

# Reduction of Health Inequalities in the Roma Community

	Publication Details
Title:	Roma Health Concerns: The View from Bulgaria
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Publication date:	30 September 2002
Country:	Bulgaria
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<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

	Type of document (mark with an X):
Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
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### Summary (Description of the study and most relevant results):

At the start of the twenty-first century, millions of Roma across Europe still live in conditions of deprivation in access to basic healthcare.

Despite persistent effort by a variety of actors, the Roma community remains the poorest in Bulgaria, the most segregated and unprivileged. In their struggle for survival, healthcare has become a primary social good for the Roma.

Roma NGOs and international institutions alike have shone a spotlight on a number of issues of concern to Roma: access to education, employment, social services and housing; the promotion of human rights and women's rights; and community development are all priorities. But access to healthcare is neglected as a human rights issue by most actors, including the government.

Why is this so?

The issue is complex and has roots in the past: healthcare in post-communist countries was until recently free of charge for all citizens, including Roma.

This has now changed: the Bulgarian healthcare system has been reformed and is undergoing privatisation. Naturally enough, everyone now has to pay for health examinations, treatment, and medicines.

Today, the lives of those to poor to pay for these services are literally at risk. This is especially true for many Roma, who lack health insurance and are often unaware of their rights.

The issue of Roma access to healthcare is interlinked with other problems. Factors both external and internal to the Roma community must be considered. In my view, external obstacles are the more problematic and urgent. These include:

Lack of information about health reforms. Adequate information about reforms to the Bulgarian healthcare system has not been made available to the population at large. For Roma the problem is more acute, as no effort has been made to send information through the right channels, and in an appropriate manner, to reach the community.

Unemployment. Accurate data on the number of unemployed among Roma is lacking, but most estimates put the figure near 80% of the Roma workforce. Many unemployed Roma do not register and have no health insurance. Most are not aware that it is possible to be insured without employment - and Bulgarian municipalities generally insure only registered unemployed, who have rights to social benefits. The ensuing lack of resources to pay for medical examinations, and the higher fees for hospital treatment and medicines, are a direct result of the unstable economic and financial situation of the Roma community.

Bad infrastructure of Roma settlements. Roma settlements typically suffer from catastrophic standards of basic infrastructure, including bad potholed roads or dirt-tracks (paramedics frequently refuse even to enter Roma neighbourhoods), an absence of telecommunications, shortages of transport, and little or no access to clean water.

Discriminatory attitudes. Staff in medical institutions near Roma settlements often display negative attitudes towards Roma.

Widespread poverty and the resulting bad living conditions negatively impact the quality of nutrition available to many Roma, leading in turn to epidemics of infectious diseases.

Documentation. An absence of official identity documents can lead to severe delays in obtaining healthcare services, and may make health services entirely inaccessible.

Research. Little or no in-depth research has been conducted at local levels, to allow for the design of appropriate strategies to combat the specific problems of access faced by Roma. This stems largely from an absence of appropriate governmental policy. A number of NGOs have taken up the issue of Roma access to health care, but the problem is so widespread that it is clear that governmental policies and ac tions are needed.

Obstacles internal to the Roma community include the fact that health does not have pride of place in the Roma cultural value system. In their struggle for survival, Roma tend to seek out medical assistance only in emergencies.

Like the majority of the Bulgarians, Roma tend to view public health purely in terms of the provision of

medicines. This is also true for Roma NGOs who, additionally, do not consider themselves competent to take on the larger issues of public health. This can be addressed through a combination of awareness-raising and capacity building of Roma NGOs, training mediators and promoting access to information.

The health indicators of the Roma community are difficult to measure, for reasons partly related to census taking (establishing the true size of the Romani community is a fraught issue). But anyone on the ground can make out certain clear distinctions between the Roma population and the rest of Bulgarian society:

The life expectancy of Roma is reckoned to be lower.

Infant mortality rates are higher. Vaccinations are no longer obligatory for all children. As a result many children are never vaccinated, either because their families do not have a family doctor or the children do not attend school, or because mothers are simply unaware of the importance of vaccination.

Infectious diseases are widespread, as are certain other conditions, such as cardiovascular diseases, diabetes or hypertension.

In recent years there has been a significant increase in the number of cases of tuberculosis.

Drug abuse, a phenomenon unknown to Roma during the communist period, now appears to be widespread among Roma youth. For example in the course of its work in the "Fakulteta" neighbourhood in Sofia, the Foundation for Promotion of the Roma Youth has come across many young Roma drug users. This was not the case some 10 years ago.

Reproductive health. Abortion remains the most popular method of contraception among Roma. In comparison with other cultures, Roma societies are patriarchal and conservative the level of promiscuity is comparatively low. Nevertheless, as traditions and values change it is important to promote knowledge about sexually transmitted infections. This should not obscure the fact that primary healthcare is, in my view, a more urgent consideration than reproductive health.

Solutions to the problems described in this article will not be easy to find. All concerned actors must start work without delay ... because tomorrow will be too late to save the lives of our children - and our parents.

And I am sure that all are agreed on one thing. Faced with a choice between the isolated efforts of individual NGOs and comprehensive policies designed and implemented by all relevant actors, the second option is the better way forward.



# Reduction of Health Inequalities in the Roma Community

	Publication Details
Title:	Improving Access of Roma to Health Care through the Decade of Roma Inclusion
Author(s):	Heather Doyle <sup>1</sup>
Publication date:	Feb 2005
Country:	USA
Language:	English
Contact address if more information is required: (where applicable)	Heather Doyle is Program Coordinator with the Open Society Institute's Network Public Health Program based in New York
Published by:	ERRC web site:www.errc.org
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

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#### Summary (Description of the study and most relevant results):

Despite the continual lack of solid data, there is general agreement among health and policy experts that Roma suffer from poorer health than the general population. Various studies documenting the health status of Roma have shown a higher rate of vitamin deficiencies, malnutrition, anaemia, dystrophy and infectious diseases than the majority population <sup>4</sup>. Rates of infant mortality are substantially worse and the life expectancy of Roma is on average ten years less than that of non-Roma. In 2004, UNAIDS announced that Eastern Europe and Central Asia regions were experiencing the fastest growing HIV epidemic in the world. International and national health experts predict Roma will be disproportionately affected by AIDS due to high poverty rates, high mobility, and limited access to social services in comparison with majority populations. The lack of access to quality medical care continues to contribute to the poor health of Roma. This includes both documented discrimination against Roma in health care settings across Eastern and Central Europe as well as perceptions by Roma of unequal treatment and discrimination. This discrimination and marginalisation is further reflected in the fact that Roma are far more likely to be less educated, unemployed, and live in substandard housing than the majority population in each of these countries. It is these socio-economic characteristics that are the strongest determinants of Roma health status.

Attempting to address these larger social determinants of health in order to close the gap in health status between Roma and majority populations is an enormous challenge. It is especially complex for governments still struggling with major systems transformations with extremely limited financial resources, including money for health programs. Even if strong willingness exists on the part of the government to address these inequities, it must be recognised that major hurdles exist in the widely entrenched discrimination against Roma in all segments and social strata of these societies.



# Reduction of Health Inequalities in the **Roma Community**

**Publication Details** 

Title:	The Health of Foreign Romani Children in Italy: Results of a Study in Five Camps
	of Roma from Macedonia and Kosovo
Author(s):	Lorenzo Monasta <sup>1</sup>
Publication date:	Jan 2005
Country:	Hungary
Language:	English
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	Presentations or communications
	Doctoral thesis
	Other:

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#### Summary (Description of the study and most relevant results): **Main Results and Discussion**

Almost all of the camps considered in this study presented degrees of squalor. With regards to Florence, Brescia and Venice, the dumpsites were cleared next to the settlements only after the camps were set up. Aggressive and dangerous rats were seen in Florence, Venice and Bergamo, indicating unsanitary conditions. Furthermore, precarious housing structures don't always prevent the entry of rats, especially at night, and several attacks on children have been reported. The areas in which the camps were set up were often very poor prior to the construction of the camps and only aggravated the effects of the poor planning, lack of basic services and overcrowding in the camps.

The overcrowding in the camps of Bergamo and Florence was not simply a problem of habitability but also of safety. In the limited space of the housing units, highly inflammable materials and poor wiring systems could cause any domestic accident that would be fairly insignificant in a normal house to turn into a tragedy involving dozens of families. A camping gas burner that is knocked over, an electric heater that short circuits or a pan of boiling oil that tips over can destroy an entire settlement in an hour.

All of the camps were equipped with electricity, although in the Florence and Bergamo camps the wiring systems were in critical condition.

Only 39 percent of families had running water at home. Bathing was almost impossible in Bergamo where only two showers in dreadful condition were available; in Florence no showers were provided and in Venice showers were communal. In these three camps there were also serious problems regarding availability of hot water. During winter in Florence, the water pipes often froze, leaving the camp for days without water supply.

Throughout the research work being conducted in the five camps under consideration, 137 families were interviewed [Table 1]. In total, 737 people were included with an average of 5.4 people per family. Fifty-two percent of the people covered in the study were female (380/737).

On average, those interviewed had lived in these settlements – temporary camps both by definition and structure – for almost six years. This is enough time for children to be born, to grow, and to start going to school while their families continue to experience uncertainty regarding their status in Italy and the prospects of their integration into society at large.

The number of minors aged between 0-5 years was 167, distributed amongst 97 families. The age distribution of the children covered in the study is fairly regular, as is the gender distribution, with 48 percent males (80/167) and 52 percent females (87/167) [Table 2].

Table 2: Demographic characteristics of the children in the study from zero to five years, by city

Age	Florence N(%)	Bergamo N(%)	Brescia N(%)	Venice N(%)	Bolzano N(%)	Total N(%)
0	14(20)	6(29)	3(15)	6(17)	4(21)	33(20)
1	10(14)	6(29)	3(15)	10(28)	3(16)	32(19)
2	9(13)	3(14)	6(30)	3(8)	4(21)	25(15)
3	16(23)	2(10)	2(10)	7(19)	3(16)	30(18)
4	13(18)	3(14)	4(20)	5(14)	2(11)	27(16)
5	9(13)	1(5)	2(10)	5(14)	3(16)	20(12)
Sex	Florence N(%)	Bergamo N(%)	Brescia N(%)	Venice N(%)	Bolzano N(%)	Total N(%)
Male	34(48)	13(62)	8(40)	17(47)	8(42)	80(48)
Female	37(52)	8(38)	12(60)	19(53)	11(58)	87(52)
Total	71(100)	21(100)	20(100)	36(100)	19(100)	167(100)

Birth weight was recorded in 147 out of 167 children. Ten percent of the children had a birth weight of less than 2.5 kg (14/147). In Italy, according to reports by UNICEF and the World Health Organization (WHO), the percentage of children born underweight in the period 1995-99 was 5 percent. For comparison, countries with 10 percent of children born underweight include Egypt, Iran and Zimbabwe<sup>5</sup>.

The interviewees were asked whether, in the previous 15 days, the children had suffered from diarrhoea, coughing, skin complaints or other illnesses and whether and where the children had been taken to see a doctor with regards to each symptom.

Thirty-two percent of the interviewees (53/165) stated that their child had suffered from diarrhoea in the 15 days prior to the interview. The highest percentage was recorded in Brescia (50 percent, 10/20), while the lowest was in Bergamo (14 percent, 3/21) [Table 3].

No comparable data was found on the child population of Italy, but to provide an example, a study of more than 15,000 children under the age of five carried out in Bangladesh in 1999 produced a result of 9 percent (1424/15321).6

Table 3: Children who had diarrhoea in the 15 days prior to the interview, by city

City	Florence N(%)	Bergamo N(%)	Brescia N(%)	Venice N(%)	Bolzano N(%)	Total N(%)
Yes	23(33)	3(14)	10(50)	11(31)	6(32)	53(32)
No	46(67)	18(86)	10(50)	25(69)	13(68)	112(68)
Tctal	69(100)	21(100)	20(100)	36(100)	19(100)	165(100)

Seventy-four percent of all the children who had suffered diarrhoea in the 15 days prior to the interview had been taken to see a doctor (39/53). Use of health services was highest in Bolzano and Florence with 83 percent, while Brescia had the lowest use at 50 percent (5/10) [Table 4].

Table 4: Children with diarrhoea taken to see a doctor, by city

City	Florence N(%)	Bergamo N(%)	Brescia N(%)	Venice N(%)	Bolzano N(%)	Total N(%)
Yes	19(83)	2(67)	5(50)	8(73)	5(83)	39(74)
No	4(17)	1(33)	5(50)	3(27)	1(17)	14(26)
Tctal	23(100)	3(100)	10(100)	11(100)	6(100)	53(100)

With regards to diarrhoea, without considering the San Giuliano camp in Venice,7 the survey indicates that the proportion of children with diarrhoea in families that have lived in the camp for more than five years is greater than in those families which have lived in the camp for a shorter period. This result is uniform across all of the children's age groups and in all the remaining four cities. It would therefore be worthwhile to reflect on the possible effects a prolonged period of life spent in a camp would have on health, behaviour and habits.

Fifty-five percent of children had suffered coughing in the fifteen days prior to the interview. The percentage was highest in Brescia (70 percent, 14/20), and lowest in Bolzano (37 percent, 7/19) [Table 5]. However, it should be pointed out that the flu was widespread among the children in Brescia and gave rise to diarrhoea, coughing and vomiting.

A lesser number of children were taken to see a doctor in reference to coughing and bronchitis (71 percent, 64/90) [Table 6] than with regards to diarrhoea, even if, or perhaps precisely because, coughing is more common than diarrhoea.



# Reduction of Health Inequalities in the Roma Community

	Publication Details
Title:	Differences in Access to Primary Healthcare – Structures, Equal Opportunity and Prejudice
Author(s):	Hungarian Delphoi Consulting research group of Ministry of Health
Publication date:	Feb 2004
Country:	Hungary
Language:	English
Contact address if more information is required: (where applicable)	http://www.delphoi.hu
Published by:	ERRC web site-www.errc.org
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	Presentations or communications
	Doctoral thesis
	Other:
	other.

