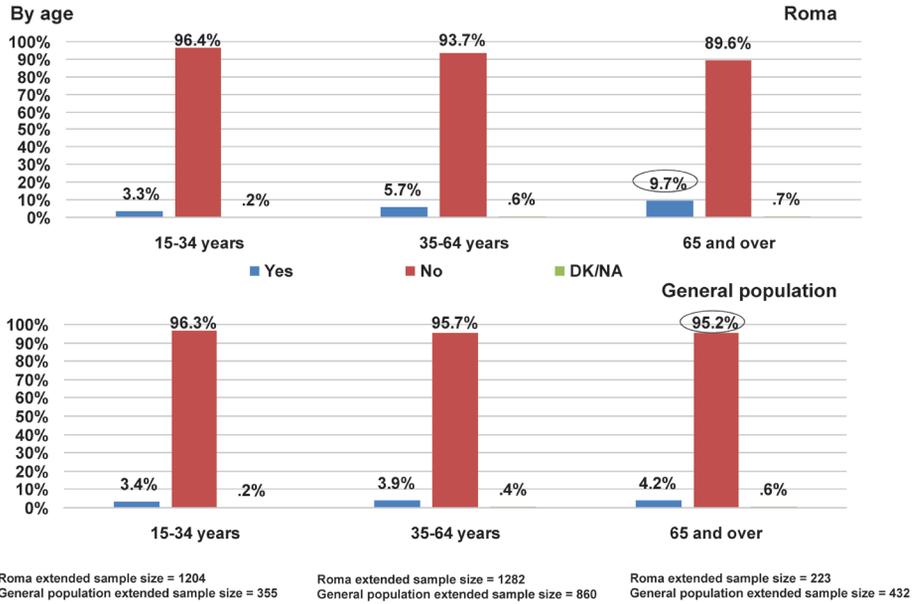
**Chart 15: Are you currently suffering from tuberculosis (TB)? Source: Gallup, 2013.**



These figures show that Roma are not only more likely to be diagnosed with TB, but that the preventive programmes and treatments available appear to be less effective or are failing to reach Roma; over half of all Roma who have ever been diagnosed are currently suffering from TB, compared to a quarter of those diagnosed from the general population.

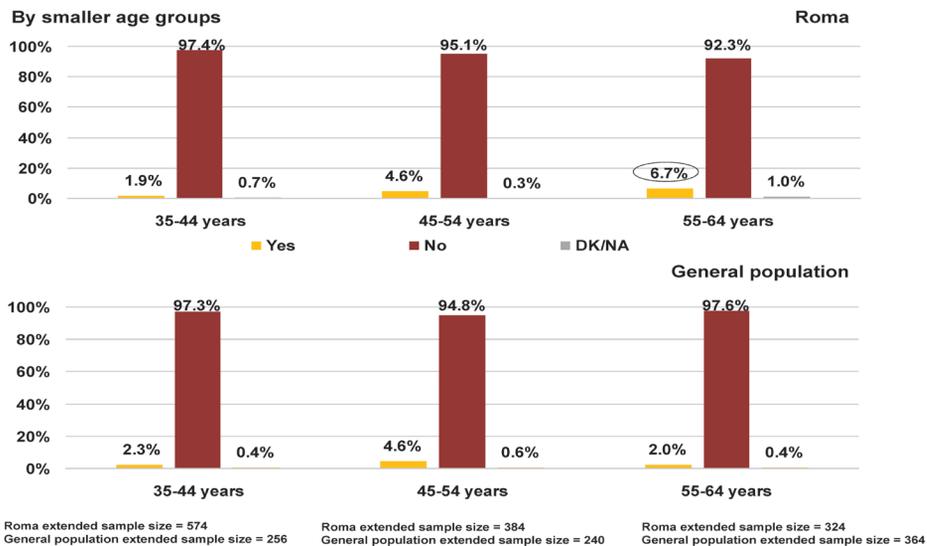
**Pneumonia:** Diagnosis of pneumonia is higher among Roma respondents across all age groups, and to a significant degree between the ages of 45 and 54 and in those aged 65 and over. Among those who are currently suffering from pneumonia, the results are significantly higher among Roma respondents aged 35 and over.

**Chart 16: Have you ever been diagnosed by a physician or a health professional with pneumonia? Source: Gallup, 2013.**



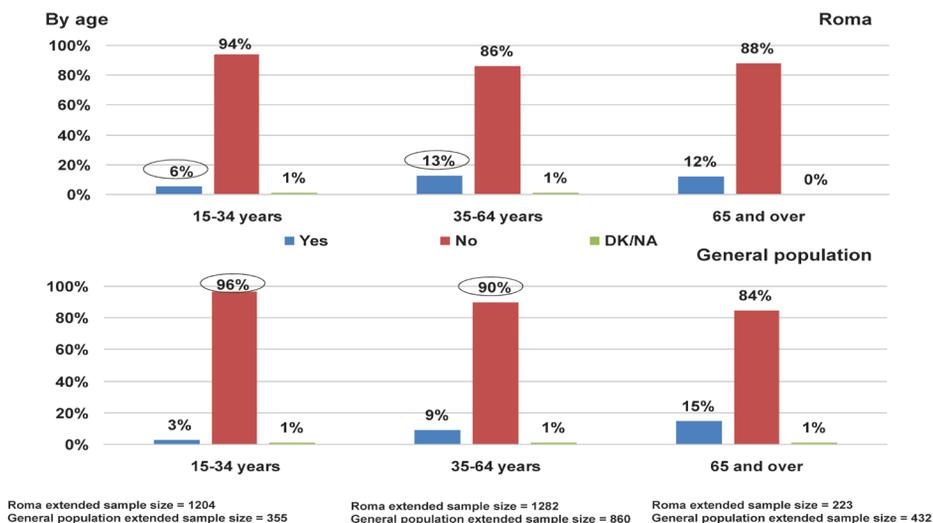
**Chronic bronchitis or emphysema:** When disaggregated by age, results for chronic bronchitis or emphysema also show statistically significant results in the 55 to 64 age group.

**Chart 17: Have you ever been diagnosed by a physician or a health professional with chronic bronchitis or emphysema? By smaller age groups. Source: Gallup, 2013.**

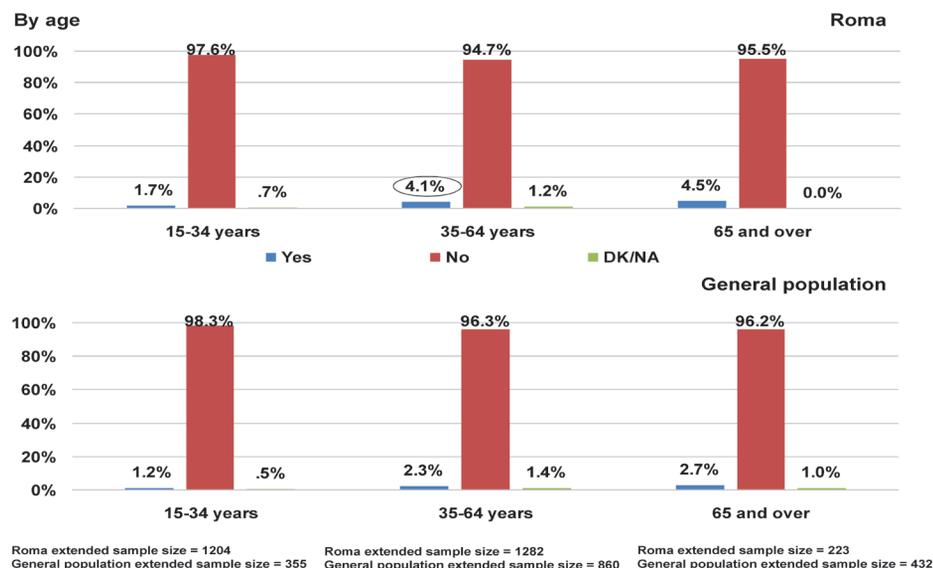


**Kidney disease:** In relation to kidney disease and nephritis, responses show that again Roma are more likely to be diagnosed with these conditions. Diagnosis of nephritis is also significantly higher among certain age groups in Roma households. In the 35 to 44 age group, the rate of diagnosis among Roma respondents is more than three times higher than in the general population.