#### Summary (Description of the study and most relevant results):

One of the primary purposes of our research is to establish whether or not various groups in society, including Roma and others that suffer multiple social and economic disadvantages, have full and equal access to primary healthcare services. If there is unequal access to basic services, what are the causes of this inequality, and what are the actual differences in access among the various groups? Because our research focuses partly on the access of Roma, when determining which doctors and health visitors we would question (that is, the actual group that would constitute the subject of our survey) we selected settlements where, on the basis of authoritative estimates <sup>2</sup>, the percentage of Roma inhabitants equalled or exceeded 1%. Consequently, the results are representative only of those general practitioner (GP) practices and health visitor districts that are located in these settlements.

#### **General Practitioners**

#### Structural issues

In the beginning we sought to establish, on the basis of the national statistics, whether the presence or absence of a GP in a settlement is in any way related to the settlement's social standing, the number of its inhabitants, the age distribution of those living there, or to the ratio of unemployed persons or of Roma within its population.

The data suggests that settlements with multiple disadvantages do not offer local practitioner services directly. These settlements, mostly because of an ageing population and the lack of local funds also tend to be lacking in other basic institutional services. If we look at the national picture, we find that the number of pensioners is generally higher in settlements that do not have a local GP. However, the older segment of the population, with its greater health concerns and higher health risks, suffers from the lack of local health services only to a slightly greater extent than does the population as a whole. This slight difference, however, is significant when we look at the actual number of pensioners affected: approximately 128,000 out of over 2 million.

The ratio of the Romani population shows a dramatic difference. Excluding Budapest, 18.6% of the country's total Romani population lives in a settlement without a local GP.

The social and material conditions of Roma and pensioners living in settlements where there is no local GP are significantly worse than average, especially since the social and economic circumstances of these small settlements tend already to be among the worst in the country. The social disadvantages may well compound the problems arising from a lack of direct access to a local GP.

We know that the high rate of health problems among Roma is due directly to poverty, and in this regard, the Romani population of the poorest small settlements – amounting to more than 100,000 individuals – is in an especially grave situation: It simultaneously suffers from poverty, a high incidence of health problems, and the lack of direct and immediate access to the services of a local GP.

To summarise the local inequalities of access to healthcare on the basis of the national statistics, the country is "divided" in terms of the population of smaller settlements, especially small villages. Small settlements with a local GP are well supplied in respect of the patient/doctor ratio, despite the fact that the population of smaller settlements tends to be older, have higher unemployment rates and inadequate funds, and to suffer from poverty. In settlements where there is no GP or where the GP post is unfilled, the ratio of Roma among the general population tends to be significantly higher, and the number of pensioners is also high. The inhabitants of these settlements suffer multiple disadvantages: they are affected by the unfavourable position of the settlement with all its consequences, and by the lack of local and immediately accessible healthcare.

The analysis of national data shows that the significant inequality of access based on location also adds to the doctors' workload. While a little over 80% of doctors work in one settlement and less than 10% work in two settlements, the maximum number of settlements served by one doctor can be as many as eight, according to our data.

The characteristics of a settlement, and the administrative status and size of settlements, fundamentally determine the access of their inhabitants to health services, as well as the workload of their GPs. Just as there are considerable differences in access among patients, so there are significant differences between GPs in terms of their workload, how many patients they serve directly, how long their office hours are and how many hours they are on call.

The distribution by age of doctors is not consistent among practices with considerably differing workloads. The oldest GPs can afford to avoid practice with a higher workload. The youngest ones do not choose practices with higher workloads but are forced to take them in the absence of other options.

An aspect of structural inequalities is the amount of time (attention and work) a GP can spend on a patient. We have observed great differences, which are a result of structural inequalities.

GPs' offices also differ in how well equipped they are, and we have found considerable differences. However, the causes of the presence or absence of equipment are not structural. The practices of the youngest doctors are significantly more well-equipped, middle-aged doctors' practices are more often moderately well-equipped, the offices of older doctors are more often than not below average in equipment. The analysis demonstrated that age is a factor but education is not. Younger doctors have better-equipped offices even when their level of training is lower.

Socially disadvantaged, poor or Roma patients tend to be taken care of by GPs who belong to the younger generation because in settlements where the number of Roma is higher doctors tend to be young. Because young doctors have better-equipped offices, Roma patients are usually served by better-equipped practices. However, the structural advantages or disadvantages seem to be stronger and more significant than, for example, the equipment of a doctor's office.

#### **Equal Opportunity and Social Status**

In analysing doctors' attitudes, the issue of whether equal or unequal access is provided to patients of different social status seemed to us more widespread and more complex than simply an issue of prejudice. In our research we considered prejudicial attitudes as a sub-system of mechanisms that promote inequality. We did so because it is obvious from our analyses thus far that one of the most important bases of inequality is structural.

According to our data, indirect discrimination against various social groups, which may not be a result of prejudice, is more frequent than direct discrimination.

Certain GPs offer less expensive medical services to the poor, the unemployed, the Roma or other socially marginalised patients than to others. Their communication with these patients is below average, and conflicts occur with greater frequency than average. The social deprivation of these patients is a causal factor because, among other things, doctors believe that these patients' potential to reduce health risks is low. GPs perceive these patients on the basis of their socio-economic and socio-psychological status, while certain significant dimensions of a GP's practice are defined by these differences in status and not by the patient as a human being.

In addition, GPs determine the level of institutional care <sup>3</sup> on the basis of patients' social and sociopsychological status, and therefore the level of institutional care is determined by status and not by a selected protocol.

A certain number of GPs provide therapy at a lower institutional level to patients that are socially marginalised. The social deprivation of patients, as we have seen in relation to the cost of examinations, is a contributing factor. The low assessment of patients' potential to reduce risk to their own health is also an important factor in this regard.

GPs' compassion, or lack thereof, in terms of their taking into consideration the cost of medicine is an independent dimension and has an independent effect on the affordability of the cost of medicine paid by socially disadvantaged patients. A number of GPs can be shown to lack this type of compassion.

A significant number of GPs are not at all or not sufficiently familiar with the considerably higher incidence of disease among Roma and the risks associated with this. Consequently, they do not regard the Romani community as more eligible for increased screening and prevention or intervention which might reduce the incidence of disease among them.

Anti-Romani sentiment or the lack thereof is a measurable factor that impacts the perception of Roma and the level of services provided to them. The causal impact of rejecting anti-Romani sentiments is significant and explains whether a GP has a more or less clear picture of the level of health problems among Roma. It can be proven that the primary cause of the lack of information about the higher incidence of disease among Roma is common and average – not extreme – level of anti-Romani prejudice. On the other hand, it is identified that rejection of anti-Romani feelings is the cause of the clear understanding among doctors of the incidence of Romani health problems.

Anti-Romani sentiments have an impact on medical practice extended to Roma and the attitude towards Roma is to some extent independent of how doctors generally relate to their socially marginalised, poor, and socially disadvantaged patients. This may not be that surprising, since the propensity for anti-Romani feelings appears to have "a life of its own" and is becoming increasingly widespread in society.

Certain versions of anti-Romani feelings do not necessarily result in detrimental situations for Roma with respect to primary healthcare. Even among GPs whose anti-Romani prejudices are strong, there are few who, in comparison with doctors who do not share such prejudices, provide a lower level of services to their Romani patients.

Anti-Romani feelings have a negative, even though not significant, impact on the Roma-doctor relationship. Certain doctors with anti-Romani feelings do not provide the same level of services to their Romani patients as they do to others. However, according to our study, anti-Romani feelings are not a significant factor in primary healthcare services because they can be modified given the right methods.

More important than the damaging effect of negative attitudes towards Roma is the marginalisation of poor, disadvantaged segments, regardless of ethnicity.

We would like to make the following note in closing. It cannot be proven that the apparent inequalities between the level of care received by the social elite and the disadvantaged respectively are caused by direct and open discrimination. In addition, a study conducted among doctors providing the services cannot demonstrate the actual chances for recovery and rehabilitation of socially deprived patients. We can only assume that if the cost and institutional level of care provided to them is lower, if follow-up among them is more infrequent, and the affordability of medications is not always considered, their chances of health maintenance, recovery or rehabilitation will be negatively affected.

Our research has shown, however, that the basic principle that each citizen must receive the same level and the best possible service regardless of social status or ethnicity, suffers.

#### Recommendations

The writer of this study faces the difficult problem of having to recommend solutions that would ameliorate structural disadvantages and the different degree of disadvantage suffered by healthcare patients in relation to their social status.

The difficulty lies in the fact that structural disadvantages are primarily caused by the structure of settlements in this country, as well as by the resulting economic inequalities, and eliminating them would require considerable long-term inter-ministerial cooperation.

The differences arising from the social status of the patients, namely that certain GPs offer a lower level of services to socially disadvantaged patients, indicate a fundamental deficiency in the solidarity among the various segments of society. Analyses have shown that the number of specialisations or the years of training doctors have, has no bearing on how they relate to socially disadvantaged groups. The level of post-graduate training does not affect the level of anti-Roma feeling either, because it is influenced by deeper causes of socialisation. With that said, we have the following proposals.

• The level of social solidarity demonstrated by GPs should be improved. Each GP, without exception, should regard the members of socially disadvantaged groups as equally valued recipients of services, on a par with the members of the elite who can stand up for their rights. Therefore, courses that focus on the causes and consequences of social stratification must be mandatory (and not elective) in basic and continuing medical training. For this purpose, academic workshops (e.g. ELTE's social work faculty, etc.) and outstanding scholars on poverty in Hungary must be commissioned to prepare targeted course material for basic and continuing medical training. The introduction of suitable course material into medical training must be considered an urgent matter.

• In order to improve the services offered to Roma, new training courses must be prepared and introduced in the framework of continuing education in order to inform GPs of the actual conditions, and the health and social problems of Roma. Concurrently with this effort, a bulletin must be compiled on the basis of available information and research that provides information to GPs about the actual social and health conditions of Roma, including their underlying causes. This bulletin must be distributed among GPs, especially in those settlements where, as far as we are aware, some of the inhabitants are Roma.

• Because it is to be expected that certain GPs will contest the data or claim that all patients receive the same level of services, it is advisable to organise and moderate debates with the participation of

appropriate experts (either directly or by creating a specifically targeted Internet portal) which will assist GPs in processing and approving the results.

• Independent of training courses, programs that are effective in creating long-term changes in attitude and in decreasing the existing negative feelings towards the poor and the Roma must be prepared and adapted, after gaining an overview of the relevant international experience.

• Since the most effective way of combating prejudicial attitudes is to penalise the prejudicial behaviour, and the discrimination to which it gives rise, a measuring and monitoring system must be developed for regular application among doctors and patients which is capable of rendering these negative phenomena transparent. Transparency must be followed by indicating that these attitudes are socially unacceptable (socio-psychological punishment).

• A PR programme must be developed which can effectively portray in the media the situation of Roma, as well as the harmful consequences of prejudicial attitudes.

#### **Health Visitors**

The designation of health visitors' districts, and the number of health visitors in the various counties and settlements, fail to meet statutory requirements, and in some cases actually contradict them.

Health visitors' tasks are unevenly distributed. While the majority of health visitors work in one settlement on average and perform one basic task at low or moderate levels of intensity, one fifth of health visitors perform several tasks at a high level of intensity in a number of settlements.

Behind the distribution of health visitors' districts within counties and settlements are very serious inequalities in access caused by a structural imbalance. In disadvantaged, poorer areas consisting of small villages, a smaller number of health visitors carry higher workloads and perform extra services, while counties and settlements in more favourable positions employ more health visitors with lower workloads.

More than one fifth of all the health visitors studied carry high workloads and also care for a high number of Roma.

In most cases the high number of Roma is a simple accompanying feature of the settlements' characteristics. The reason why health visitors work with so many patients and in several settlements is not because Roma live there, but the opposite: Roma tend to live in such settlements where health visitors already have a higher workload.

However, the differences between workloads resulting from serious structural imbalances do not mean that health visitors with higher workloads invest less energy in their work or attend fewer training courses. Health visitors in districts with high percentage of Roma did not participate in more hours of training than in other places, and the high number of Roma does not (so far) indicate a greater participation in training.

Therefore, the distribution of health visitors' districts points to serious structural inequalities. In many cases the actual number of patients is three times the optimum number specified in the relevant government regulations (quite apart from the other work commitments). It is a fundamental problem that the local distribution of health visitors' districts and the fluctuating number of patients are both contrary to the letter and the spirit of the law, and do not serve the principle of equal opportunity and equal access.

Health visitors' training and their attitude towards their patients determine the extent to which they take into consideration the needs of their patients. Counselling, the communication of basic information and health-related advice that comprise a health visitor's tasks are interactive processes that greatly depend on the health visitors' attitudes (and not so much on the characteristics of their patients). This observation, however, is more relevant to their attitude to Roma patients than to others.

A fairly large percentage of health visitors are well-trained, care for many persons and are also committed to what they do, which means that they have an excellent grasp of their patients' needs.

A higher percentage of highly trained health visitors who are tolerant towards Roma understand that their Roma patients have numerous healthcare needs.

On the other hand, health visitors with lower levels of training and who are unable to perceive their patients' needs, and health visitors who have some form of anti-Romani attitude have a lesser

understanding of their Roma patients' needs. This "blinkered" attitude hinders the true perception of Roma patients' healthcare needs.

The occasional lack of understanding with respect to patients' needs interferes with the provision of equal services because counselling is an interactive activity, which is performed through communication between the counsellor and the patient. If a counsellor creates a communicational space that the patient perceives as inadequate in assessing his/her real needs, the counsellor will be unable to help because an atmosphere of mistrust has been created (towards the potential help).

Health visitors who display some form of anti-Romani attitude have been proven to be less effective in meeting their patients' needs. As a result, on the basis of our knowledge of the communicative dynamics of service-oriented professions, these health visitors are less effective than average in assisting their Roma patients.

A brief summary of our recommendations, aimed at improving, and sometimes creating, equal access to health visitors' services, is as follows:

• Because inequalities in access are fundamentally structural in nature, a new distribution of health visitors' districts must be created which complies more strictly with the stipulations of the relevant decree and is better adapted to the patients' location demographics and socio-economic conditions, as well as to health visitors' work capacity.

• We have two proposals in relation to training which are aimed at improving health visitors' performance with regard to Roma patients: We need to ensure that most health visitors participate in general training courses that encompass all aspects of a health visitor's work, consisting of at least 150 hours of training spread out over a minimum of 5 years. In addition, training courses must be developed and introduced that provide information on the health status and social problems of the Roma population (on the national and local level). These training courses must also increase health visitors' ability to perceive the actual needs of Roma patients (even though they may not be explicitly stated) and to provide appropriate responses for these needs.

• Independent of the training courses, programs must be developed and/or adapted (after gaining an overview of international experiences) that can effectively and permanently modify attitudes and reduce anti-Romani feelings. We emphasise that these programs should be independent of the trainings because the relevant literature, experiences and hypotheses suggest that modifying purely cognitive content and obtaining new information has no bearing on prejudicial attitudes.

• Since the most effective way of combating prejudicial attitudes is to penalise the prejudicial behaviour, and the discrimination to which it gives rise, a measuring and monitoring system must be developed for regular application among doctors and patients which is capable of rendering these negative phenomena transparent. Transparency must be followed by indicating that these attitudes are socially unacceptable (socio-psychological punishment).

• A PR programme must be developed that can effectively portray in the media the situation of Roma as well as the harmful consequences of prejudicial attitudes.

#### Anti-Romani Attitudes

We examined anti-Romani attitudes among three groups: general practitioners and health visitors who work in settlements where Roma account for more than 1% of the local population, and medical students in Hungarian medical schools.

We treated anti-Romani attitudes as a complex system of attitudes consisting of three basic issues: negative stereotyping of Roma, attitudes to discrimination against Roma, and an emotional distance towards Roma. This concept of measuring anti-Romani sentiment is based on national and international tests that examined prejudicial attitudes against minorities by the majority population.

During the study we identified five markedly different groups. 6.3% of the people studied strongly reject all types of anti-Romani attitudes, 21% do not have anti-Romani attitudes, and 28.3% have no propensity towards accepting discrimination. Consequently, 55.6% cannot be characterised by any form of anti-Romani attitude.

Therefore, only less than half of the people studied have some form of anti-Romani attitude. 14.1% of the people in the study can be characterised as having strongly negative attitudes towards Roma, which means

that they engage in negative stereotyping, approve of discrimination, and have a marked emotional distance. Thirty percent have a tendency towards anti-Romani attitudes, which means that they can be characterised by all three components of anti-Romani attitudes but to a lesser degree than those who have strong anti-Romani feelings.

Causal analyses suggest that the tendency towards anti-Romani attitudes is fairly deep-seated in society, and is more widespread among the younger generation than the older. The people we studied belong to the social elite and practice or prepare for service-oriented professions. Therefore the extent, deep roots and pervasiveness among the younger generation of anti-Romani attitudes presents a scary picture.

The intensity of anti-Romani attitudes among GPs and health visitors, in other words those who actively practice a service-oriented profession, is lower than among medical students.

Nevertheless, working with a larger or smaller number of Roma does not have an effect on anti-Romani attitudes. Anti-Romani attitudes are primarily the result of deeply ingrained social values such as intolerance.

Managing and decreasing anti-Romani attitudes is an urgent social problem and is not solely the concern of a particular profession or institution. Because the fundamental cause of anti-Romani attitudes is not lack of information but ingrained, socialised values, decreasing anti-Romani attitudes is not primarily a matter of education. We must create conditions with the help of regulation and education that make anti-Romani attitudes socially unacceptable in both everyday life and in relation to social attitudes. Only then can we expect the prevalence of anti-Romani attitudes to diminish among the next generation.



# Reduction of Health Inequalities in the Roma Community

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	Bodner, A. & Leininger, M. (1992). Transcultural nursing care values, beliefs, and practices of American (USA) gypsies. <u>Journal of Transcultural Nursing</u> . <u>4</u> (1), 17-28.
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Х	Article
	Book
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	Study / Public administration report
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	Presentations or communications
	Doctoral thesis
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#### Gypsy (Roma)

**Notes:** The authors are aware that the term "Gypsy" is not favored by the Romani people to whom the term is applied by non-Roma. The term Gypsy is used in the title of this document only to aid in internet searching. For the most part we will use the correct terms: Romani, Roma, or Rom as explained below. We urge informed readers to critique this document. What mistakes have we made? What have we left out? Let us know.

This document is a result of involvement in sponsoring and providing health care for a Romani family from Eastern Europe. We knew little about one another's health or socio-cultural beliefs and practices, and the experience was less than satisfying for all concerned. I hope this document and accompanying links (especially the Patrin Journal) will help others in interacting with the Romani people. Charles Kemp

#### Introduction

A few Romani terms are helpful to understanding this culture. Romani, the adjective; Roma, plural noun; or Rom, singular noun, are the preferred terms when referring to people commonly and incorrectly known as Gypsies. Not all Romani people refer to themselves as Roma. Gadje (or gazho) is the plural term referring to non-Roma. An individual Romani household is a familia consisting usually of three generations of six to fifteen relatives. Unrelated familia living cooperatively in a given geographical region is called a kumpania and the vista is comprised of numerous kumpania and can span across a country. Familia who live apart will unite during transitions such as marriage, serious illness and death. There are numerous variations on these basic structures.

Most Roma maintain their social isolation through their own conscious and asserted effort, and through prejudice from non-Roma. In the United States, there are two primary reasons why the Roma are so successful at remaining largely invisible. First, the large number and variety of minority groups in the U.S. afford the opportunity to blend into other cultures, with Roma sometimes presenting themselves as American Indians, Hispanic or southern Europeans rather than Roma. Second, misconceptions arise from folklore and media with the image of the "gypsy" based on either romanticized or pejorative fiction. As a result, little of substance or accuracy is known about the Roma. Elsewhere in the world (e.g., Eastern Europe), there are recognized Romani communities that are the subject of significant discrimination and in some cases (e.g., post-war Kosovo), significant repression.

There is a strong unwavering social and culture bond forged among the Roma to sustain their way of life. Traditionally they turn inward and reject the outside world to become a self-perpetuating system that renews itself with each new generation (Bodner, 1992). Loyalty to the family is maintained at all cost. Education and technology are not significant factors within the culture and are not traditionally considered important; though there are indications that this is changing. Many older Roma are not literate. In recent years, some younger members of the familia have been allowed to attended Gadje schools until about the age of ten and are thus able to read important Gadje documents. There now are increasing numbers of college-educated Roma - at least in countries like Canada and the U.S.

#### **History of Immigration**

The Roma originated in India and migrated to Europe around 1000 A.D. It is unclear why they left India, and there are no explanatory written documents. They reached the Balkans by the 14<sup>th</sup> Century and spread throughout Western Europe by the 15<sup>th</sup> Century. The Roma were the first people of color to immigrate in large numbers to Europe, and Europeans tended to treat them as outsiders. In the 18<sup>th</sup> century, groups of Roma were deported to the American colonies.

Because of their alternative lifestyle and refusal to conform the Roma were also persecuted in the American colonies and were exiled from several places. Their occupations included "magic," fortune-telling, copper-smithing, tinkering, mechanics, horse dealing, and music.

Another large group of Romani people migrated to the United States in the late 19<sup>th</sup> and early 20<sup>th</sup> Centuries. They came from Argentina around 1920, after previously residing in Russia. Current Romani population estimates in the United States are difficult to determine as the census does not record their cultural identity, and the Romani population does not record births or deaths. The national population of Romani Americans is estimated to be one million with the largest concentrations of Romani people in urban areas such as Log Angeles, New York, Chicago, Boston, Atlanta, Houston, Seattle, Portland, San Francisco and Fort Worth. In Europe, large Romani ghettos exist at the outskirts of many urban areas, especially in Eastern Europe. The largest number are in Romania, followed by Hungary, Bulgaria, Slovakia, and Yugoslavia/Serbia (Patrin Journal, 1999). There are an estimated 12,000,000 Romani worldwide (Smith, 2000).

Throughout their history in the West, the Roma have experienced discrimination because of gadje folklore, Romani practices, and the prejudice inherent in all societies. Even the Bible has been used to justify discrimination against the Roma:

"Cursed be Canaan; A servant of servants He shall be to his bethren" Genesis 9:25

There is also the legend (still alive in rural Balkan countries) that the Roma made the nails that were used to crucify Christ and/or that they stole the fourth nail, thus making the crucifixion more painful. Gypsy hunting and other such persecutions have occurred almost from the beginning of the Roma presence in Europe, and continue to this day. Nazi Germany institutionalized the hatred and killing, with Gypsies treated the same as Jews in all respects. Approximately 500,000 - 1,500,000 Roma were murdered in the Holocaust ("the devouring" to Roma). Persecution and discrimination is now carried out by governments, communities, and individuals - especially in Eastern Europe and increasingly so since the fall of communism (Berlanger 2000). The growth of xenophobic nationalism and the skinhead movement are

#### current and significant forces in repression of the Roma.

Recent Romani refugees and immigrants to the U.S. have come primarily from Eastern Europe, e.g., Romania, Bosnia, Bulgaria, and Kosovo. They tend to have less education, more health problems, and greater difficulty with resettlement than other Eastern European refugees and immigrants. It is not known to what extent recent Romani arrivals have assimilated into indigenous Romani culture in the U.S. or other countries of second asylum.

#### Communications

The language of the Roma is called Romani and is derived primarily from Sanskrit; with strong influences from Persian, Greek, and Slavic languages (note that these track the Roma diaspora). Until recent years, Romani was solely a spoken language, but there is increasing use of written forms of Romani. There are different forms of Romani depending on which clan the Rom belongs to. Interaction between different clans is limited, and the form of Romani spoken is an important means of distinguishing between clans.

There also are customs in communicating with Gadje. In the healthcare setting, only the elder males are likely to communicate with healthcare personnel. Women are not permitted to interrupt men nor to be alone with a man who is not her husband or relative.

#### Social Structure and Kinship

There is an extensive and complicated social structure among the Romani people. Generally, there are four loyalties and/or identities (nation, clan, family, and vista). First, Roma are divided into Natsias or nations, which is their main identity group. The four common Romani nations are the Machwaya, Kalderasha, Churara and Lowara. The nations are then divided into Kumpania or clans. A clan is "an alliance of families united by ancestral, professional, or historical ties" (Thernstrom, 1980, p 442). This loyalty or group consists of extended family that travel and reside together and maintains economic control over a particular territory. The clans that are most numerous in the United States are the Romnichals, Bayash and Rom. Each clan has a leader and the social structure of the clans may differ. There are, incidentally, no "Gypsy Kings."

Some clans are further subdivided into tribes, but many clans are simply composed of familia. The one common thread in all clans is the importance of the familia, the most important social group to the Roma. A vista is an extended familia, which includes anywhere from 20 to 200 members who are all related by blood or marriage. The familia has a social structure of its own that is very similar within all clans. Families are male dominated, with a group of male elders within the familia being the major decision makers. Romani women are often not included in the decision making process and generally have a much more subordinate role within the familia.

#### Culture

The Roma are ethnocentric, tending to demonstrate a sense of moral superiority and contempt toward the Gadje. The Roma have a strict taboo code that classifies all outsiders as soiled or unclean. This code prevents interaction with the Gadje and further limits acculturation. Some refuse to use the Gadje language to record births, participate in census or other surveys, or to record deaths. They maintain enough of a link with the outside world to meet their primary economic and cultural needs. Very few are employed by Gadje except as contractors and then nearly always on a temporary basis.

Important Romani concepts related to health care are "wuzho" and "marimé". Wuzho is the Roma word for pure while marime is a broad term referring both to a state of pollution or impurity or a sentence of expulsion imposed for violation of a ritual or moral nature. Other terms for marimé are moxadó, melali, mageradó, mokadi, kulaló, limaló, prastló, palecidó, pekelimé, gonimé or bolimé.

The Romani culture has strict rules about anything considered polluted. A person can be found to be marime for violations of sexual conduct, not following Romani rules for food preparation, clothes, washing or cleaning, or other activities involving pollution. Women are particularly associated with marimé, with any part of a woman's body above the waist being wuzho or pure and below the woman's waist being marimé or polluted - especially the genitoanal area and its secretions. Secretions from the upper half of the body are not polluting or shameful. Washing hands after touching the lower body before touching the upper body is required. Separate soap and towels are used on the upper and lower parts of the body and they must not be allowed to mix. To the Roma, failure to keep the two sections separate in everyday living may result in serious illness. For this reason, most Romani women will not agree to a gynecologic examination unless the procedure is clearly explained as being essential to her well being. Certain food or animals (birds and cats) may also be considered marimé.

When a young women reaches menarche, she is introduced to shame and must begin observing the washing, dressing, cooking, eating and behavioral rules of adult women for her own protection as well as the protection of others. Her clothes must be washed separately from those of men and children because of the impurities of her body. She cannot cook food for others during menstruation. She must show respect to men by not passing in front of them, stepping over their clothes, or allowing her skirts to touch them. Prepubescent girls and older women are placed in a different category because they do not menstruate. This allows them freedom, and they are allowed to socially interact with fewer restrictions.

The Roma are supposed to wash only with running water, with a shower acceptable but a bath looked upon as sitting or lying in dirty, stagnant water. Dishes cannot be rinsed in the same sink or basin that is used for washing clothing. The kitchen sink is used only for washing dishes and cannot be used to wash one's hands.