**Chart 18: Have you ever been diagnosed by a physician or a health professional with kidney disease? Source: Gallup, 2013.**

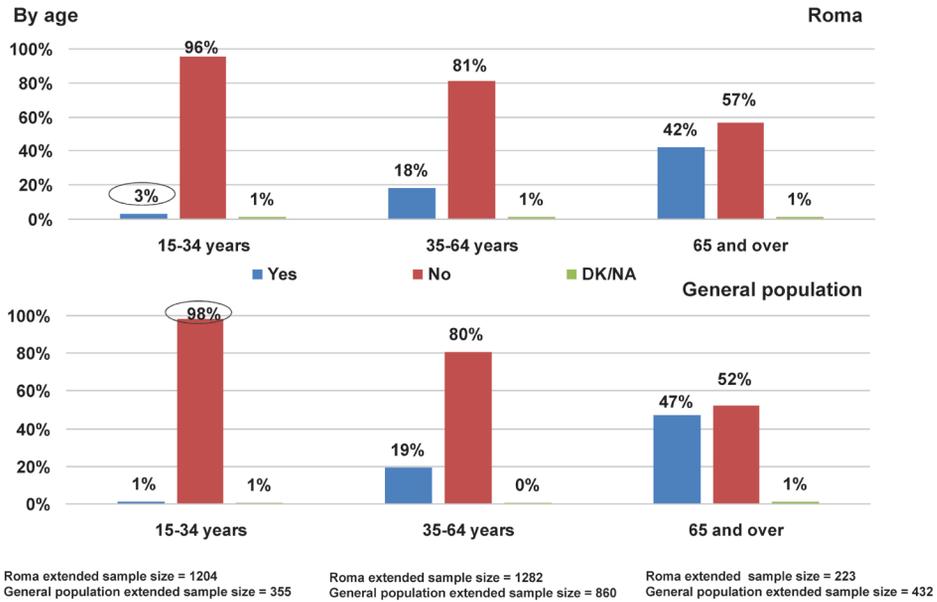


**Chart 19: Have you ever been diagnosed by a physician or a health professional with nephritis? Source: Gallup, 2013.**



**Rheumatic disease:** Rheumatic diseases, although much more frequently diagnosed in the general population, are three times more frequent among young Roma.

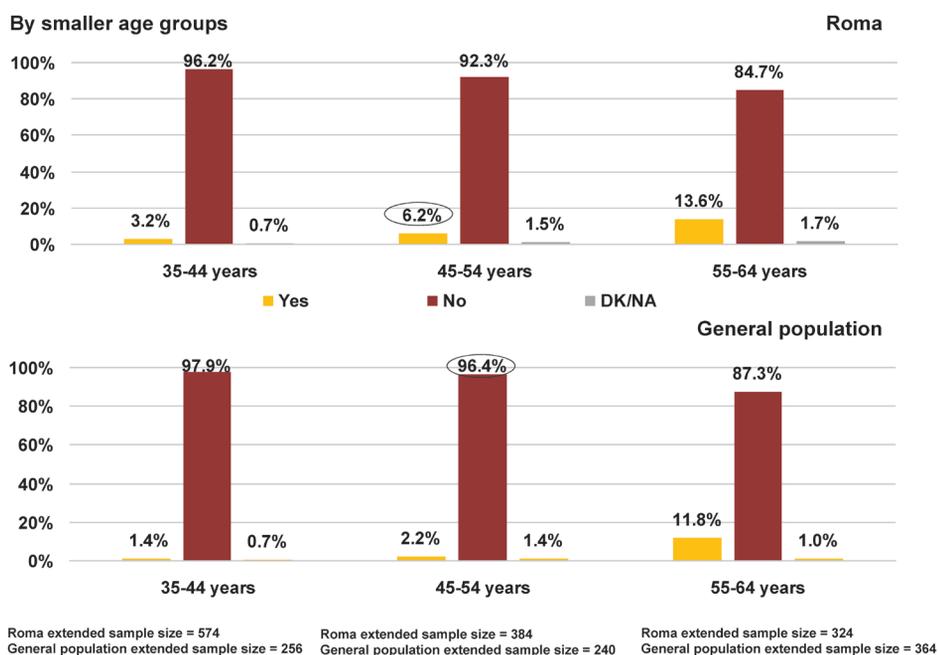
**Chart 20: Have you ever been diagnosed by a physician or a health professional with rheumatic disease? Source: Gallup, 2013.**



**Diabetes:** A complex situation is shown in relation to diabetes, with 4% of the general population stating that they are currently suffering from this condition, compared to 2.4% of the Roma population. Rates of diagnosis are higher for both men and women in the general population.

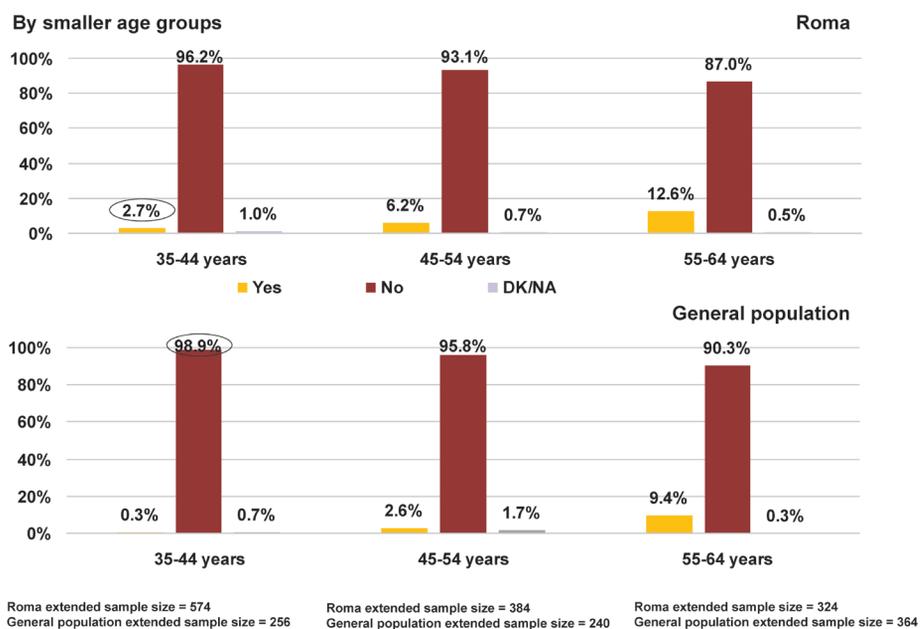
Nonetheless, when figures are further disaggregated by age, the results show that some statistically significant results are revealed in the age group 45 to 54. While the overall results on diagnosis of diabetes show that it is diagnosed more in the general population, a deeper examination of these results show that the condition is diagnosed at a younger age among the Roma population.

**Chart 21: Have you ever been diagnosed by a physician or a health professional with diabetes? By smaller age groups. Source: Gallup, 2013.**



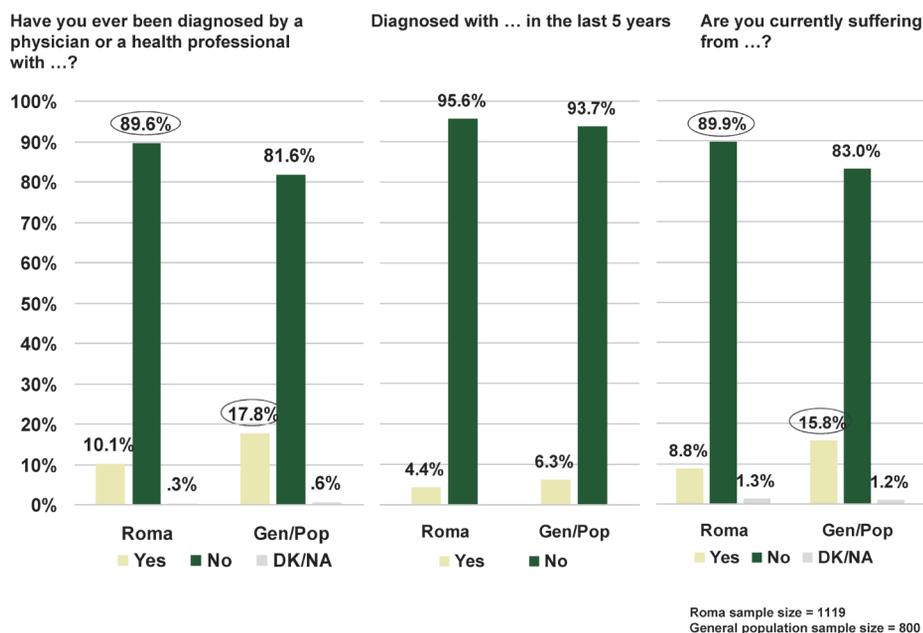
**Heart disease:** Although there was no reported difference in incidence compared to the general population sample overall, younger Romani respondents are more likely to report diagnosis of certain types of heart disease. In the 35 to 44 age group 2.7% of the Roma population have been diagnosed with some form of heart disease, while for the general population the figure is 0.3%. In all other age categories the result is also higher for the Roma population, but not to a statistically significant degree.

**Chart 22: Are you currently suffering from coronary heart disease or ischemic heart disease? By smaller age groups. Source: Gallup, 2013.**



**Hypertension:** The survey shows that the rate of diagnosis of hypertension, or high blood pressure, among non-Roma is significantly higher: 17.8% of non-Roma have been diagnosed with hypertension, compared with 10.1% of the Roma population. Hypertension is a major risk factor for several serious and life-threatening conditions such as stroke, heart attack, and renal failure.<sup>24</sup> Despite the seriousness of hypertension as a risk factor, it often remains under-diagnosed, partly due to lack of access to healthcare.<sup>25</sup> Given that the survey shows many serious health problems are diagnosed more frequently among Roma, it is noteworthy that hypertension stands out as something less frequently diagnosed. Under-diagnosis of hypertension is common, and could be a problem - a possible explanation for this is the lack of regular access to healthcare.

**Chart 23: Hypertension. Source: Gallup, 2013.**



24 World Health Organisation, International Society of Hypertension Writing Group, 2003 World Health Organisation (WHO)/International Society of Hypertension (ISH) statement on management of hypertension, available at: [http://www.who.int/cardiovascular\\_diseases/guidelines/hypertension\\_guidelines.pdf](http://www.who.int/cardiovascular_diseases/guidelines/hypertension_guidelines.pdf).