Because they do not observe body separation, Gadje are seen as a source of impurity and disease. The impure public places where Gadje are congregate are also considered potential sources of disease. These places are considered less clean than the Romani home or open outdoors. The Roma generally avoid touching as many impure surfaces as possible. They will attempt to lessen the pollution by using disposable paper cups, plates and towels.

#### Marriage

Gypsies tend to marry young. Some tribes practice arranged marriages while others allow courtship. If the marriage is arranged, the groom's father selects and pays for a bori or daughter-in-law through the help of a marriage arranger. Marriage is not always for love but may be arranged or undertaken according to practical, economic, and/or social considerations of the family or clan. Marriage in the Romani culture has occurred as early as age nine but usually does not take place before the age fourteen. Outside marriage is considered a serious transgression in some clans and may be grounds for expulsion. In other clans, if a Romani male marries a female Gadje his community may eventually accept her provided she adopts the Romani way of life.

Marriage festivities last three days after which time the bride and groom are allowed to consummate the marriage. The newlyweds traditionally live with the groom's parents until they have several children of their own, and the family is satisfied with their adult behavior and skills, at which time they are allowed to establish a semi-independent nuclear household. The daughter-in-law must prove herself to her new family and is expected to perform services with little in return. She is expected to care for her in-laws and

produce grandchildren. With the birth of her first child the daughter-in-law moves from the child or bori status to mother-of-the-child status.

#### Religion

There is not a separate Romani religion. Since they are generally a nomadic people, they have traditionally adopted the dominant religion of the country in which they live. For example, the Roma and Boyash clans are largely Roman Catholic while the Romnichals are largely Protestant. There are also Eastern Orthodox, Hindu and Muslim believers among the Roma. Many of the cultural practices of the Roma can be traced to other religious beliefs. For example, Roma practices of ritualistic cleansing can be traced back to ancient Hindu customs. If Roman Catholic, they will also celebrate the days of the Saints believed to have helped the familia. Evangelical activities among the Roma have increased in recent years.

Although the Roma adopt the religious practices of those around them, they also maintain several strong faith practices and beliefs in the supernatural, omens and curses. They believe in charms, amulets and talismans which they will carry in their pockets for safety, good luck and to prevent illness. They also have female healers, called drabarni or drabenhgi, who prescribe traditional healing rituals and cures. One traditional means of healing is to carry a moleís foot as a cure for rheumatism or a hedgehogís foot to prevent toothaches. Interestingly, the Roma do not believe in fortune telling. This practice is used only to earn money from the Gadje.

#### **Health Care**

Roma who enjoy good health are believed to be blessed with good fortune, and those who are ill are said to have lost their good luck. Roma believe that actions (e.g., clean or polluting) can promote health or result in illness. To return to a state of purity, cure, and good health one must conform or correct the marimé social behavior.

The Romani people tend to use the Gadje health care system only in crisis situations when there is an acute and/or unresolved condition for which folk medicine has failed (except as noted under "Pregnancy . . . " below. Generally, they see the mainstream healthcare system as causing more harm than good. Romani may request specific "famous name" physicians and demand specific treatment even if the treatment or physician is inappropriate. There also is preference for older physicians over younger ones. Sharing medications is common and Roma have also been known to request a specific color of medication for a specific illness.

For the Roma, illness is not just the concern of the individual but a problem shared by the entire clan. When a clan member must enter a hospital, family members are expected to remain with that person day and night to watch over, protect, and perform caring and curing rituals. This cultural coming together is one of the strongest values of the Romani culture. Cultural care and accommodation of this group kin presence is a major factor to be considered in planning and providing care for a Rom. Roma are especially fearful of any surgical procedure that requires general anesthesia because of a belief that a person under general anesthesia undergoes a "little death". For the family to gather around the person coming out of the anesthesia is especially important.

#### Health Risks Among the Roma

In parts of Europe, most Roma have a life expectancy of under 50 (Reyniers, 2000). Poverty, isolation, predjudice, and other factors discussed above and below contribute to this appallingly short life span.

The Romani culture in itself can sometimes increase risk for certain illnesses. For example, the belief in purification rituals and ritualistic cleansing to prevent illness translates to resistance to childhood and adult immunizations. Social isolation can be carried to such extremes (refusal to register births and deaths) that significant trends in morbidity and mortality may be hidden. Isolation also results in lower participation in health screening, and beliefs about marimé mean that cervical and colon cancer screening are especially difficult to promote.

Dietary habits include high fat and salt content in foods. A large percentage of Roma smoke and are obese.

These practices put the Roma at increased risk for hypertension, diabetes, occlusive vascular disease, strokes and myocardial infarctions (occurring in Rom as young as 20 years). Again, social isolation and resistance to screening result increased health risk such as end-organ damage from undiagnosed hypertension or diabetes, especially among women who are even less likely than men to be screened.

Social (or societal) isolation also leads to an increase in consanguineous marriages, and thus an increased risk for birth defects. Crowded living conditions lead to an increase incidence of gastrointestinal infections, respiratory infections and hepatitis. Romani infants are more likely to be born prematurely and low birth weight due to a lack of prenatal care. In some clans, the infant mortality rate and abortion rates are high. Romani babies also have an increased risk for the development of phenylketonuria. Please see section on screening and risks at the end of the document.

#### Pregnancy, Childbirth and Child-rearing

A woman is considered to be marimé (polluted or unclean) during her menses, pregnancy and for six week after the birth of the child. Childbirth should not occur at the familia's usual home lest the home lose its purity. For this reason, there is increased acceptance of hospital births.

A new baby is immediately swaddled tightly and should only be handled by his/her mother to maintain a state of wuzho. When a baby is delivered in a hospital, the mother should be allowed to practice ritualistic cleansing and the father not pushed to visit during this marimé time. There are rituals (that vary with tribe) involving the formal recognition of the infant by its father. In some cases, the child is wrapped in swaddling on which a few drops of paternal blood are placed. Other rituals involve the child being covered by a piece of clothing that belongs to the father. In some tribes, the mother puts the infant on the ground and the father picks up the infant and places a red string around its neck, thereby acknowledging that the child is his (Patrin Journal, 1999). The Patrin Journal has more extensive information on this and other aspects of birthing.

In the first weeks postpartum at night, no member of the family is allowed to go in and out of the mothers room, and all the windows and doors are kept shut lest the spirit of death called "the night" enter and harm the baby. If a baby dies, it is bad fortune and the parents must avoid the baby's body. Traditionally, the body is buried in a secret place by the grandparents. Another way to avoid bad luck after the death of a baby is to leave the funeral and burial to hospital authorities. Note that bad luck here is far more than bad

luck finding a parking space or in game of chance! Bad luck in the life of the Roma is lifealtering for individuals, families, and clans.

Children are a major focus of Romani culture and are believed to bring good luck. Child rearing is the responsibility of everyone in the family. Due to the large and complex social structure, most of the children are raised and cared for my many different people including extended family members and clan members living in the same residential area. Infant care tends to be both permissive and

protective. Infants and young children enjoy freedom from most social restraints and are not expected to understand or demonstrate shame. It is not until puberty that they are introduced to the concept of shame and expected to observe marime. Children are not expected to take many of the precautions that adults do to ensure cleanliness in their daily lives, and in contradistinction to adults, may eat food prepared by Gadje. They are weaned and toilet trained in a very gradual fashion as these are not considered important events in the Romani culture.

In Romani culture older children act as miniature adults. Teenagers do not experience a carefree adolescent period as with many Western cultures. They are expected to begin adult socialization and to start a profession by ten years of age. Separation is by gender to learn the skills of the adult. Children are expected to respond with respect to multiple parent figures.

#### **Dying and Death**

Romani belief in the supernatural and fears about death play a significant role in their rites and customs related to dying and death. When a Rom is about to die, there is an extensive ritualistic process that must initiated. Through an elaborate communications system, relatives from other geographic areas come to be with the dying or dead. If the person is dying, it is essential that relatives be allowed to be present at the moment of death. When the person is near death, a special candle is brought into the room. At the time of death this candle is lit and a window opened. It is believed that the candle will light the way to heaven for the deceased person's soul. The body is rubbed with holy oil, and family displays intense grief. For three days, all Roma must grieve by remaining in the presence of the dead. During this time they do not bathe, shave, wear jewelry, change clothes or prepare food. They are allowed to drink coffee, brandy or other liquors. Mirrors may be covered and vessels containing water may be emptied.

It is culturally acceptable for relatives to be deeply absorbed in their grief. Displays of grief may include moaning and shouting out to the deceased, scratching their faces, pulling their hair out and throwing themselves to the floor or into a wall. There is great fear among the survivors that the dead might return in a supernatural form to haunt the living. For this reason the name of the deceased should not be mentioned, the body is not touched and all objects belonging to them destroyed. After a three day wake, the funeral is held, which is followed by a death feast in honor of the deceased. For this feast, food is always prepared in units of three (three chickens, three pots of potatoes, etc.). Additional feasts are held to mark the three days, nine days, six weeks and one year intervals after the death. Close relatives of the deceased wear mourning clothes for a full year. It is believed that after one year the deceased soul enters heaven.



## Reduction of Health Inequalities in the Roma Community

	Publication Details	
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Country:	Hungary	
Language:	English	
Contact address if more information is required: (where applicable)	Rita Izsák is ERRC legal monitor. The present article summarises the results of ERRC research conducted by the following ERRC staff and interns: Kerieva McCormick, Lydia Gall, Rita Izsák, Orsolya Szendrey and Angela Wu.	
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Х	Article
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	Study / NGO report
	Presentations or communications
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#### Summary (Description of the study and most relevant results):

The complaints described above indicate possible abuse of the principle of equal treatment in the provision of health care services to Romani women. Romani women are humiliated by being segregated from non-Romani women in maternity wards; in many cases they are subjected to less qualified treatment and sometimes to negligent treatment; finally, they experience constant verbal abuse on racial grounds by both nurses and medical doctors. Apart from the lack of access to equal standards of health care due to discriminatory treatment by medical personnel, Romani women are exposed to the risks of less qualified treatment due to the fact that they cannot afford to offer doctors tips for better health services. Evidence of numerous cases of egregious human rights violations by medical professionals such as coercive sterilisation of Romani women like the ones documetned by the ERRC in Slovakia and the Czech Republic, is not available in Hungary. However, the existence of cases of interference with the Romani

women's reproductive rights cannot be precluded. Indeed, an ERRC/NEKI complaint on behalf of a Romani woman who was sterilised without full explanation about sterilisation in a public hospital in the Hungarian town Fehergyarmat, is pending before the UN Committee on the Elimination of Discrimination against Women<sup>10</sup>.

Filing legal cases against hospitals or medical staff involved in abuse of Romani women, however, in the ERRC's experience has proven difficult. The main reason for that is the Romani women's fear of retaliation by doctors. Romani women appear to be more willing to endure discriminatory treatment than to undertake actions which may threaten their relationship with local doctors and therefore possibly risk their own – and their children's – health.

A new prospect for litigating discrimiantion in health care is opened with the adoption of the Hungarian anti-discrimination act, Article 20 of which allows for non-governmental organisations (NGOs) to litigate in their own capacity if the violation complained of affects a large number of people. This opportunity potentially opens new possibilities for eliminating racial discrimination in the health care system and providing equal opportunities to all patients regardless of their origin and economic or social status.



## Reduction of Health Inequalities in the Roma Community

#### **Publication Details**

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#### Type of document (mark with an X):

х	Article
	Book
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	Study / Public administration report
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#### Summary (Description of the study and most relevant results):

The health status of a community is the simplest direct indicator of the access this community has to the goods and benefits a society provides for its members. When disparities in health status overlap with racial or ethnic boundaries, a myriad of other divisions along racial or ethnic lines are implicated.

Although scarce, existing research on Roma health status indicates serious inequalities between Roma and non-Roma. In addition to frightening data pertaining to differences in infant mortality, Roma are also generally more likely to die prematurely than non-Roma and to be affected by communicable diseases. While some evidence is already available, the basis of these disparities remains poorly studied and explained.

According to the dominant views among researchers and policy-makers, poverty is the central determinant of poor health among Roma. These views oversimplify the issue and tend to ignore or underestimate the particular, independent obstacles posed by racial discrimination. On the one hand, racial discrimination – past and present – has predetermined to a large extent the socioeconomic status of Roma. In general, Romani communities are disproportionately exposed to substandard living conditions and hazardous environments. Roma also have fewer educational opportunities than non-Roma. Racial discrimination in health care – direct and indirect – magnifies already existing inequities establishing separate and independent barriers for Roma to enjoy the right to the highest attainable standard of health. Thus, health disparity of Roma is the cumulative result of both past and current racism.

Racial barriers to health care are exhibited in the systemic disadvantages facing Roma in access to health. Certain general policies and administrative procedures have an adverse effect on Roma. Systemic disadvantages are visible in the disproportionate numbers of Roma excluded from health insurance; the large number of Roma living in neighbourhoods without health care facilities; the large number of Roma living in settlements not covered by general practitioners; the severe underrepresentation of Roma in the medical profession. Furthermore, barriers to quality health care manifest themselves in the disparate impact of the intersection of race and gender. Discriminatory treatment based on the compounded influence of race and gender magnifies the difficulties Romani women face in gaining equal access to quality health care. Coercive sterilisations of Romani women in Slovakia and in the Czech Republic documented by the European Roma Rights Center loom as an extreme example among a plethora of daily manifestations of this phenomenon. The unique experiences of Romani women have been largely ignored by the health care system. Finally, Roma are subjected to medical treatment of inferior quality based on their race and not related to their socioeconomic status. Again, what has pierced the curtain of indifference to this problem has been only the most egregious and therefore visible examples of negligent treatment or malpractice that has caused serious harm or death of the patients, while many other practices denying quality health services to Roma remain undisclosed. There can be no doubt that widespread discriminatory and segregatory practices in the provision of medical services - whether intentional or resulting from other processes, influence in no small degree the disparity in health status of Roma.