25 Abdishakur M Abdulle, Nico JD Nagelkerke, Samra Abouchacra, Javed Y Pathan, Abdu Adem, and Enyio-ma N Obineche, 'Under-treatment and under diagnosis of hypertension: a serious problem in the United Arab Emirates' in BMC Cardiovascular Disorders, 2006.

# **Section Two**

**A Duty to Collect and Publish  
Disaggregated Data**



## 6 Making the Case for a Legal Duty to Collect Disaggregated Data<sup>26</sup>

### 6.1 Why is a Legal Duty Necessary?

The use of relevant and reliable indicators is crucial in order to assess human rights situation(s) and/or violation(s).<sup>27</sup> In this respect, the collection and dissemination of disaggregated data is essential to reveal the situation of the most deprived and/or vulnerable population groups and measure inequality and discrimination.<sup>28</sup> International human rights monitoring mechanisms have encouraged the disaggregation of data<sup>29</sup> on the basis of the prohibited grounds of discrimination. Regarding discrimination against Roma populations, the Committee on the Elimination of Racial Discrimination indirectly asked for disaggregated data by ethnicity to measure the respect for the rights of Roma.<sup>30</sup> The Council of Europe has stated that due to a lack of collected statistics based on ethnicity and gender, the outcome of government policies and programmes could not be accurately monitored, assessed and improved.<sup>31</sup>

The United Nations Independent Expert on minority issues has stated that collection of disaggregated data constitutes an “essential means” of identifying the scale of social and economic problems experienced by ethnic groups and developing “appropriate and effective policy and practice.”<sup>32</sup> Indeed, Landman and Carvalho explain that **when data is disaggregated based on factors such as gender, region, religion and ethnicity, policy makers are able to discern the relative enjoyment of rights among members of different social groups and identify “de facto discrimination and exclusion.”**<sup>33</sup> In the area of health specifically, the UN

<sup>26</sup> Research on the legal framework on disaggregated data collection was done in conjunction with the Human Rights Centre of Essex University.

<sup>27</sup> Office of the High Commissioner for Human Rights, *Human rights indicators: A Guide to Measurement and Implementation* (2012, UN Doc. HR/PUB/12/5), 21

<sup>28</sup> *Ibid.*, p. 68

<sup>29</sup> See inter alia CEDAW, *General Recommendation No 9 on Statistical data concerning the situation of women* (1989), *General Recommendation No 19 on Violence against women* (1992) and *General Recommendation No 23 on Article 7, political and public life* (1997); CRC, *General Comment No 4 on Adolescent health* (2003) and *General Comment No 5 on General measures of implementation of the Convention on the Rights of the Child* (2003); CERD, *General Recommendation No 25 on related dimensions of racial discrimination* (2000) and *General Recommendation No 34 on Racial discrimination against people of African descent* (2011); CESCR, *General Comment No 20 on Non-discrimination in economic, social and cultural rights* (2009).

<sup>30</sup> CERD, *General Recommendation No 27 on Discrimination against Roma*, para 46: ‘States parties include in their periodic reports, in an appropriate form, data about the Roma communities within their jurisdiction, including statistical data about Roma participation in political life and about their economic, social and cultural situation, including from a gender perspective, and information about the implementation of this general recommendation.’

<sup>31</sup> Council of Europe, Parliamentary Assembly, Resolution 1740 (2010), *The situation of Roma in Europe and relevant activities of the Council of Europe*, para. 15.7

<sup>32</sup> Report of the UN Independent Expert on Minority Issues, *Mission to Hungary* (2007, UN Doc. No. A/HRC/4/9/Add.2), para. 100.

<sup>33</sup> Landman and Carvalho, *Measuring Human Rights*, 116.

Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health has argued that without disaggregating data the extent of problems related to ethnicity and race would remain unknown to authorities, who need such information to devise appropriate interventions and evaluate their effectiveness.<sup>34</sup> The Special Rapporteur has also stated that “from the human rights perspective” the aim should be to disaggregate data as widely as possible with respect to “internationally prohibited grounds of discrimination,” including gender, race, ethnicity and socio-economic status.<sup>35</sup>

Data disaggregated by ethnicity is necessary for tackling discrimination, especially indirect discrimination. The European Union (EU) Directive **2000/43/EC** (Racial Equality Directive),<sup>36</sup> with which all EU Member States must comply, defines indirect discrimination as occurring:

“where an apparently neutral provision, criterion or practice would put persons of a racial or ethnic origin at a particular disadvantage compared with other persons, unless that provision, criterion or practice is objectively justified by a legitimate aim and the means of achieving that aim are appropriate and necessary.”<sup>37</sup>

Article 5 of the Racial Equality Directive explains that within the context of the principle of equality of treatment, States should adopt specific measures aimed at preventing or compensating disadvantages related to race or ethnic origin. Therefore, collecting disaggregated ethnic data on health does not constitute discrimination within the meaning of the Racial Equality Directive.

Similarly, Article 7 of the EU Employment Directive (Directive 2000/78/EC) refers to the concept of positive action and specific measures that may be taken by States. In particular it outlines that:

“For ensuring full equality in professional life, the principle of equal treatment allows the state to maintain or adopt specific measures aimed at preventing or compensating disadvantages based on grounds explained in article 1.”

These provisions of EU law imply the need for a quantitative mechanism for comparing the impact of the provision, criterion or practice in question on ethnic minorities and on the majority. In order to ensure the realisation of the right to equality and freedom from discrimination, this right must be seen to include the right of individuals to access disaggregated data to prove discrimination. States which legally mandate the right to equality and the right to be free from discrimination should be seen to have a legal duty to collect and analyse disaggregated data disaggregated in order to reveal inequalities and to monitor the effectiveness of State measures aiming at ensuring equality.

<sup>34</sup> Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of health, *Mission to Sweden* (2007, UN Doc. No. A/HRC/4/28/Add.2), para. 120.

<sup>35</sup> *Ibid*, para. 119.

<sup>36</sup> Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin.

<sup>37</sup> *Ibid*, Article 2 b.

However, the EU Racial Equality Directive stops short of legally mandating disaggregated data collection, providing that States may regulate for “indirect discrimination to be established by any means including on the basis of statistical evidence.”<sup>38</sup> The approach of European States varies greatly in relation to the collection and publication of disaggregated data, with most countries taking the most conservative of approaches; that is, they do not collect such data. In the UK the collection of data disaggregated by ethnicity (and other protected grounds) is a legal requirement. Good practice can also be observed in states such as Ireland and Sweden, where such data is used to inform public policy.

It has to be emphasised that a positive measure or positive action is by its nature, a temporary measure. As the Human Rights Committee has stated, “the principle of equality sometimes requires States parties to take affirmative action in order to diminish or eliminate conditions which cause or help to perpetuate discrimination prohibited by the Covenant”. The Committee further states that “as long as such action is needed to correct discrimination in fact, it is a case of legitimate differentiation under the Covenant.”<sup>39</sup>

In relation to Romania, a number of International Institutions have identified the failure of the state to collect sufficient disaggregated data. In 2006 the Committee on the Elimination of Discrimination against Women (CEDAW)<sup>40</sup> considered the sixth periodic report<sup>41</sup> on Romania, examining the implementation of the Convention between 1998 and 2002. The Committee stated that Romania did not collect adequate disaggregated data on gender to be able to effectively assess whether the programmes to benefit women that were being implemented were successful. Particular reference was made to the lack of data disaggregated by gender collected within the Roma community.<sup>42</sup> In response to the Committee, Romanian authorities stated that the National Agency for Roma had been set up to combat discrimination of the Roma community, but stated that they did not compile statistics disaggregating by gender.

In 2009, the Committee on the Rights of the Child examined the 3rd and 4th periodic reports on Romania and noted that even though the Committee had raised the issue before, Romania was still not collecting disaggregated data, a fact which restricted the Government’s ability to evaluate progress. The State replied that their data system was not utilised effectively but reported an intention to improve this, especially at the local level.<sup>43</sup> In relation to children’s rights in Romania, UNICEF has stated that “[t]here are also remaining gaps in the capacity to

38 *Ibid*, Preamble point 15.

39 Human Rights Committee, *General Comment No. 18: Non-discrimination*, (1989), paragraph 10.

40 Romania ratified the *Convention on the Elimination of all Forms of Discrimination against Women* in 1982 (and the Optional Protocol in 2003).

41 CEDAW, *Consideration of reports submitted by States parties under article 18 of the Convention on the Elimination of All Forms of Discrimination against Women: Romania* (2003, UN Doc. CEDAW/C/ROM/6).

42 Committee on the Elimination of Discrimination against Women 735<sup>th</sup> & 736<sup>th</sup> Meetings (General Assembly WOM/1564), *More Gender-Based Disaggregated Data Needed To Evaluate Country’s Programmes Benefiting Women*, available from: [www.un.org/News/Press/docs/2006/wom1564.doc.htm](http://www.un.org/News/Press/docs/2006/wom1564.doc.htm).

43 State Party Examination of Romania’s 3<sup>rd</sup> and 4<sup>th</sup> Periodic Reports: 51<sup>ST</sup> Session of the Committee on the Rights of the Child. 25 May to 12 June 2009. As reported by NGO Group for the CRC.

assess and analyze the situation of children, especially regarding disaggregated data highlighting disparities among children.”<sup>44</sup>

## 6.2 European Law Enabling Ethnic Data Collection

There are several mechanisms by which data collection is regulated and which provide safeguards for the protection of individuals. The Council of Europe Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (Convention ETS 108)<sup>45</sup> and European Directive 95/46/EC<sup>46</sup> regulate data protection and the possibilities with respect to the collection of so-called “sensitive data”, which includes ethnic data.<sup>47</sup> Many European States are of the opinion that their legal frameworks prohibit the collection of ethnic data but this is incorrect. There are also concerns in relation to the collection of disaggregated data and the questions of privacy and data protection.

Neither one of these regulations creates a blanket prohibition on the collection and dissemination of such data in Europe – they restrict the collection of such data and provide for safeguards in the instance of its collection. European data protection laws differentiate between individually identifiable personal data and aggregate data, with the collection of the latter being permitted. Council of Europe law allows for the collection of ethnic data but prohibits its automated storage, alteration, erasure, retrieval or dissemination. Council of Europe law also notes that statistical results are not personal data because they are not linked to an identifiable person.<sup>48</sup>

With respect to concerns about the collection and use of individually identifiable sensitive data, Directive 95/46/EC<sup>49</sup> provides safeguards to address these concerns. Article 8.1 prohibits the processing of personal data revealing, *inter alia*, racial or ethnic origin, in the absence of sufficient safeguards, including the explicit consent of the subject.<sup>50</sup> Convention ETS 108 entered into force in Romania on June 1<sup>st</sup> 2002. Convention ETS 108 again establishes protection for individuals in

44 UNICEF, *Romania: Overview*, available at: [www.unicef.org/romania/overview\\_1610.html](http://www.unicef.org/romania/overview_1610.html).

45 Council of Europe, *Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data*, (Strasbourg, 1981).

46 Council and Parliament Directive (EC) 95/46 on the protection of individuals with regard to the processing of personal data and on the free movement of such data (1995) OJ L281.

47 Simon, “Ethnic” statistics and data protection in the Council of Europe countries: *Study report*, 8.

48 Council of Europe, *Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data*, (Strasbourg, 1981) and Recommendation No. R(97) 18 of the Committee of Ministers *Concerning the Protection of Personal Data Collected and Processed for Statistical Purposes* (1997).

49 Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data (Directive 95/46/EC), available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:31995L0046:en:HTML>.

50 Article 8.2a, Directive 95/46/EC, available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:31995L0046:en:HTML>.

the area of data collection. Personal data revealing, *inter alia*, racial origin or data concerning health may not be processed automatically unless domestic law provides appropriate safeguards.<sup>51</sup>

Indeed, Directive 95/46/EC and Convention ETS 108 stipulate that sensitive personal data can be collected under certain circumstances. For example, Directive 95/46/EC sets out that:

“Member States must also be authorized, when justified by grounds of important public interest, to derogate from the prohibition on processing sensitive categories of data where important reasons of public interest so justify in areas such as public health and social protection [...]”<sup>52</sup>

It further stipulates that sensitive personal data can be collected:

“where processing of the data is required for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of health-care services, and where those data are processed by a health professional subject under national law or rules established by national competent bodies to the obligation of professional secrecy or by another person also subject to an equivalent obligation of secrecy.”<sup>53</sup>

It finds that the processing of data for historical, statistical or scientific purposes shall not be considered as incompatible provided that Member States ensure that appropriate safeguards exist.

The Council of Europe has also found that the collection of ethnic data may be permitted even when individuals are identifiable if the subject is important or in the event of “major public interest, such as “where statistical information is needed to [...] develop aid to social groups in difficulty” or anything else in society’s essential interests. It has also found that “to obtain representative, up-to-date and useful information about the population’s health, for example, data on individuals’ illnesses and medical or hospital care received may be collected from doctors, health workers or hospitals without patients consent.”<sup>54</sup>

The case law of the European Court of Human Rights (ECtHR) also suggests that the European Convention on Human Rights (ECHR) may require the collection of health (and other) data disaggregated by race. There are two ways in which the ECHR may impose such a duty:

1. In a general sense, the ECHR may require the collection of disaggregated data in order to protect the lives of Romani people by correcting historical health inequalities that lead to the unnecessarily early death of so many of them. The ECtHR stated in

<sup>51</sup> Article 6, Council of Europe *Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data* (Convention ETS 108), January 28<sup>th</sup> 1981.

<sup>52</sup> Directive 95/46/EC, available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:31995L0046:en:HTML>.

<sup>53</sup> *Ibid*, Article 8.3.

<sup>54</sup> Explanatory Memorandum to Recommendation No. R (97) 18, para 85.

*Panaïtescu v Romania* (application number 30909/06, judgment of 10 April 2012) that “the acts and omissions of the authorities in the field of health care policy may in certain circumstances engage their responsibility under Article 2 (the right to life)” (§ 28). Elsewhere, the ECtHR has found in relation to education for Roma that “structural deficiencies call for the implementation of positive measures” and that “These obligations are particularly stringent where there is an actual history of direct discrimination”; *Horvath and Kiss v Hungary* (application number 11146/11, judgment of 29 January 2013, § 104). The same principle should also apply to healthcare, which falls within the scope of Article 2 of the ECHR (as well as Article 8), to the extent that the collection of data disaggregated by race is necessary in order to make it possible for the Romanian authorities to fulfill their obligations to correct historical inequalities.

2. Governments may only be able to defend themselves against accusations of systemic discrimination if they collect such data; if they do not, they may be found in breach of Article 14 of the European Convention on Human Rights, taken with other substantive articles. The Grand Chamber of the European Court of Human Rights condemned France for discriminating against sexual minorities when deciding whether to grant single persons permission to adopt. The judgment was based in part on the fact “that the Government, on whom the burden of proof lay... were unable to produce statistical information on the frequency of reliance on that ground”. *E.B. v France* (application number 43546/02, judgment of 22 January 2008, § 74). Those States (including Romania) which have ratified Protocol 12 of the Convention (a free-standing right to be free from discrimination in law and at the hands of public authorities) may be found in breach if they are unable to produce statistical data that can dispel a *prima facie* case of systemic discrimination.

In May 2012, the European Commission sent a communication to the European Council, the Parliament, the European Economic and Social Committee and the Committee of Regions about the state of the implementation of the EU Framework for National Roma Integration Strategies.<sup>55</sup> In this report, the Commission recommends that States:

“develop or make use of existing robust monitoring systems by setting a baseline, appropriate indicators and measurable targets in collaboration, where possible, with the National Statistical Offices; ensure each programme makes provision for the assessment of its relevance, effectiveness, efficiency and impacts.”

The Commission also emphasises the crucial importance of registration of Roma in the national population registers in order to ensure equal access to public services and recommends states take steps in this direction.

<sup>55</sup> European Commission Communication, *National Roma Integration Strategies: a first step in the implementation of the EU Framework* (COM 2012), 226.

## 7 Making Data Collection a Reality Through a Legal Duty in Romania

### 7.1 The Connection Between Health and Human Rights

The World Health Organization (WHO) has stated that there is a strong connection between the right to health and other human rights. Therefore, a violation of the right to health may affect the exercise of other rights such as the right to education or the right to employment. The connection between the right to health and other human rights is especially important in the context of poverty. “For people living in poverty, their health may be the only asset on which they can draw for the exercise of other economic and social rights, such as the right to work or the right to education. Physical health and mental health enable adults to work and children to learn.”<sup>56</sup>

The Constitution of Romania, which makes all international human rights instruments to which Romania is a party binding in the Romanian legal order, guarantees the right to protection of health and outlines an obligation on the state to take measures to ensure public hygiene and health, establishing that the medical care and social security system in case of illness shall be established by law.<sup>57</sup> Furthermore, the Romanian Constitution states that respect for dignity, rights and liberties of the persons form supreme values.<sup>58</sup> The Romanian state has the obligation to protect the health of its citizens and to take measures to ensure public hygiene and health for all.<sup>59</sup> Article 34 of the Romanian Constitution establishes a complex and comprehensive right, the right to health.

### 7.2 Public Health and Roma Health in Romania

Public health in Romania is frequently reported to be in crisis, and there have been difficulties in successfully implementing reforms. The health system is underfunded, facilities are poor, and the average salary for doctors is low. Low salaries have led to the development of a system

<sup>56</sup> World Health Organization, Office of the United Nations High Commissioner for Human Rights, *The Right to Health, Fact Sheet no. 31*, p 6.

<sup>57</sup> *Constitution of Romania*, Article 34. The Article in full is as follows:

- (1) The right to the protection of health is guaranteed.
- (2) The State shall be bound to take measures to ensure public hygiene and health.
- (3) The organization of the medical care and social security system in case of sickness, accidents, maternity and recovery, the control over the exercise of medical professions and paramedical activities, as well as other measures to protect physical and mental health of a person shall be established according to the law.

<sup>58</sup> *Constitution of Romania*, Article 1 (3).