In their everyday work, human rights practitioners focusing on Roma rights witness and document these barriers with a frequency which invalidates attempts to deny their existence. Systematic research on the deleterious effects of racial discrimination on Roma health, however, is almost non-existent. Lack of data on the adverse impact of certain policies on Roma health as well as on the quality of health care services received by Roma perpetuates the problem. Moreover, the interference that racist stereotypes have on the quality of treatment Roma receive is vehemently opposed by medical practitioners and often covered up by public authorities. In some cases it appears that public officials are more concerned with preserving the honour of medical professionals than with eliminating the barriers for Roma access to quality medical services. In this issue of Roma Rights, the ERRC presents a summary of a survey on Roma access to health care commissioned by the Hungarian Ministry of Health but never published, presumably due to opposition to its conclusions. These included documentation of structural and individual influences diminishing the quality of health care provided to Roma and impairing Romani access to health.

The issue of discrimination of Roma in health care has come up in a number of previous editions of Roma Rights focusing on individual cases of malpractice and disparate treatment of Roma. This edition of Roma Rights takes the theme a step further, revealing several aspects of the problem of access of Roma to health care: (a) the pervasiveness of the stereotype of pregnant Romani women; (b) health care that is disproportionately inaccessible and undignified; and (c) the multifaceted impact of racial discrimination on health. These themes encompass social, political, and economic factors affecting the experiences of Roma in health care and mandate further investigation and intervention. Future ERRC activities will increasingly focus on health research and legal action to remedy discrimination of Roma in the health care system.



Reduction of Health Inequalities in the Roma Community

**Publication Details** 

Title:	Reflections on the Access of Roma to Health Care
Author(s):	Ivan Ivanov
Publication date:	Jan 2004
Country:	Hungary
Language:	English
Contact address if more information is required: (where applicable)	Ivan Ivanov is staff attorney of the ERRC. He has medical training and worked as a paramedic in Bulgaria.
Published by:	ERRC web site:www.errc.org
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

	Type of document (mark with an X):
Х	Article
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	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

#### Summary (Description of the study and most relevant results):

To date, governments in Central and Eastern Europe have not undertaken to implement comprehensive programmes to tackle exclusion of Roma from health care. Government action tends to focus on preventive health care such as vaccination campaigns or training of medical personnel. The structural problems affecting Roma health, however, remain largely unaddressed. Governments should take a multi-sectoral approach to addressing discrimination, as well as to tackling problems related to social benefits, education, living conditions and housing.

Discrimination in access to health services should be prohibited by law and the implementation of antidiscrimination law vigorously pursued. The approach for elimination of barriers to health care will be more effective if governments include Roma in the process of conceiving, designing, implementing and monitoring the policies and programs aimed at improving their health situation.



### Reduction of Health Inequalities in the Roma Community

#### **Publication Details**

Title:	Healthcare Policy and Provision for Roma in Slovakia and the Czech Republic
Author(s):	James Grellier and Katarína Šoltésová <sup>1</sup>
Publication date:	Feb 2005
Country:	Hungary
Language:	English
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Published by:	ERRC web site-www.errc.org
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
Х	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

#### Summary (Description of the study and most relevant results):

#### Conclusions

Monitoring of Roma access to health services must be improved in both Czech Republic and Slovakia. The state of affairs at the current time is seriously affecting both effectiveness and appropriateness of research and project proposals, it is obscuring the true importance of Roma health issues, and it encourages continued, poor majority-media representation of the Roma. In the current absence of high-quality quantitative data, research yielding quantitative information must be carried out by responsible parties and be focused on relevant topics. In both the Czech and Slovak republics, the transition to needs-led research within academia is still far from complete: the small degree of work carried out at the present

time is poorly funded, and is supported by a culture of research for research's sake. Personal authorial responsibility for research that has been carried out is essential, particularly when work has been carried out with government funds or as a constituent part of a state project. The authors met with considerable difficulty on several occasions in obtaining reports summarising project findings, and those responsible for these reports were reticent to discuss their research, unavailable for comment completely, or had a very limited amount of interest in the way in which government had subsequently used their findings in future policy-making.

The means of communication between those managing projects and the field and those coordinating projects in the ministries needs to be reconsidered. As the coordinator of PHARE projects at the Slovak Ministry of Health pointed out, all official communication must be carried out by post, which takes a considerable amount of time. Streamlining of the communication process between field project managers and civil servants could lead to better timeliness in project implementation, greater efficiency in the use of financial resources and a clearer idea of any individual project's process relative to its goals.

Improved communication between the various ministries and governmental levels is essential in improving the effectiveness of healthcare policies on Roma. Projects and programs are all too often slowed down by a lack of appropriate planning and cooperation between different government bodies. As the current plight of Roma becomes clearer through appropriate research, efforts to support integration and lower levels of poverty-risk should become a priority at all levels of government; improved levels of health status and equality in access to healthcare provision should serve as keystones in this broader development process.



# Reduction of Health Inequalities in the Roma Community

Publication Details	
Title:	Roma in Finland
Author(s):	Janette Grönfors
Publication date:	March 2005
Country:	Hungary
Language:	English
Contact address if more information is required: (where applicable)	Janette Grönfors is a Finnish Romani woman who has worked for the Finnish Government in the National Board of Education, Romani Education Unit, since 1995. She is also communication' s coordinator for the International Roma Women Network (IRWN).
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#### Type of document (mark with an X):

х	Article
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	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

#### Summary (Description of the study and most relevant results):

#### Background

The largest traditional ethnic group in Finland, the Roma, has been studied extensively from different angles, often to clarify their social, educational and cultural status. With a few exceptions, the studies and surveys have been conducted by non-Roma.

Roma have lived in Finland since the 1500s and perhaps precisely for that reason we feel ourselves to be very Finnish. We have taken part, alongside other Finns, in all of the wars the country participated in. Our

mother tongue is Finnish and we are Finnish citizens. We also obtained the status of a traditional Finnish minority in the 1990s.

At the moment, at least 10,000 Roma reside in Finland. In addition, approximately 3,500 Finnish Roma live in Sweden. Regardless of their small number, Roma have been able to preserve and maintain their distinct cultural traditions.

The status of Roma has traditionally been very different from that of the majority. Roma were persecuted in Finland, too, from 1600 to 1800. Efforts to improve the living conditions of Roma began about 100 years ago, when two state committees were created to handle Romani affairs. The committees submitted their findings in 1900 and 1955. Both studies concluded that only an assimilation programme would make the Romani population acceptable? for society. This stemmed from a general view that the cultural features of the Roma, such as their language and way of life, were so drastically different that they were not to be supported or maintained. The idea of promoting diversity, and maintaining the Romani culture, came about much later in Finland.

In 1956 an Advisory Board for Gypsy Affairs was established within the Ministry for Health and Social Services (presently the Advisory Board for Romani Affairs). The most important issues the board dealt with included housing and education, as well as the status of the Romani language and culture. The social and educational status of the Roma has also been supported by the establishment of the Romani Education Unit of the National Board of Education in 1994. Its main goal is to represent expertise in education and culture, and to influence the planning and implementation of educational programs so that the basic and vocational education of Roma could be realised on an equal basis. The National Romani associations (Romano Missio, The Finnish Romani Association, The Finnish Free Romani Mission) have played a key role in improving the status of Roma in Finland.

#### **Roma and Health**

The health affairs of Roma have not received the same attention as education and culture. Due to the fact that there are few Roma with higher medical education, there are hardly any studies or surveys on health issues created by Roma themselves. Traditionally, Roma find hospital environments frightening and accept to be treated in hospitals only in emergency situations. The fear stems from the fact that many of us find hospital environments strange and foreign. Even today, many Roma do not use health services as much as the rest of the population, partly because of a lack of information. Some Roma tend to keep children at home, partly because mothers tend to stay home themselves. By school age the children have to be sent where? with the rest of the population which is difficult for many families.

It is only during the past 10-15 years that Romani mothers have started using the services which the Finnish state provides for childcare, but still only a small portion of Romani children attend pre-school. This fact may create an obstacle to children's progress at the beginning of their school career.

The effects of the difficult housing situation of the Roma in the 1960s and 1970s can still be seen today on the condition of our elderly and middle-aged. General diseases include (no specific data) cardiovascular diseases and pulmonary problems. On the other hand, we must keep in mind that all cultures see illnesses in a different light. In general, the Roma tend to ignore minor health problems and think of themselves healthy unless illness makes their everyday life too difficult.

An interesting point is that hospital care is regarded as a last resort. It is still part of the Romani tradition that families take care of their sick. The same applies to the elderly or the handicapped; sending them to an institution is uncommon.

It is vitally important that Roma receive enough information on how to take care of their own and their loved ones' health. For Romani women, the National Board of Education's Romani Education Unit, has arranged national health education days which are very popular. The next one will be in the fall of 2004. Even though there are no cases of discrimination in health care, the health care professionals do need topical information on ethnic groups, their cultural characteristics, and how to take them into consideration in their work.

#### Equality Legislation in Finland

During the 1970's the Finnish society finally started to accept Roma as a national minority. Since that time, the society has taken special measures to enhance the social and educational status of Roma. Support for Roma culture was provided simultaneously. A general change in attitude is visible in the national legislation: Article 5 of the Constitution that took effect in 1995 has a universal prohibition of discrimination: "No one can be treated unequally on the grounds of gender, age, origin, language, religion, conviction, opinion, health, disability or other reason relating to the person." In addition, Article 14(3) of the Constitution guarantees the right of minorities to their own culture: "The Sami as an indigenous people and the Roma and other groups have the right to maintain and develop their culture and language."

Discrimination has been criminalised since 1995 in Finland. Article 11(9) of the Criminal Code states that if a public official or servant does not treat everyone equally, regardless of their race, national or ethnic origin, skin color, language, gender, religion or other comparable reason, he/she shall be issued a fine or convicted to serve a prison term of up to six months. The Criminal Code at Article 47(3) also provides for punishment of discrimination in employment.

Despite existing anti-discrimination provisions, Finnish law does not meet the standards set by the EU equality directives. The transposition of the directives was seriously delayed and in February 2004 the European Commission opened infringement proceedings against Finland for failure to communicate actions for the transposition of the directives.

#### **Discrimination of Roma in Finland**

Roma in Finland are faced with discrimination in their everyday lives.

Early education reveals deficiencies in the training of pre-school professionals when it comes to minorities. There is no sufficient material on Romani culture.

At school, the curriculum, and the teaching material do not include enough information on Roma and their culture either. Often, the knowledge of the teachers about Roma is also inadequate, and this fact is a source of tension between them and the Romani children at school.

Furthermore, in Finland as elsewhere in Europe, Romani children have been placed in special education on insufficient grounds.

Discrimination against Roma also manifests itself in a lack of service, or restricted access, to stores and restaurants.

In employment discrimination is also present. The traditional dress of Romani women sometimes raises prejudice, which leads to double discrimination, both on the grounds of sex and ethnic origin.

Media holds a key role in promoting positive attitudes. A negative image of Roma in the media will naturally increase prejudice.

#### In conclusion

Racism and discrimination based on racial or ethnic origin is prevalent all over the world, and Finland is no exception. Tolerance and equality between the diverse ethnic groups in society need to be protected by law as well as by efforts to eliminate barriers erected between the various groups whether due to lack of information about each other, or the spread of biased information. Ethnic diversity can only enrich society.



# Reduction of Health Inequalities in the Roma Community

Publication Details		
Title:	Коsоvо's Roma: a Challenge for Public Health	
Author(s):	Marta Schaaf	
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Country:	Albania	
Language:	English	
Contact address if more information is required: (where applicable)	<i>Marta Schaaf is Program Development Associate with Doctors of the World USA</i>	
Published by:	EUMAP's web site :eumap.org	
Bibliography: <sup>(1)</sup>		

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

х	Article
	Book
	Program
	Study / Public administration report
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	Presentations or communications
	Doctoral thesis
	Other:

#### Summary (Description of the study and most relevant results):

Access to healthcare for Roma in Kosovo, as in other parts of the region, is low, but this problem is compounded by a number of factors unique to Kosovo. For a start, the Albanian-speaking Ashkalia and Egyptian groups increasingly distance themselves from Serbian-speaking Roma, in line with the general ethnic tension in the country. [1] Second, the fact of ethnic violence has engendered a fear of racial victimization among Kosovar Roma, Ashkalia and Egyptians (RAE) [2] more acute than elsewhere. Third, RAE generally live in enclaves protected by the UN, separate from the general population of Kosovo, often far from health centres.

Kosovo, a province of Serbia within the Federal Republic of Yugoslavia, [3] is currently governed

by the newly inaugurated вЪњKosovar Provisional Institutions of Self GovernmentвЪќ, with administrative support and oversight provided by the United Nations Mission in Kosovo (UNMIK), [4] and security guaranteed by the NATO-led KFOR. [5] Although Yugoslavia is unlikely to join the European Union in the near future, governments in Kosovo, Serbia proper, and Montenegro have begun to incorporate Council of Europe guidelines into ongoing reforms. [6] Some of these reforms, which include respect for the rights of minority groups, have been instituted in current EU candidate countries as part of their accession. [7] Given the importance, for Yugoslavian integration with Europe, of improving conditions for RAE, and the fact that the promotion of human rights is central to UNMIKвЪ™s mandate, better access to essential services, such as healthcare, must be high on the agenda of government and international and national organisations alike.

Many Roma in Kosovo do not travel outside of the KFOR-guarded enclaves in which they live. Further, they reside in an area essentially administered by the UN. As the UN becomes increasingly involved in government-building worldwide, UN ability to address the needs of the most vulnerable is becoming more relevant to the welfare of minorities such as the RAE, as well as to the integrity of the institutions the UN seeks to establish.