<sup>59</sup> *Constitution of Romania*, Article 34. The Article in full is as follows:

- (1) The right to the protection of health is guaranteed.
- (2) The State shall be bound to take measures to ensure public hygiene and health.
- (3) The organization of the medical care and social security system in case of sickness, accidents, maternity and recovery, the control over the exercise of medical professions and paramedical activities, as well as other measures to protect physical and mental health of a person shall be established according to the law.

of informal payments, whereby patients pay an unofficial extra amount in order to receive medical attention.<sup>60</sup> A proposal for a new healthcare system, replacing the current state-controlled health insurance company with private health insurance companies, was met with major protests across Romania in January 2012, and was subsequently withdrawn. Although groups representing doctors and patients are in favour of reform of the health system, they believe that the main difficulty faced by the health service is underfunding. Planned spending in 2011 was 4% of gross domestic product (GDP), while the average across states in the Organisation for Economic Co-operation and Development (OECD) was 9%.<sup>61</sup> Patients frequently report being asked to pay bribes in return for treatment, partly due to the low salary of doctors.<sup>62</sup>

Roma are covered by the Romanian public health system but, as set out above, only 52% have national health insurance cover, compared with 81% for the general population. When it comes to enjoying their right to health, Roma are clearly at a particular disadvantage as compared to other members of society.<sup>63</sup> One of the main reasons is connected to the fact that Roma face high rates of poverty. Governmental Decision no. 829 of 31 July 2002<sup>64</sup> concerning the approval of the national anti-poverty and social inclusion plan identifies Roma in Romania as one of the main socially vulnerable categories facing high rates of poverty.<sup>65</sup>

In order to bring Roma to the same level of enjoyment of their rights as compared to other citizens, the state needs to adopt affirmative measures. The general importance of affirmative action has already been established in the literature: disadvantaged groups benefit in order to facilitate their integration in society and offer them equal opportunities.<sup>66</sup> Equality, affirmative action and collection of disaggregated data in the case of Roma are interconnected concepts. The data obtained would allow efficient policies to be developed in the area of Romani people's health in Romania. Moreover, the collected and published data would not only allow public health institutions to evaluate the health situation of Roma in the country efficiently, allowing for the development of more effective programs, but it would also help NGOs, think tanks and other international organisations to advance their efforts towards developing effective policies aimed at the integration of Roma into society.

<sup>60</sup> See for example 'Health Care in Romania: Fighting collapse' in *The Canadian Medical Association Journal*, April 2010; and Marian Chiriac, 'Romanian Healthcare Privatisation Stirs Debate' in *Balkan Insight*, (10 January 2012). Available at: [www.balkaninsight.com/en/article/changes-in-romanian-healthcare-system-stir-debate](http://www.balkaninsight.com/en/article/changes-in-romanian-healthcare-system-stir-debate).

<sup>61</sup> Ed Holt, 'Romania redrafts health-care law after violent protests', *The Lancet*, Vol. 379, Issue 9815, (11 February 2012), 505. World Bank data shows that 2011 spending on health was 5.8% of GDP.

<sup>62</sup> *Ibid*, 505.

<sup>63</sup> See for example Mireanu, Manuel, *Acțiunea Afirmativă*, available at: <http://pretext.wordpress.com/eseuri-academice/mireanu>.

<sup>64</sup> The disadvantaged category is defined as a distinct category of persons who are in an unequal position in society compared to other citizens, due to identity differences or general rejection behaviour and societal marginalisation. See [www.stpcentru.ro/fileadmin/user\\_upload/grupuri\\_de\\_lucru/valeriu\\_toma/cadrul\\_normativ/HG\\_nr.829\\_din\\_31\\_iulie\\_2002\\_privind\\_aprobarea\\_Planului\\_national\\_antisaracie\\_si\\_promovarea\\_incluziunii\\_sociale.pdf](http://www.stpcentru.ro/fileadmin/user_upload/grupuri_de_lucru/valeriu_toma/cadrul_normativ/HG_nr.829_din_31_iulie_2002_privind_aprobarea_Planului_national_antisaracie_si_promovarea_incluziunii_sociale.pdf).

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

<sup>66</sup> Mireanu, Manuel, *Acțiunea Afirmativă*, available at: <http://pretext.wordpress.com/eseuri-academice/mireanu>.

The need to adopt affirmative action measures is especially critical in the context of the adoption of the Strategy of the Government of Romania for the Inclusion of the Romanian Citizens belonging to Roma Minority for the period 2012-2020 (hereinafter the Strategy).<sup>67</sup> Following the adoption of the European Framework for National Roma Integration Strategies, all EU Member States adopted National Strategies for Roma Inclusion in 2011. The strategies represent the commitment of EU member states to take measures so as to ensure integration of the Roma within their territories by 2020, based on four areas of action: education, housing, employment and health. The specific objective within the area of health is to “stimulate health promotion measures which can contribute to increasing the access of citizens belonging to Roma minority to public health services and to an increase in life expectancy”.<sup>68</sup> The objective of the strategy should be met through directions for action, *inter alia*, by assessing the degree of access of Roma people to public health services both in the urban and rural environment.<sup>69</sup> However, it is not clear how the state will assess the degree of access of Roma people to public health services or how the authorities will follow up on the assessment carried out. That is why the collection of ethnic data, with particular relevance to health, is critically important for efficiently implementing the Strategy in order to meet its objectives.

### 7.3 Protection Against Discrimination in the Enjoyment of the Right to Health

Governmental Ordinance 137/2000 (hereinafter the Anti-Discrimination Law) states that Romania is a democratic state where all citizens are equal and should not be discriminated against in connection with, *inter alia*, their right to health, medical care, social security and social services.<sup>70</sup>

All citizens are equal and should have access to their right to health without any sort of discrimination – be that direct or indirect discrimination. Article 2 of the anti-discrimination law outlines the grounds on which discrimination can be based and includes, *inter alia*, race, nationality and ethnicity.<sup>71</sup> Article 2 c (4) of the Romanian anti-discrimination law guarantees

67 Strategy of the Government of Romania for the Inclusion of the Romanian Citizens belonging to the Roma Minority for the period 2012 – 2020, available at: [http://ec.europa.eu/justice/discrimination/files/roma\\_romania\\_strategy\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_romania_strategy_en.pdf).

68 *Ibid*, Section C. Health, Specific objective.

69 *Ibid*, Directions for action.

70 Governmental Ordinance 137/2000, the Anti-Discrimination Law, (1) În România, stat de drept, democratic și social, demnitatea omului, drepturile și libertățile cetățenilor, libera dezvoltare a personalității umane reprezintă valori supreme și sunt garantate de lege. (2) Principiul egalității între cetățeni, al excluderii privilegiilor și discriminării sunt garantate în special în exercitarea următoarelor drepturi: e) drepturile economice, sociale și culturale, în special: (iv) dreptul la sănătate, la îngrijire medicală, la securitate socială și la servicii sociale;

71 Governmental Ordinance 137/2000, the Anti-Discrimination Law, Article 2. (1) Potrivit prezentei ordonanțe, prin discriminare se înțelege orice deosebire, excludere, restricție sau preferință, pe baza de rasă, naționalitate, etnie, limba, religie, categorie socială, convingeri, sex, orientare sexuală, vârsta, handicap, boala cronică necontagioasă, infectare HIV, apartenența la o categorie defavorizată, precum și orice alt criteriu care are ca scop sau efect restrângerea, înlăturarea recunoașterii, folosinței sau exercitării, în condiții de egalitate, a drepturilor omului și a libertăților fundamentale sau a drepturilor recunoscute de lege, în domeniul politic, economic, social și cultural sau în orice alte domenii ale vieții publice.

to everyone access to their right to health, medical care, social security and social services without discrimination. According to Article 2 (3) of the same law, all apparently neutral provisions, criteria and practices are likewise discriminatory if they place certain persons at a disadvantage unless objectively justified for a legitimate purpose and when the means to attain that purpose are adequate and necessary.

In addition to meeting legal obligations, the collection of health data disaggregated by ethnicity would also serve the Romanian authorities' stated policy goals in respect of Roma. According to the National Strategy for the Social Inclusion of Roma, the Government "considers Roma social inclusion an issue that should be reflected in all fields of activity on the agenda of each central and local institution". Consequently, the goal of social inclusion of Roma should be reflected in the regulatory and policy-making endeavours of these institutions. However, the Romanian legal framework falls short of mandating explicitly the collection of data relevant for formulation of State policies.

Consequently, to ensure that Roma social inclusion goals, including those relating to health, are indeed taken into account by all state institutions, in a policy-making process which aspires to be evidence-based and data-driven, there is a need for broad-based collection of relevant data disaggregated by ethnicity.

## 8 The Legal Framework on Disaggregated Data Collection in Romania

### 8.1 Law and Policy

It is often assumed that it would be contrary to Romanian data protection law to collect health data disaggregated by ethnicity. While this is a complex subject, there is no blanket prohibition on collecting this kind of data in Romanian law.

Law 677 of 2001, which transposes into domestic legislation Directive 95/46/EC, establishes that the collection of ethnic data is only permitted under certain conditions.<sup>72</sup> Regarding the safeguards set out in the law, personal data must be collected for “specific, explicit and legitimate purposes” in accordance with Article 4. All data must be processed fairly and within the rules set out in law. There are additional provisions for the storing of data, notably a requirement for the data to be accurate and if necessary updated. Article 4 also provides that “further processing of personal data for statistical, or historical research, or for to scientific purposes, shall not be considered as incompatible with the purpose of their collection if it is done according to the provisions of this law [...]”

Sensitive data have special protection and can only be processed with the express written consent of the individual concerned.<sup>73</sup> Data may also be processed if:

- it is necessary to protect the life, physical integrity or health of the data subject;
- it is necessary to determine, exercise or protect a right in a court of law;
- it is necessary for preventive medical care, or to provide medical care and treatment, or to administer the health system, in the interest of the data subject;
- there is a specific legal provision regarding the protection of an important public interest.<sup>74</sup>

The Law also recognises the rights of the data subject, such as the right to be informed about processing, to access the information, and to oppose the processing at any time (provided that the person has legitimate reasons).<sup>75</sup>

Article 7.2 g of Law 677/2001 which allows the use of sensitive data for the purposes of preventive medicine, the provision of medical care and treatment, or the administration of the health system, in the interest of the data subject, leaves it unclear whether sensitive data, including data on ethnicity, can be processed for public health purposes.

<sup>72</sup> Law No. 677/2001 on the Protection of Individuals with Regard to the Processing of Personal Data and the Free Movement of Such Data, Chapter III, Special Rules on Personal Data Processing, Article 7: Processing Special Categories of Data, paragraph 1.

<sup>73</sup> Bogdan Manolea, *Institutional framework for personal data protection in Romania* (2005), 6.

<sup>74</sup> Law No. 677/2001 on the Protection of Individuals with Regard to the Processing of Personal Data and the Free Movement of Such Data, Article 7.2.

<sup>75</sup> Bogdan Manolea, *Institutional framework for personal data protection in Romania* (2005), 5.

The National Authority for the Supervision of Personal Data Processing (the Data Protection Agency) has issued specific regulations on the processing of health data by health professionals.<sup>76</sup> This regulation does not contain any provision on the processing of ethnicity data or other sensitive data.

The Data Protection Agency has also issued a regulation on the processing of sensitive data,<sup>77</sup> including data on ethnicity. It provides that any data controller intending to process sensitive data, including ethnicity data, is required to undergo an *ex ante* control by the Data Protection Agency, which may have a dissuasive effect.

The interplay of these regulations results in uncertainty over the processing of ethnicity data for public health purposes. Tellingly, according to their notices registered with the Data Protection Agency, neither the Ministry of Health, nor the National Health Insurance House process ethnicity data.

## 8.2 Institutional Framework

The National Authority for the Supervision of Personal Data Processing was set up under Law no. 102/2005 and exerts the competence established by Law no. 677/2001 mentioned above. The competences of this authority are the control and investigation of personal data processing conducted under Law no. 677/2001. They are also empowered to impose sanctions, if it is found, as a result of self-notification or based on complaints filed by the people whose rights were infringed, that the legal dispositions were infringed by the personal data processors.<sup>78</sup>

The National Institute for Statistics in Romania collects national data on ethnicity through the census every ten years but no other official, national statistics are collected on Roma in the intervening period.<sup>79</sup> The lack of disaggregated data by ethnicity has also been identified as impacting negatively on the Romania Government's ability to address issues that affect Roma communities disproportionately, with human trafficking and the number of children taken into State care both being specifically mentioned.<sup>80</sup>

<sup>76</sup> Decision no. 101/2008 on the issuance of the authorisation for processing personal data regarding a person's health status under article 9 (3) and 9(4) of Law 677/2001, available at: <http://dataprotection.ro/servlet/ViewDocument?pid=462>.

<sup>77</sup> Decision no.11/2009 determining the categories of data-processing operations posing special risks for the rights and liberties of persons, available at: <http://dataprotection.ro/servlet/ViewDocument?pid=489>.

<sup>78</sup> *The National Supervisory Authority for Personal Data Processing*, available at: <http://www.dataprotection.ro/index.jsp?page=home&lang=en>.

<sup>79</sup> Open Society Foundations, *No Data-No Progress: Data Collection in Countries Participating in the Decade of Roma Inclusion 2005-2015* (2010), 62.

<sup>80</sup> ERRC, *Parallel report concerning Romania to the Human Rights Council, within its Universal Periodic Review, for consideration at its 15th session*, 4-6.

### 8.3 The Collection of Disaggregated Data in Romania

A number of International Institutions have identified the failure of Romania to collect sufficient disaggregated data. In 2006 the Committee on the Elimination of Discrimination against Women (CEDAW)<sup>81</sup> considered the 6th periodic report<sup>82</sup> on Romania, examining the implementation of the Convention between 1998 and 2002. The Committee stated that Romania did not collect adequate disaggregated data on gender in order to be able to effectively assess whether the programs to benefit women that were being implemented were successful. Particular reference was made to the lack of data disaggregated by gender collected within the Roma community.<sup>83</sup> In response to the Committee, Romanian authorities stated that the National Agency for Roma had been set up to combat discrimination of the Roma community but stated that they did not compile statistics disaggregated by gender.

In 2009, the Committee on the Rights of the Child examined the 3rd and 4th periodic reports on Romania and noted that even though the Committee had raised the issue before, Romania was still not collecting disaggregated data, a fact which restricted the Government's ability to evaluate progress. The State replied that their data system was not utilised effectively but reported an intention to improve this, especially at the local level.<sup>84</sup> In relation to children's rights in Romania, UNICEF has stated that '[t]here are also remaining gaps in the capacity to assess and analyze the situation of children, especially regarding disaggregated data highlighting disparities among children.'<sup>85</sup>

The importance of collecting disaggregated data in respect to health services is particularly important due to the high levels of infant mortality in Romania. The mortality rate of children in Romania is the highest in the EU. In 2011 the infant mortality rate was 9.4 per 100,000 births, while the EU average was 3.9. This is the highest rate within the EU, although it represents a significant reduction from 17.3 in 2002.<sup>86</sup> A survey in 2000 showed that Roma communities have a 40% higher infant mortality rate than the general population.<sup>87</sup> Since that time, data disaggregated by ethnicity in relation to infant mortality has not been published by

81 Romania ratified the Convention on the Elimination of all Forms of Discrimination against Women in 1982 (and the Optional Protocol in 2003).

82 CEDAW, *Consideration of reports submitted by States parties under article 18 of the Convention on the Elimination of All Forms of Discrimination against Women: Romania* (2003, UN Doc. CEDAW/C/ROM/6).

83 Committee on Elimination of Discrimination against Women 735<sup>th</sup> & 736<sup>th</sup> Meetings (General Assembly WOM/1564), *More Gender-Based Disaggregated Data Needed To Evaluate Country's Programmes Benefiting Women*, available from: [www.un.org/News/Press/docs/2006/wom1564.doc.htm](http://www.un.org/News/Press/docs/2006/wom1564.doc.htm).

84 State Party Examination of Romania's 3<sup>rd</sup> and 4<sup>th</sup> Periodic Reports: 51<sup>ST</sup> Session of the Committee on the Rights of the Child. 25 May – 12 June 2009. As reported by NGO Group for the CRC.

85 UNICEF, *Romania: Overview*, available at: [www.unicef.org/romania/overview\\_1610.html](http://www.unicef.org/romania/overview_1610.html).

86 EuroStat, *Infant Mortality Rates*, available at: [http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=demo\\_minfind&lang=en](http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=demo_minfind&lang=en).

87 Sorin Cace and Cristian Vladescu, 'The health status of Roma population and their access to health care services' (Bucharest, Expert Publishing House, 2004) in *European Observatory on Health Systems and Policies*, & 'Health Systems in Review: Romania', *Health Systems in Transition* (2008, Vol. 10, No. 3), 136.

Romanian authorities, despite the significant health inequality between different ethnicities. Due to the lack of data, it is not known if infant mortality rates in Roma communities have been reduced to the same degree as in other communities.

The Open Society Justice Initiative in its report *No Data, No Progress*, argues that there is evidence public authorities in Romania are interpreting the law on data collection incorrectly and consequently avoiding collecting ethnic data. However, the report states that “there is evidence of some local authorities collecting ethnic data, usually to support project grants that target Roma.”<sup>88</sup>

The ongoing rollout in 2013 of the national insurance health cards, which incorporate data on gender and age, alongside a host of medical data,<sup>89</sup> also presents a good opportunity to collect data on ethnicity. Furthermore, currently debated plans<sup>90</sup> for the distribution of the national health insurance card should include a role for the Roma health monitors, as they are uniquely positioned to facilitate effective distribution in Roma communities.

<sup>88</sup> Open Society Foundations, *No Data-No Progress: Data Collection in Countries Participating in the Decade of Roma Inclusion 2005-2015* (2010), 61.

<sup>89</sup> National Health Insurance house Order No. 633/2012 on the structure of information entered on the national health insurance card.

<sup>90</sup> See Ministry of Health debate on draft rules on the distribution of the card, available at: [http://www.ms.ro/documente/Varianta%20din%208%20oct.%202013%20a%20proiectului%20de%20Lg.%20pt.%20modificarea%20Lg.%2095%20din%202006%20-%20disp.%20ref.%20la%20card\\_828\\_1655.pdf](http://www.ms.ro/documente/Varianta%20din%208%20oct.%202013%20a%20proiectului%20de%20Lg.%20pt.%20modificarea%20Lg.%2095%20din%202006%20-%20disp.%20ref.%20la%20card_828_1655.pdf).