Although public health indicators for Kosovo residents are currently quite poor, figures for the RAE population, where available, point to even worse health conditions. For example, according to community reproductive health surveys conducted by Doctors Of the World (DOW), 56 percent of mothers surveyed in the RAE-inhabited Internally Displaced Persons (IDP) Camp in Plemetina gave birth at home; 12% reported losing a child in the first month after birth. For a rough comparison, the overall Kosovar вЪњperinatal mortality ratesЪk (including stillbirths and deaths under 7 days) stood at 2.82 percent in 2001. [8]

Reasons for the gaps in health conditions are manifold and difficult to isolate. Security concerns, both real and perceived, remain a primary barrier to improving the health status of the RAE population. Only some RAE enclaves have medical facilities, many of which provide only primary care for a few days a week at most. Travel outside of the enclave is therefore often necessary for healthcare access, but is not always safe. The Organization for Security and Cooperation in Europe (OSCE) recently reported вЪња gradual decrease in security incidentssЪk affecting ethnic minorities in Kosovo, but the organization also reported вЪњthe continued existence of day-to-day intimidation and harassment, as well as the occasional [BЪ¦] occurrence of extremely violent ethnically-motivated attacks.sЪk [9] These incidents include murder, threatening letters, grenade attacks, attempted rape, arson, and street abductions. Violence towards RAE has been perpetrated by both Serbian and Albanian offenders. [10]

Even in cases where RAE do not fear travelling to health facilities outside their community, they are often unable to gain access due to lack of transportation. In some RAE communities, no public transportation exists and very few families own a vehicle. In others, public transport is prohibitively expensive. Many Kosovar RAE have so little income that they cannot afford the five or six Euros necessary to travel to secondary (or in some cases, even primary) healthcare in neighbouring towns.

In addition, RAE often cannot pay for the health services themselves. Although healthcare is nominally free in many East European countries, including Kosovo, healthcare providers routinely require payment for services and accept bribes to prioritise patients. In many cases, these payments are essential to receiving healthcare services. As RAE in Kosovo are generally poorer than other minority groups and the majority population, out-of-pocket payments affect this group disproportionately. [11] Moreover, in some cases, fees are reportedly higher for RAE. The OSCE and UNHCR assessment of the situation of ethnic minorities confirms that RAE living in the Prizren region have complained of being charged high fees for both services and medicines, despite having the right to receive both free of charge. [12]

Many of those RAE who overcome security, transport, and financial barriers to access healthcare report discrimination and poor treatment once they reach a facility. Poor treatment of RAE patients on the part of providers stems in large part from the providersвъ™ perceptions of their working conditions and their work assignment. Serb providers working in the Plemetina IDP

Camp health clinic, a small primary care facility in a community served by DOW, report low morale due to working at what is regarded as a degrading post. This outlook, exacerbated by the great inadequacy of the facility itself, negatively affects the quality of care provided. In other cases, providers simply refuse to work in facilities serving RAE communities. In the winter of 2001-2002, Kosovo Serb doctors refused KFOR transportation from Mitrovica to neighbouring RAE enclaves, resulting in a discontinuation of healthcare services and distribution of medicines in those areas. [13] This reluctance or refusal to work in facilities serving the RAE populations is indicative of the discrimination RAE sometimes claim to face when accessing healthcare. [14]

The barriers to healthcare access described above are compounded by low levels of knowledge within the RAE communities regarding the importance of consulting health providers, and of other general health issues. According to community health surveys conducted by DOW, 40 percent of Ashkalia mothers in the community of Fushe Kosove did not see a doctor during their pregnancy; all but nine percent of these said they did not think it important. Seventy-five percent of sexually active women surveyed did not use any method of contraception; 79 percent of these had no information about contraceptives.

Human Rights Watch, the European Roma Rights Center, and Voice of Roma have all criticized the failure of international and national entities to make a commitment to improving the situation of RAE, including access to healthcare. UNMIK, WHO, and the newly formed Kosovar Ministry of Health (which leads health reform in Kosovo) have all failed to improve the situation significantly. For example, for much of 2001, RAE living in the UNHCR-run Plemetina IDP camp were only able to access healthcare in the nearby Obilic health centre using transport provided by the UNHCR implementing partner, the Italian Consortium of Solidarity (ICS). The health centre available to the Ashkalia population of Medvec is supposedly staffed two days a week by a physician; in fact the doctor attends the facility only sporadically. The health centre serving the Ashkalia population of Fushe Kosove is larger and thus regularly staffed, but basic equipment, including an examination table, was unavailable prior to a DOW donation. All these gaps are contrary to standards laid out in the Kosovo Health Policy. [15]

The failure of UNMIK and the new Ministry of Health to address these issues is in part enabled by the absence of an organized RAE political voice and a concomitant incapacity to seek international assistance. The RAE population is itself increasingly fragmented as different groups attempt to align themselves with either the Serbian or Albanian population. [16] In addition, RAE often lack capacity to access the international assistance provided to their Serbian or Albanian compatriots, due to having little project management experience and low levels of English proficiency. [17]

To address these issues at both provider and client levels, Doctors of the World initiated its "Minority Health Education Project". Utilizing a two-pronged approach, RAE community members are trained as Peer Health Educators (PHE) and healthcare providers are trained in the provision of culturally appropriate care. The Project also includes advocacy training and support related to healthcare access.

The Project has had considerable success in training PHEs, but has encountered obstacles in implementing training for providers. Although the RAE population has become fractured, DOW has been able to foster unified groups within and between communities. Working from the assumption that RAE are not only the target group, but also the practitioners of solutions to poor health service access, DOW has convened meetings for PHE training at which members of different communities share experience and participate in training activities together. This has fostered the formation of a cohesive but mixed (incorporating Roma, Ashkalia, and Egyptian) group of educators who have already proceeded to educate over 1,300 members of their respective communities on nutrition, hygiene, and basic reproductive health issues. PHE enthusiasm has enabled significant project expansion to occur, such as the provision of graphic art training and the formation of community-based Health Committees, in addition to enhancing planned activities such as week-long advocacy training sessions. The Project has expanded to include a youth component, which addresses the issues included in adult training, as well as sexually transmitted infections (STIs), HIV/AIDS, and life skills. DOW has been able to link up with the OSCE-initiated RAE Community Advocates Training, and has established relationships

with RAE NGOs.

PHEs have visited health facilities both inside and outside of their enclaves, and, where relevant, relayed positive experiences to fellow community members, decreasing fear of either discrimination or abuse at the hands of Albanian or Serbian providers. Although DOW has not yet conducted a mid-project impact assessment, anecdotal evidence suggests that the PHE-led trainings have improved knowledge regarding the importance of accessing healthcare. Providers in community and neighbouring facilities report that attendance of RAE at healthcare facilities has increased, and that these individuals are more actively participating in their care, asking pertinent questions and engaging providers. Health centre records support this conclusion; in one health centre accessed by Roma and Ashkalia living in a targeted community, utilization by Roma and Ashkalia increased by a factor of ten after five months of PHE-led community sessions.

A significant continuing obstacle is the unreceptive response of healthcare providers to training addressing the specific needs of the RAE population. DOW has been able to garner health facility support in providing health education to RAE, but has not succeeded in convincing Albanian or Serbian providers of the importance and necessity of improving the quality of care provided to RAE. [18] The infrequency with which most health facilities in RAE areas are staffed presents another barrier to provider training.

DOW has thus reoriented project activities to focus more on the client side, while DOW staff and PHEs continue to lobby UN and the Ministry of Health to give greater attention to the low health status and access barriers faced by the RAE population. For example, DOW PHEs successfully lobbied Lipjan municipal authorities and the health centre Director to improve attendance of health professionals at the Medvec clinic. The doctor now reliably attends two days per week. DOW continues to work with providers by involving them in discussions regarding the outstanding health needs of RAE communities, and by donating basic hygiene and examination equipment to these facilities. PHEs now work alongside doctors in the clinics and conduct health educations sessions in waiting room areas, encouraging the doctors and nurses to participate in sessions. This involvement should increase morale, and thus the support of healthcare providers for the project and their willingness to treat RAE patients.

It is discouraging that the RAE in Kosovo face such a low level of international and national commitment to improving their health access and status. Given that Kosovo is the only province in the region that is effectively governed by the United Nations, an organization founded to Bbureaffirm faith in fundamental human rights, Bbk and that the newly formed Kosovar government is effectively undergoing a trial period in terms of its treatment of resident minorities, it is imperative that UNMIK, WHO, and the respective Kosovar ministries lead the development of a multi-sectoral approach to address the barriers to healthcare access outlined above, and that these initiatives incorporate RAE populations in identifying ways to improve their own health

#### Footnotes

[1] Sani Rifati, President of the advocacy organization "Voice of Roma" and a native of Kosovo, explains that "while both the Ashkalia and the Egyptians have for some time had a separate minority identity from the rest of the Romani population in Kosovo, until the past few years, they still acknowledged to themselves and others that they were Roma." Cited in: Bloom, C. et al. *The Current Plight of Kosovo Roma*, Voice of Roma, 2002.

[2] For the sake of inclusiveness this paper uses the term RAE to cover вЪњRoma, Ashkalia and EgyptiansвЪќ, although we are cognizant of the fact that not all members of all groups would accept the appellation.

[3] On 14 March 2002, it was agreed that Yugoslavia is to be renamed "Serbia and Montenegro". At time of publication this change has not yet occurred. See here: http://www.mfa.gov.yu/Facts/agreement\_e.html.

[4] Since 1999, UNMIK has performed the whole spectrum of essential administrative functions and services in Kosovo, covering such areas as health and education, banking and finance, post and telecommunications, and law and order. See here: http://www.unmikonline.org.

[5] The Kosovo Force (KFOR) is a NATO-led international force responsible for establishing and maintaining security in Kosovo, and providing assistance to UNMIK. For more see here: http://www.nato.int/kfor.

[6] Including the European Convention for the Protection of Human Rights and Fundamental Freedoms, the Framework Convention for the Protection of National Minorities, and the European Social Charter. Yugoslavia is a вЪњSpecial Guest to the Parliamentary Assembly" of the Council of Europe.

[7] Goldston, J. A., "Roma Rights, Roma Wrongs", *Foreign Affairs*, March/April 2002, pp.146-162.

[8] World Health Organization and UNICEF. *Report of Maternity Wards Year 2001*. These two figures are not directly comparable, as perinatal mortality does not include deaths occurring between 7 and 30 days and relates to numbers of infants, rather than mothers. The gap is nevertheless instructive.

[9] OSCE /UNHCR, *Ninth Assessment of the Situation of Ethnic Minorities in Kosovo*, Pristina, Kosovo: OSCE /UNHCR, 2002.

[10] European Roma Rights Center, "Snapshots from Around Europe" in *Roma Rights*. Online here: http://www.errc.org.

[11] Makhalev, V. et al, *Qualitative Poverty Assessment Kosovo: Review of Secondary Materials*, Pristina, Kosovo: Inter-Agency Sub-Group on Poverty, 2000.

[12] OSCE /UNHCR, *Ninth Assessment of the Situation of Ethnic Minorities in Kosovo*, Pristina, Kosovo: OSCE /UNHCR, 2002.

[13] *Ibid*.

[14] One DOW peer health educator reports being told that a particular medicine was not available at a certain health centre, although boxes were clearly displayed on a nearby shelf.

[15] World Health Organization, *Interim Health Policy Guidelines for Kosovo*, Pristina, August 2000. Online here: http://www.who.int/disasters/repo/5635.doc.

[16] For example, the community leader in Fushe Kosove presented DOW with a document explaining that the Ashkalia population of that community was not related to the Roma, but was in fact descended from Persian ethnic groups.

[17] Ringold, D, *Roma and the Transition in Central and Eastern Europe: Trends and Challenges*, Washington D.C.: World Bank, 2000.

[18] In one case, UNMIK supervisors mandated that a health centre Albanian staff member attend PHE training, but she attended only a few sessions



Publication Details	
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Author(s):	Karen Plafker
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Contact address if more information is required: (where applicable)	Karen Plafker works with the Network Public Health Program at the Open Society Institute
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х	Article
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## Summary (Description of the study and most relevant results):

 The World Health Organization defines health as вЪњ a state of complete physical, mental and social well-being [вЪ\] not merely the absence of disease or infirmity [вЪ\] the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.вЪќ [1]

The Roma peoples of Central and Eastern Europe are in the unique position of suffering the worst health conditions of the industrialized world together with some of the worse health problems associated with the third world. Rates of both infectious and non-communicable

diseases are high. [2] The proportion of Roma living in poverty exceeds 75% in countries throughout the region. [3] Unemployment is also high, with reports of total unemployment in certain Roma areas. [4] Access to preventive and curative healthcare services is low. [5]

Perhaps most disturbingly, the health status of Roma is consistently worse than that of populations as a whole. [6] The fact that there is a disparity between Roma and majority communities in virtually every health indicator is not in dispute, nor is the fact that Roma are invariably on the wrong side of that gap. But debate continues on the causes of this gap and the steps that should be taken to close it.

**Obstacles to promoting Roma health** 

Efforts to promote the health of Roma populations often fail to confront the social structures which shape health in the first place: inequity and discrimination in education, employment, and housing; poor access to clean water and sanitation; lack of social integration; minimal political participation; poor access to food; disparities in income distribution; etc. [7] In better cases, this results in well-intentioned, charitable health programs which offer no systemic or sustainable change. In the worst cases, the health needs of Roma communities are deliberately ignored, efforts are focused on the majority populations b™s fears about infectious disease and fertility, [8] or the Roma are simply blamed for their predicament.