## 9 Good Practice in Disaggregated Data Collection

While some States argue that they are prevented from collecting and publishing disaggregated data on ethnicity due to EU legislation on data protection, this is not the case. In fact, examples of good practice in disaggregated data collection can be found within the EU, including in the UK.<sup>91</sup> UK legislation not only allows the collection of sensitive ethnic data, but makes it a legal requirement.<sup>92</sup> Ethnic data collection is routine and uncontroversial.<sup>93</sup> At the same time, there are safeguards in place to protect the privacy of individuals, and ensure that data is collected and used only for legitimate purposes.

### 9.1 Collection of Data Disaggregated by Ethnicity in the UK

Legislation in the UK provides a framework in which disaggregated data can be collected. The Data Protection Act (1998) is central to this, as it includes equal treatment as an exception to the prohibition on collecting sensitive data, and considers racial or ethnic origin as one of the areas where inequality may exist.<sup>94</sup> The independent authority responsible for monitoring the application of this act (the Information Commissioner), also allows named data to be processed without explicit consent, if the processing is necessary in order for an employer to comply with a legal obligation.<sup>95</sup> The Race Relations Act (1976) originally created this obligation, stating that collecting statistical data based on ethnicity is a legal obligation. This act built upon the Race Relations Acts of 1965 and 1968, which targeted direct discrimination but were largely unable to achieve significant decreases in racial inequality.<sup>96</sup> It was therefore considered necessary to combat indirect discrimination, which first had to be assessed through the collection of statistical data.<sup>97</sup> The 2010 Equality Act, which replaced the Race Relations Act, continued the legal obligation to collect data. As both acts include explicit prohibitions on indirect discrimination,<sup>98</sup> this necessitates the collection of data which may provide a statistical picture of whether indirect discrimination has occurred.<sup>99</sup>

91 Open Society Foundations, *No Data-No Progress: Data Collection in Countries Participating in the Decade of Roma Inclusion 2005-2015* (2010), 17.

92 Simon, "Ethnic" statistics and data protection in the Council of Europe countries: Study report, 60.

93 European Commission, *Comparative Study on the Collection of data to Measure the Extent and Impact of Discrimination in a selection of countries: Final Report on England*, Measurement of discriminations Projects (2004), 3.

94 *Data Protection Act* (1998), Chapter 29, Schedule 3, Para. 9; See also Simon, "Ethnic" statistics and data protection in the Council of Europe countries: Study report, 60.

95 Simon, "Ethnic" statistics and data protection in the Council of Europe countries: Study report, 60-1. See also Information Commissioner's Office, *Data Protection: The Employment Practices Code* (2011), 40.

96 Hansard, Vol. 907, (HC Deb 07 March 1976), c1580 Frederick Wiley and c1662, Alex Lyon.

97 *Ibid*, c1580, Frederick Wiley.

98 *Race Relations Act* (1976), pt 1, para 1, sub para b, and *Race Relations Act* (1976)(Amendment) Regulations (2003), pt 1, para 1a; Equality Act (2010), pt2, c.2, para 19.

99 European Commission, *Comparative Study on the Collection of data to Measure the Extent and Impact of Discrimination in a selection of countries: Final Report on England*, Measurement of discriminations Projects (2004), 54.

Since 2000, when amendments were made to the Race Relations Act to that effect, the obligation to collect disaggregated data has applied to local authorities, public authorities, and all firms with 150 employees or more. The Equality Act 2010 built on this with a more detailed list of bodies included.<sup>100</sup> Under the Equality Act and its Specific Duties of 2011, public bodies must publish information to show their compliance with the Equality Duty at least annually, and set and publish equality objectives at least every four years.<sup>101</sup> This has led to the compilation and analysis of a range of data disaggregated on the grounds of ethnicity. However, it is worth noting there is no single repository in which this data is held.

There are also a number of regular surveys which collect disaggregated data on ethnicity in the UK, but which are not directly obliged to do so by the Equality Act. The Census, which included a question on ethnicity in 1991 for the first time, is the most obvious of these,<sup>102</sup> but there is also the Health Survey for England, the Health Survey for Scotland, the General Household Survey and the British Household Panel Survey.<sup>103</sup>

Generally data disaggregated by ethnicity has been collected on a wider scale and more complete basis than data disaggregated by other characteristics, such as disability. This is largely due to the Race Relations Act.<sup>104</sup> However, the introduction of the Equality Act in 2010 can be seen as a move to change this, creating a single framework "with clear, streamlined law to more effectively tackle advantaged and discrimination."<sup>105</sup> The Act includes discrimination on the grounds of age, gender, race, religion, sexual orientation and disability.

Disaggregated data collection appears to be uncontroversial in the UK. This has not always been the case. For instance attempts to include an ethnicity question in the census in 1979 created alarm, partly due to fears of data being misused, in light of a nationality act being considered at the time.<sup>106</sup> However, these fears did not seem to materialise in relation to the 1976 Race Relations Act, and since the introduction of this act the collection of data based on ethnicity has become routine. In the parliamentary debates surrounding the 2010 Equality Act there was no direct discussion of disaggregated data, as its necessity was assumed. Not only was it not debated, but disaggregated data was relied upon by Members of Parliament to support arguments.<sup>107</sup>

<sup>100</sup> *Equality Act*, 2010.

<sup>101</sup> Government Equalities Office, *Equality Act 2010: Specific Duties to Support The Equality Duty, What Do I Need to Know? A Quick Start Guide For Public Sector Organisations* (2011), 3.

<sup>102</sup> Mair Ni Bhrolchain, 'The Ethnicity question for the 1991 Census: background and issues', *Ethnic and Racial Studies*, Vol.13, Issue 4 (Oct 1990).

<sup>103</sup> Bernd Rechel, Philipa Mladovsky and Walter Devillé, 'Monitoring the health of migrants' in Rechel, D., et al. (eds) *Migration and Health in the European Union* (New York, 2011), 92.

<sup>104</sup> European Commission, *Comparative Study on the Collection of data to Measure the Extent and Impact of Discrimination in a selection of countries: Final Report on England*, Measurement of discriminations Projects (2004), 53.

<sup>105</sup> Equality and Human Rights Commission, presentation of the 'Equality Act' available at: [www.equalityhumanrights.com/legal-and-policy/equality-act/](http://www.equalityhumanrights.com/legal-and-policy/equality-act/).

<sup>106</sup> Mair Ni Bhrolchain, 'The Ethnicity question for the 1991 Census: background and issues', *Ethnic and Racial Studies*, Vol.13, Issue 4 (Oct 1990), 561 – 2.

<sup>107</sup> Hansard, Daily Deb, (HC Deb 11 May 2009, c617), John Bercow.

The only apparent criticism of disaggregated data was in relation to compulsory pay audits, which were considered costly for the private sector in light of the financial crisis.<sup>108</sup> However, even in pointing this out, it was not suggested that disaggregated data should be abandoned, but rather should only be required of those employers found to be providing unequal pay.<sup>109</sup>

## 9.2 Collection of Data Disaggregated Based on Ethnicity in the Health Sector

A guide published by the government for public authorities states that “[t]he aim of ethnic monitoring is not to collect ethnic data for its own sake, any more than the aim of consultation is to collect people’s views. The race equality scheme is about making race equality a reality and using monitoring, assessment and consultation to achieve this.”<sup>110</sup> This commitment is also present within the health service specifically: “there is general support from the National Health Service (NHS) for the principle of collecting ethnic data in a consistent manner.”<sup>111</sup>

The 2010 Equality Act applies to much of the NHS.<sup>112</sup> As such, there are a number of areas where statistics in relation to ethnicity are legally required; for instance when recording hospital admissions, or in all secondary care (except outpatient, accident and emergency care and community settings).<sup>113</sup> This data is collected relatively effectively and comprehensively. In 2007-8 there was 86% coverage of ethnicity in hospital episode statistics.<sup>114</sup> There have also been moves to encourage data collection in areas where it is not yet mandated. For instance, primary care incentives have recently been provided to general practices to collect ethnic group data from patients.<sup>115</sup>

In the area of health data the NHS Information Centre acts as a form of central repository for Health and Social Care, although it does not appear to be compulsory, or to contain all data.<sup>116</sup> Of the 61 health indicators which had been considered in relation to ethnic data, disaggregated data was potentially available in some form for 40 of the indicators. Eleven are listed as “currently collected and available” while 29 are listed in the following manner: “the breakdown itself is not currently published but is collected (or can be constructed from data

108 Hansard, Daily Deb, (HC Deb 11 May 2009, c568), Theresa May.

109 Hansard, Daily Deb, (HC Deb 11 May 2009, c565), Theresa May.

110 Commission for Racial Equality, ‘The Duty to promote race equality: A Guide for Public Authorities (Non-Statutory) (2002), 22.

111 National Health Service Information Authority, (DSC Notice: 21/2000), p 1.

112 *Equality Act 2010*, Schedule 19, Part 1.

113 Rechel, Mladovsky and Devillé, ‘Monitoring the health of migrants’ in Rechel, D., et al. (eds) *Migration and Health in the European Union*, 88.

114 *Ibid.*

115 Hiranthi Jayaweera ‘Health and Access to Health Care of Migrants in the UK: A Race Equality Foundation Briefing Paper’, *Better Health Briefing 19*, (2010), 2.

116 NHS: The Information Centre for Health and Social Care, ‘About us’, available at: [www.ic.nhs.uk/about-us/more-about-us](http://www.ic.nhs.uk/about-us/more-about-us).

that is already collected)”. For eight of these 29 points, it is suggested that results should be treated with caution as there may be issues with reliability or collection methods. Additionally of the 21 indicators where data was not currently available, there were only ten indicators where data was disaggregated by sex and age, but not by ethnicity.<sup>117</sup>

<sup>117</sup> Department of Health, *Improving outcomes and supporting transparency. Part 1: A public Health Outcomes Framework for England, 2013-2016* (2012).

## 10 Conclusions and Recommendations

This report has highlighted the existing health inequalities between Roma and non-Roma communities in Romania, and shown that Roma face significant and worrying disadvantages in the area of health. The report has shown this through the use of disaggregated data, disaggregated by ethnicity. Without such data, these inequalities would remain hidden.

The report has analysed the legal framework around data collection, and highlighted good practice in the area of disaggregated data collection.

In order to monitor and address inequalities faced by marginalised and vulnerable groups, the collection and publication of disaggregated data is essential. To that end, we present the following recommendations:

- Ensure that statistical data is collected and published by public authorities and disaggregated by all relevant factors including ethnicity, nationality, age, sex, and any other factor which may be a ground for either direct or indirect discrimination;
- Introduce or amend relevant legislation to facilitate the collection of disaggregated data;
- Establish robust safeguards to protect the anonymity of all individuals when data is being collected;
- Ensure that public policy in all areas, including health, education, employment and housing, is guided by disaggregated data and any inequalities which such data reveals;
- Ensure that public policy based on disaggregated data pays particular attention to vulnerable groups, including national, ethnic, and other minorities;
- Ensure that public policy based on disaggregated data pays particular attention to Roma, who have been historically subjected to social exclusion and discrimination, and remain particularly vulnerable to social exclusion, poverty, and inequalities in health, education, employment, housing, and other areas.
- Introduce information campaigns to highlight the importance of data collection and the importance of registering one's self-identified nationality or ethnicity; address fears that minorities, including Roma, legitimately hold due to historic misuse of data on ethnicity and nationality;
- Ensure that disaggregated data is collected frequently by public bodies and analysed to measure the impact of any measures which may have either a positive or negative impact on addressing inequalities faced by vulnerable groups;
- Provide disaggregated data in state reports to international human rights monitoring bodies and other relevant bodies on the enjoyment of human rights by all groups within the state;



## Annex 1: What are Health Inequalities and what are their Causes?

The widely-cited seminal work on health equity by Dahlgren and Whitehead as a background paper for WHO in 1990 examines the complexity of factors which account for health inequalities,<sup>118</sup> and underlines that health inequalities are not due primarily to poor health choices but are rather related to an amalgamation of factors such as poverty, poor living conditions, and issues in accessing education, employment, and social services. Similarly, the European Commission has outlined the impact of various factors on health, including living and working conditions, as well as exclusion and marginalisation.<sup>119</sup>

The study identifies some of the critical factors which have an impact on health, and underlines the fact that these factors interact with each other. The work environment is identified as one of the main determinants of socio-economic inequalities, due not only to occupational accidents and diseases, but also stress related to heavy, difficult or uncomfortable work. Unemployment is also identified as a factor which is a risk to health, in particular for underprivileged groups.<sup>120</sup> Poor physical housing conditions and also social segregation in planning and allocation of housing are also recognised as factors which have an impact on health.<sup>121</sup> The importance of the education system an important tool in promoting health in general and reducing social inequalities is underlined, in particular as it offers the possibility of helping to instil positive attitudes and values in relation to lifestyle and health.<sup>122</sup>

In relation to lifestyle, the study shows that there is a link between personal behaviour and socio-economic factors. Therefore, while disadvantaged groups tend at times to adopt more health-damaging behaviour in terms of smoking, diet, lack of exercise, and lower uptake of preventive healthcare, there are underlying reasons for this behaviour which can be explained by socio-economic circumstances. Those on lower incomes may only be able to afford the cheapest goods, which are less healthy. The article also found that:

“Several in-depth studies of why people continue with unhealthy ways of living show how families on low income are limited in their choice of lifestyle by practical constraints of time, space and money. For example, lack of money restricts food choice and sometimes spending on food is cut down to keep the family out of debt or to pay essential costs like the rent.”<sup>123</sup>

118 Dahlgren, Goran & Whitehead, Margaret, *Policies and strategies to promote social equity in health – background document to WHO – Strategy paper for Europe*, September 1991, Institute for Futures Studies, Stockholm.

119 European Commission, ‘Background Document to Solidarity in Health: Reducing health inequalities in the EU’, October 2009, 16.

120 Dahlgren, Goran & Whitehead, Margaret, *Policies and strategies to promote social equity in health – background document to WHO – Strategy paper for Europe*, September 1991, Institute for Futures Studies, Stockholm, 20 – 23.

121 *Ibid*, 28.

122 *Ibid*, 33 – 33.

123 *Ibid*, 45.

Of course, education and awareness of the risk involved in certain activities is also a key factor. The study highlights the cumulative impact of a combination of some or all of the factors outlined above; for example, those working in unhealthy or stressful conditions may also be more likely to be living in poor housing. In the same way, more prosperous individuals are less likely to be exposed to environmental hazards and more likely to benefit from health education.<sup>124</sup>

The root causes of health inequality are complex, and these causes are usually related to the socio-economic situation. Furthermore, the root causes interact with each other and can have a multiplying effect. Poor health outcomes and health inequalities are not a result of personal choices but of circumstances which are often beyond the control of the individuals concerned.

<sup>124</sup> *Ibid*, 47.

## Annex 2: Survey Details

The survey aimed to collect and analyse data on a wide range of health topics, both in the Roma population and the general population in Romania, in order to compare the health status of Roma and non-Roma and the incidence and prevalence of various health conditions and symptoms, access to medical care, and causes of death among the two populations.

The survey covers the civilian non-institutionalised population residing in Romania at the time of the interview. Two independent samples of households corresponding to the two target population were drawn in accordance with the following specifications:

Quasi-probability sample design for both Roma and non-Roma households.

In segregated/compact Roma communities the households were selected using random route procedure, while in mixed communities Roma households were identified by interviewers through focused enumeration methods. The sample of non-Roma households was selected independently, also through random route procedure.

Stratified two-stage cluster sampling design.

A list with all the settlements/municipalities in Romania was employed as a sampling frame. For Roma sample the settlements was stratified according to three criteria: region (NUTS II level – eight regions), degree of urbanisation (six categories) and the existence of known segregated/compact communities of at least 20 Roma households. Only settlements with at least 1% of Roma population were included in the sampling frame, thus the survey covered at least 92%<sup>125</sup> of the total Roma population. The primary sampling units (PSU) were virtual clusters consisting of 20 Roma people. Sample allocation was proportional to the size of the Roma population in each stratum. Also, from each stratum PSUs were selected with probability proportional to size (PPS).

For the non-Roma sample, the settlements were stratified using two criteria: region (NUTS II level – eight regions), and degree of urbanisation (six categories). All settlements in Romania were included in the sampling frame. The primary sampling units for the non-Roma sample were drawn independently of the selection performed for the Roma sample.

For Roma households living in mixed (non-segregated) areas a focused enumeration using random route procedure was conducted starting from a given starting point (address).

<sup>125</sup> This is an estimate based on census data from 2002. For this survey data from the last Census in 2011 will be used.

## ANNEX 2: SURVEY DETAILS

The target sample size was at least 1100 households for Roma sample and 800 households for the non-Roma sample. Each sample included at least 150 PSUs, and in each PSU an average of seven Roma households and five non-Roma households were interviewed.

A household is defined in this survey as a group of persons who live and eat together. A Roma household is any household in which at least one person identifies himself/herself as Roma, while a non-Roma household is any other household, regardless of its ethnic composition.

In each household which accept to participate in the survey an adult randomly selected was considered the main respondent, but all persons aged 15 and above who are at home at the time of the interview were asked to answer questions pertaining to their persons. Moreover, in each household certain data for each member of the household, including all children, was requested from an adult. This resulted in a total sample of around 2000 individuals in the non-Roma sample and around 4000 individuals in the Roma sample, permitting statistical analysis on subgroups breakdown by various demographics such as age and gender.

The European Roma Rights Centre (ERRC) is an international public interest law organisation working to combat anti-Romani racism and human rights abuse of Roma. The approach of the ERRC involves strategic litigation, international advocacy, research and policy development and training of Romani activists. The ERRC has consultative status with the Council of Europe, as well as with the Economic and Social Council of the United Nations.

This report examines the extent of health inequalities experienced by Roma in Romania. It shows that Roma are at greater risk in relation to many medical conditions, are less able to access healthcare and medicine, and are living shorter and less healthy lives than their non-Roma peers. The report highlights the need for disaggregated data, disaggregated by ethnicity as well as by other factors, in order to highlight the indirect discrimination which Roma experience. It outlines the legal framework for the collection of such data, including the safeguards which are in place to protect the privacy of individuals.

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CHALLENGING DISCRIMINATION PROMOTING EQUALITY