The gaps in health status between Roma and majority populations reflect  $B\overline{D}^{\text{"}}$  and are compounded by  $B\overline{D}^{\text{"}}$  official discrimination and marginalization of Roma throughout the countries of Central and Eastern Europe. The conventional wisdom that lifestyle explains the health status of Roma communities fails to take into account the social structures which determine health and create the context in which these lifestyles are taught and learned.

- Official and popular misconceptions about the determinants of health.
- To date, much of the national and local-level discussion about the relatively poor health of Roma has focused on a perceived lack of health data and on the poor health behaviour of the Roma. To acknowledge the underlying causes of ill health and inequitable health status within national populations would require acknowledging the inequity inherent in existing political and economic structures that result in the inequitable distribution of resources. Refusal to challenge the status quo fuels the limited understanding among politicians, policymakers and the general public of the broad social influences which shape the health of all, including the Roma. This is virtually a defining characteristic of official responses to minority health in the developed world.

Compounding this situation are challenges specific to national governments and Roma communities in Central and Eastern Europe:

- Weak civil society advocacy skills in Central and Eastern Europe.
- Civil society skills in promoting health are limited, a fact reflected by the relatively small number of NGOs, Roma or non-Roma, working specifically on health and their limited experience in effecting change in health. Health rights and conceptual frameworks which understand health as a social product B<sup>-</sup>b<sup>-</sup> as something more than just sickness and medicine B<sup>-</sup>b<sup>-</sup> are not widely shared. In addition, there are few alliances among Roma NGOs, or between Roma groups and non-Roma groups concerned with social justice, which might facilitate an alternative vision of health.
- Citizenship issues and fear of repression.
- Meanwhile, the citizenship of many Roma remains unresolved in many countries. This
  has left many people in Roma communities without some of the basic tools of citizenship
  and political participation, including voting and standing for political office. The lack of

documents also raises specific concerns about the ability of Roma to access health services directly or to secure the insurance or social security documents they need to utilize services. While only a small proportion of what we understand as "health" is attributable to utilization of health services, lack of access to services is the proverbial "canary in a coal mine," a warning sign and, in this case, concrete evidence of the wider discrimination which permeates every aspect of life in many Roma communities. Meanwhile, efforts to secure documents receive a mixed response from Roma communities, including the fear that registering with authorities creates the opportunity for government repression.

- Inadequate public response to minority health issues.
- Inadequate official action has virtually created the poor health conditions in which Roma live. Yet there is still an absence of both political will and popular support for needed policy, infrastructure and programmatic change. For example, there are numerous reports of racism on the part of health providers towards Roma. But remedy is available neither in the courts, in the training framework for healthcare providers, nor through any other mechanism. In fact, there is an almost-complete lack of structures for protecting and promoting health-related rights, such as codes of ethics for health professionals, patientsb™ rights charters, complaints mechanisms of any kind, or ombudsman offices concerned with health rights.
- Policies discriminate directly against Roma or affect them disproportionately even as states present them under the guise of other objectives. Examples include fees for documents needed to access health services, or health insurance schemes covering up to three children only. This signals how little contact there is between government and Roma communities and illustrates the lack of Roma participation in government and in healthcare delivery systems.

We may be underestimating the existing opportunities to challenge this reality and place responsibility for disparities in health between Roma and others squarely at the door of government policy and practice. Responses are needed which re-shape the terms of the causality debate and integrate health into the broader rights-based Roma political, social and economic justice agenda.

## **Opportunities to promote Roma health**

It is time to move beyond frameworks which focus exclusively on individual responsibility, and instead claim the rightful place of Roma health within the broader struggle for human rights and full economic, social and political participation.

There *are* opportunities for change. First of all, there is interest in health issues at the community level: Roma women leaders often cite health  $B\bar{D}$ " along with education  $B\bar{D}$ " as a top community priority. And there is a growing community of Roma rights organisations. While many of these do not work on health as yet, they may be encouraged to integrate health into their advocacy agenda and to use health data as evidence of discrimination in other areas of public life, including employment, education and delivery of public services, including health care.

Second, although decisions about European Union enlargement often seem to be a foregone conclusion, the EU accession process still offers opportunities to influence official Roma health policies and practice. The EUMAP monitoring project, of which this website is part, is one example of monitoring government compliance with the political criteria for EU membership. The вЪњRoma strategies,вЪќ which were prepared by the accession country governments as part of the accession process and which make explicit governmentsвЪ™ commitments to promote Roma rights in all spheres, offer another opportunity for NGO monitoring and advocacy.

Finally, the international human rights system provides plenty of space for advocating Roma rights to health. The International Covenant on Economic, Social and Cultural Rights (ICESCR)

guarantees the right to health, specifically "the highest attainable standard of physical and mental health," [9] and other human rights instruments contain additional guarantees related to health. [10] What this language actually means and, therefore, what states can be held accountable for continues to evolve. For example, in a General Comment issued in 2000, the UN's Committee on Economic, Social and Cultural Rights noted that:

 $B\bar{D}_{B}B\bar{D}$  the highest attainable standard of physical and mental health $B\bar{D}^{M}$  is not confined to the right to health care. On the contrary, the drafting history and the express wording of article 12.2 [of the ICESCR] acknowledge that the right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and health working conditions, and a healthy environment. $B\bar{D}\kappa$  [11]

In other words, despite some lack of clarity about the вЪњcontentвЪќ of the right to health, there is recognition at the international level that health cannot be described or improved in isolation.

The UN treaty monitoring bodies are increasingly interested in health and the ways in which human rights and health intersect. Some have guidelines on health for use by states parties during the reporting process, or in seeking input from non-state parties  $B\overline{b}^{\mu}$  intergovernmental and non-governmental organisations  $B\overline{b}^{\mu}$  to complement state reports. The  $B\overline{b}$ -bshadow reportse $\overline{b}$  in reproductive health prepared by NGOs for submission to the Committee on the Elimination of Discrimination Against Women (CEDAW) [12] is one example of advocates using the international human rights machinery to advance the right to health, up to and including health care. These efforts should be encouraged and relationships fostered between the treaty-monitoring bodies and Roma NGOs.

Litigating claims of discrimination in the right to health is another mechanism for advancing Roma health. A pilot initiative is underway in one Central European country to assess how antidiscrimination litigation at the national level can contribute to social change around Roma health. Bringing claims to the regional or international human rights commissions remains underexplored

A reconceptualisation of the determinants of health suggests new ways to respond to the disparities between the health status of Roma and majority populations. Defining health as more than disease makes it possible to integrate health into wider Roma rights agendas. Simultaneously, understanding health as a human right opens the door to using enforcement mechanisms related to national, regional and international law to advance Roma health.

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Footnotes

[1] Constitution of the World Health Organization (WHO). The Constitution was adopted by the International Health Conference, New York, 19 Junes 5"22 July 1946, signed on 22 July 1946 by the representatives of 61 States (*Off. Rec. Wld Hlth Org.*, 2, 100), and entered into force 7 April 1948.

[2] Hajioff, S. and McKee, M., "The health of the Roma people: a review of the published literature", 54 *Journal of Epidemiology and Community Health* 864-9 (2000).

[3] Ringold, D, *Roma and the Transition in Central and Eastern Europe: Trends and Challenges*, Washington, DC: The World Bank, 2000, pp 10-12.

[4] *Ibid*., p. 14.

[5] Zoon, I. On the Margins: Roma and Public Services in Romania, Bulgaria, and Macedonia,

New York: Open Society Institute, 2001; Zoon, I. On the Margins: Roma and Public Services in Slovakia, New York: Open Society Institute, 2001.

[6] Ringold, p. 20.

[7] See, e.g., Marmot, M. and Wilkinson, R.G. (eds.) *Social Determinants of Health*, Oxford: Oxford University Press, 1999; Berkman, L.F. and Kawachi, I. (eds.) *Social Epidemiology*, Oxford: Oxford University Press, 2000.

[8] Hajioff and McKee; Koupilova, I., Epstein, H., Holcik, J., Hajioff, S., McKee, M., "Health needs of the Roma population in the Czech and Slovak Republics", 53 Social Science & *Medicine* 1191-1204 (2001).

[9] ICESCR, Article 12.

[10] International Convention on the Elimination of All Forms of Racial Discrimination (Article 5); International Convention on the Elimination of All Forms of Discrimination Against Women (Articles 10, 12, 16).

[11] Committee on Economic, Social and Cultural Rights, General Comment 14, UN ESCOR, 2000, Doc. No. E/C.12/2000/4.

[12] See, e.g., Center for Reproductive Law and Policy (CRLP), in collaboration with Be Active, Be Emancipated (B.a.B.e.), *Womenb*<sup>™</sup>*s Reproductive Rights in Croatia: A Shadow Report*, 2001. Online here: http://www.crlp.org/pdf/sr\_croatia\_0301\_eng.pdf . See also Center for Reproductive Law and Policy (CRLP) and the Family Planning and Sexual Health Association, Vilnius, Lithuania, *Womenb*<sup>™</sup>*s Reproductive Rights in Lithuania: A Shadow Report, 2000*. Online here: http://www.crlp.org/pdf/sr\_lith\_0600\_eng.pdf.



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Summary (Description of the study and most relevant results):

The poor health status of Roma [1] generally and the inadequate access to healthcare experienced by many Romani communities across Europe require urgent attention and action. [2] The links between good health and overall welfare, including improved living conditions, employment and other opportunities, are well established. For Roma, the effects of inadequate healthcare often impact disproportionately on *women*, who frequently bear principal responsibility for family healthcare and provide the point of contact between Romani communities and public health services. Romani women are often overlooked in policies devised on behalf of Roma. Improving access to healthcare for Romani women is therefore integral to improving the health and overall welfare of entire Romani communities; greater attention should

be given to their social, economic and political integration.

These issues are particularly pressing in those post-communist societies which have shifted towards privatisation of public services and the promotion of a free market economy. Several countries are in the process of reforming their healthcare systems. In this climate, care is required to ensure that the most disadvantaged and vulnerable in society are given the same opportunities in these developments as other members of the population. They must not be allowed slip through the net of social protection. At the same time, exclusion of Roma women from adequate healthcare provision remains a pressing issue in Western Europe too, where barriers to accessing healthcare also exist. As in Central and Eastern Europe, the underlying causes go deeper and are often ingrained in prejudice and discrimination.

The development of targeted and effective policies aimed at overcoming the effects of discrimination in relation to access to healthcare for Roma, and particularly Roma women, is a necessary precondition for improving the overall situation of Roma throughout Europe. For moral and practical reasons it is in the public interest that the good health of everyone, including members of minority populations, is assured.

In response to these concerns, a number of inter-governmental organizations have cooperated in a research initiative with a view to contributing analysis and policy options to states for improved access to public healthcare for Roma women and their communities throughout Europe. [3] While the conclusions and recommendations have yet to be finalized, some preliminary findings are described in this article. The forthcoming report will include examples of good practice in the areas discussed below, for consideration as working models for other States or communities to adopt.

#### 1. Discrimination in Accessing Healthcare

The physical, economic and information-based barriers to healthcare that many Roma confront result from complex and inter-related effects of poverty, discrimination, and unfamiliarity with government institutions generally, and healthcare services in particular. The forms of discrimination that Roma experience are multifarious, depending on a variety of factors including whether a community is urban or geographically isolated or whether Roma populations are sedentary or nomadic.

Roma may experience direct discrimination in, for example, the refusal of physicians or healthcare institutions to treat them. They may be the targets of verbal abuse and degrading treatment in the course of seeking care. Roma may be separated from other patients on the basis of ethnicity. Such events may be isolated BD<sup>#</sup> the result of one individual  $BD^{MS}$  prejudice BD<sup>#</sup> or widespread and systemic. Given that women are more likely than men to interact with the health services, Romani women are disproportionately affected by these incidents.

Indirect discrimination occurs when apparently neutral legislation, regulation, policy or practice, impacts negatively and disproportionately on a particular group. [4] In the context of access to healthcare, indirect discrimination may result from policies that overlook the needs of minority populations, for instance, in determining the location of clinics. Health research may fail to examine the needs of rural women or of migrant communities. Health information may not be available in a language or manner accessible to Romani women. Criteria for social benefits that limit the number of children for whom assistance is available may exclude a disproportionate number of Roma, who tend to have larger families. Such legislation, policies and practice may perpetuate inequalities and must be prohibited in order to achieve change. [5]

Various socio-cultural and psychological factors may compound these difficulties and discourage Romani women from paying attention to their own health. A poor understanding of the value of preventive screenings combined with the desire to forego attention to personal well-being in the interest of attending to family care may cause Roma women to regard health services as generally inapplicable or unavailable to themselves. In turn, certain traditions associated with religious beliefs, purity practices, and maintaining family honour through vigilance over a daughterB<sup>™</sup>s virginity may be a source of pressure on women to conceal their interest in and efforts to obtain reproductive or sexual healthcare. These practices may result in increased health risks for women, especially adolescents, who may not have the opportunity to learn about warning signs of reproductive and other health problems. In some cases, unequal gender dynamics within Romani communities may impede access to care in a manner that may constitute gender discrimination.

## 2. Human Rights Principles

## 2.1 Non-discrimination and equality

Poor health status and inadequate access to care manifest themselves variously in different countries and conditions. While solutions must be tailored to specific needs, the underlying public policy considerations remain the same: ensuring access for Roma, including women, on an equal basis with members of the majority population. This follows from the principles of non-discrimination and equality enshrined in international human rights standards which call for everyone to enjoy equality of opportunity in all areas of public and private life, without discrimination on the basis of race, ethnicity or national origin. [6] Discrimination on grounds of gender is likewise prohibited. [7]

Whatever the form of discrimination, its function as an impediment to accessing adequate healthcare requires a response from the state. Under international law, states have an obligation to combat all forms of discrimination and to provide effective remedy and appropriate sanctions where such discrimination exists. Specifically, under the European UnionBTMS BBtheRace Equality DirectiveBBk [8] BT which will enter into force in July 2003 and with which EU candidate states must also comply BT states are required to *act* to combat discrimination, direct or indirect, on the grounds of racial or ethnic origin, in both the public and private sectors, and including in public healthcare bodies. [9] To this end they are required to abolish laws, regulations and administrative provisions contrary to the principle of equal treatment, ensure the implementation of effective proportionate and dissuasive sanctions, and adopt relevant laws specifically to implement the Directive. [10]

## 2.2 Positive action and special measures

A human rights approach highlights the need for equality, both formally and substantively. Thus, states are required not only to protect against discrimination, but to take positive action in order to ensure the equal enjoyment of rights. [11] Specifically in relation to health, states have a duty to facilitate the enjoyment of the BThehighest attainable standard of physical and mental healthbTk on an equitable basis. [12] They must ensure that minimum standards are respected with regard to the basic health needs. [13] These standards include, *inter alia*, ensuring equitable distribution of and the right of access to health facilities, goods and services on a non-discriminatory basis, especially for marginalized groups. [14]

State responsibility derives from the positive obligation to ensure equal access for all groups within society, regardless of their ethnic or cultural background and specific associated barriers. Under the ICCPR, states parties are obliged to ensure that BЂњtraditional, historical, religious or cultural attitudes are not used to justify violations of womenBЂ™s right to equality before the law and to equal enjoyment of all Covenant rightsBЂќ. [15] And under CEDAW, states parties agree to take BЂњall appropriate measures to modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women.BЂќ [16]

The enjoyment of rights and freedoms on an equal footing, however, does not mean identical treatment in every instance. [17] Indeed, the principle of equality sometimes requires states to take affirmative action in order to ensure equal opportunities to groups who have been historically and systematically disadvantaged and where the consequent conditions prevent or impair their enjoyment of human rights. In such cases, positive measures may be required to diminish or eliminate conditions which cause or help to perpetuate discrimination and so redress

the imbalance. [18]

An important complement to special measures on behalf of Roma is awareness-raising among the wider population that such measures, including preferential treatment in specific cases, serve not to place Roma women in an advantageous position, but to level the playing field. Acknowledgment of the extent to which discrimination is a cause of existing inequalities should be clear. In light of these obligations, states should take steps to understand the unique dimensions of Romani culture(s) regarding health, with the goal of providing effective interventions to achieve equality of access to care. Consideration might be given to ways in which the provision of information and services can empower Romani women to make independent and informed choices about health and related aspects of their lives.

2.3 Participation in policy-making

The basic democratic principle of participation is one that should underpin all public policymaking processes. [19] Experience shows that design, implementation and monitoring of policies with the active participation of those most affected stand the best chance of success. In the context of Romani womeneb™s health, the U.N. Committee on the Elimination of Racial Discrimination is clear: states should initiate and implement programmes and projects in the field of health for Roma, particularly women and children, and involve them in designing and implementing those programmes. [20]

In order to achieve the most comprehensive and effective outcomes, it is important that states involve Romani women in developing policies and programmes on behalf of Roma. More generally, states should mainstream gender issues and the incorporation of a gender perspective to public policy making, e.g. give adequate consideration to the biological and socio-cultural factors BЪ" including menBЪ™s behaviour BЪ" that impact upon health. [21]

Greater attention should also be paid to informing Roma women about public health services and how to utilize them, as well as specific preventative issues such as immunization, nutrition, and the harmful effects of tobacco use. This information will enhance womenвЪ™s capacity to organise themselves, assist others and mediate between their own communities and healthcare providers.

Improving access to public healthcare for Roma women depends upon the development of trust and mutual respect between Roma and non-Roma. In this respect, positive examples exist of ways to narrow the gap between health institutions and Roma communities, by means of  $B\bar{D}$ -bhealth mediators  $B\bar{D}$ . A mediator system serves to improve access to healthcare institutions by facilitating the exchange of information  $B\bar{D}$ " and hence understanding and interaction  $B\bar{D}$ " among Romani communities, healthcare workers and authorities. Insofar as most mediators tend to be women, some important by-products of this institution for women include: employment; the acquisition of negotiation skills; the assumption of a key role in assisting communities to combat stereotypes of Roma; and influence over the process of balancing integration with diverse aspects of Romani culture. While mediator programmes are not a cureall for the often-great disparities between majority and Roma health status and access to services, states might consider support for training and institutionalisation of mediators as an important force for systematic change.

- 3. A multi-sectoral approach to improving access to healthcare
- 3.1 Education and health

Prerequisites to caring for oneB<sup>™</sup>s physical and mental well-being include some knowledge of what that well-being entails as well as access to the means of achieving it. Schools are a key source of information on hygiene, nutrition, disease prevention and access to the health system B<sup>™</sup> whether through education, access to school nurses, vaccinations, etc. When Romani children have difficulties in accessing education, they are less likely to acquire the tools with which to take control over their own health and other life choices. Romani girls may face

additional difficulties in accessing education if they are withdrawn from schools by their parents to protect their virginity, prepare for marriage, or assume household duties. These girls may not acquire the literacy and critical thinking skills to care for themselves and their families, as well as to modify cultural practices which adversely impact their well-being.

It is essential that policy-makers are receptive, sensitive, and sufficiently imaginative to approach problems from fresh perspectives, particularly where matters of culture are at issue. In the context of education, states should facilitate attendance at all levels, but particularly in kindergarten programmes, in order to give Roma children a good start in the education process. States may also consider education policies such as home learning to fill the gaps in Romani girlsb™ education.

### 3.2 Housing and health

Poor living conditions, problems securing a permanent domicile, and a lack of services appropriate to isolated communities, nomadic communities, or caravan dwellers can all impact negatively on access to healthcare. As the primary users and maintainers of housing  $B\bar{b}^{\text{c}}$  often the locus of their employment, child-care, and social interaction  $B\bar{b}^{\text{c}}$  adequate housing constitutes a primary stake for Romani women. Unfortunately, many Roma are forced to live in conditions that pose health and safety hazards  $B\bar{b}^{\text{c}}$  whether due to a lack of affordable dwellings or as a consequence of discrimination and harassment in other locales. For Roma living in rural settlements or caravan sites, the isolation and possible stigma are sources of economic, physical and psychological hardship. Public services are not easily accessible; healthcare and other service providers may intentionally or inadvertently avoid these communities. Mobile clinics and other creative programmes may be required to fill the gaps in mainstream services for Roma in these situations.

Where permanent residence is required to access public services, Roma may be disadvantaged by the improper discretion of authorities in providing such documentation, or by laws or policies that provide for legal caravan sites in a manner that does not satisfy their needs. Measures should be taken to facilitate registration as permanent residents, and to provide access to healthcare in the interim for persons living in unstable conditions.

It is widely recognized that vulnerable groups such as women, children, and ethnic minorities suffer disproportionately as victims of forced evictions. Roma communities may be unfamiliar with laws and regulations governing housing and evictions, and might seek to avoid interaction with local authorities, given the often precarious conditions in which many of them live.

Evictions impact on health in a variety of ways, both psychological and physical. Typical consequences include trauma; stress due to protecting families from anxiety and violence; separation from support networks; exposure to vigilante attacks; disruption of daily living and childcare routines; health risks from unsuitable or dangerous emergency stopping places; and loss of access to healthcare services. [22] States should take measures to minimize the impact of evictions on access to health, education and social services. When those affected are unable to provide for themselves, states must BЪH adequate alternative housing, resettlement or access to productive land, as the case may be, is available.BЪK [23]

#### 3.3. Statelessness, lack of documentation, and health

Problems of statelessness, registration and a lack of appropriate documentation affect access to services in all areas of public life, including health services. [24] Many Roma, particularly those in countries facing crisis and post-crisis situations lack basic documents such as birth certificates, identity documents or those specifically related to health insurance. Likewise, many live in illegal settlements or lack legal title to their place of residence, further compounding problems in accessing healthcare. Statelessness, and consequent lack of status within the state of residence, as well as problems with documentation etc., must not be allowed to impede access to rights. In this regard, states need to be proactive in efforts to ensure that Roma have

all necessary documentation for accessing health services, e.g. by providing information about accessing information documents, facilitating birth registration and reducing the costs of registration procedures for those on low incomes. In the interim, access to health information and basic mainstream health services should be assured for those without documentation.

## 3.4 Social benefits and health

Access to social protection includes access to non-contributory health insurance and other health-related benefits. Many Roma lack access to information about social benefits, and may be unaware that access to a doctor often depends on registration with an unemployment office as proof of entitlement to care. Eligibility criteria such as civil marriage may have a disparate impact on Roma; abuse of social worker discretion in determining eligibility for benefits may further impede access. Economic barriers range from the sometimes high cost of identity documents, such as birth certificates or proofs of civil marriage, to unaffordable transport costs or the means to visit unemployment offices periodically to retain eligibility.

Forced mobility and forced stopping have been found to have extremely adverse impacts on access to social services through a combination of instability, stress, discrimination, and lack of information. Roma who follow semi-nomadic or nomadic lifestyles often face a *de facto* loss of access to social benefits, since payments are normally made to a permanent residence. As with medical records, client-held social benefits records or other non-territory based systems might be explored to avoid loss of these entitlements.

### 4. Some policy-making guidelines

### 4.1. Statistics and ethnic data

Statistical data on the ethnic composition of populations is an important tool for establishing the nature and extent of discrimination in access to healthcare. Reliable data is essential both for ascertaining the full health status of Romani populations and (together with good analysis) for the design of appropriate targeted policies in response to identified needs. More generally, states have a responsibility to assess the impact of health service reforms on various ethnic groups, including Roma. There exists surprisingly little information on Roma women, and on their health situation in particular. This is partly because wider research may intentionally or inadvertently ignore the situation of Roma health (for example, by relying on household-based studies which effectively exclude itinerant groups) or womenbb™s health. The problem is further compounded by the sensitive nature of the collection and (mis)use of ethnic data. There is, nevertheless, increasing recognition among Roma and non-Roma alike of the importance of data collection to sound policy development. In this respect, anonymous data collection, properly disaggregated on the basis of ethnicity and sex, along with legal regulation and political commitment should provide adequate safeguards against the abuse of existing or newly-collected data. [25]

#### 4.2. National programmes

It is important that measures aimed at improving the health of Roma are not treated as isolated issues (so serving to reinforce the divide between Roma and non-Roma), but are mainstreamed into general health policies. Moreover, coherence and coordination in all aspects of policy-making is required in order to reflect the needs of the entire Romani population. Thus, public policies for Roma should be formulated with the input of Romani women and incorporate a gender component. [26] This requirement extends not only to womenBЪ™s health issues but to all aspects of Roma integration plans. Likewise, state gender equality programmes should incorporate a minorities component. [27] Indeed, states might consider appointing a minority gender adviser to oversee these processes.

## 4.3 Equal treatment bodies

The implementation and effectiveness of anti-discrimination legislation can be further guaranteed

through the establishment of bodies for the promotion of equal treatment (including ombudsmen, advisory boards etc.). Specific institutional mechanisms aimed at addressing the concerns of the Roma population can also be established. [28] Measures should be taken to ensure that Roma women have meaningful input in and access to such bodies.

### 4.4. Monitoring at all levels of governance

The development and effective implementation and monitoring of programmes at all levels is required, particularly where implementation of national strategies relies on local authorities. This is especially important in the context of primary healthcare, which is primarily a local phenomenon. [29] In this respect, transparency in public administration is key. States should use all available instruments to ensure systematic legal control of decisions by authorities involved in Roma-integration plans. Emphasis should be placed on eliminating the initiation or tolerance of discriminatory practices by local authorities.

## Conclusion

Closer examination of the specific ways in which discrimination affects Roma, particularly women, in the context of healthcare has begun to attract attention at the intergovernmental, national and local levels. At the same time, greater attention to Roma women is helping to ensure that their specific needs and interests will form an integral part of policies elaborated on behalf of Roma. The intergovernmental initiative described above will expand upon the guidelines described here, as well as present good practices as a basis for governments and civil society to build better access to healthcare for Roma women and their communities along the principles of equality and non-discrimination.

The views expressed in this article are those of the authors and are not necessarily shared by the Council of Europe, High Commissioner, the OSCE, or EUMC.

Footnotes

[1] The term вЪњRomaвЪќ is used here to refer to ethnic groups who identify themselves as вЪњRomaniвЪќ or those, such as Gypsies and Travellers in the United Kingdom, Ireland and elsewhere, who share similar aspects of culture and history, and who confront similar issues of discrimination and social exclusion.

[2] See, OSCE High Commissioner on National Minorities, "Тhe Situation of Roma and Sinti in the OSCE Region", The Hague: April 2000, which identified inadequate healthcare as one of two principles elements of generally poor living conditions suffered by Romani communities.

[3] This process is a joint initiative of the Council of EuropeB<sup>™</sup>s Migration and Roma/Gypsies Department, the European UnionB<sup>™</sup>s Monitoring Centre on Racism and Xenophobia (EUMC) and the Organization for Security and Cooperation in EuropeB<sup>™</sup>s High Commissioner on National Minorities (HCNM) and Office for Democratic Institutions and Human Rights (ODIHR). A report on the findings of this research, conducted in 15 European countries, is scheduled for finalisation in late 2002.

[4] See, Committee on the Elimination of all Forms of Racial Discrimination, General Recommendation 14 on definition of discrimination, UN Doc. A/48/18, 22 March 1993, para. 2: вънля seeking to determine whether an action has an effect contrary to the Convention, [the Committee] will look to see whether that action has an unjustifiable disparate impact on the group distinguished by race, colour, descent or national originвъќ.

[5] Theodor Meron (ed.), *Human Rights Law-Making in the United Nations*, (New York: Oxford University Press) 1986, at p. 60.

[6] The prohibition of discrimination is typically a feature of all major human rights conventions and is further elaborated in specialized treaties such as the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD); Council of Europe Framework Convention for the Protection of National Minorities (Framework Convention), and the OSCE Document of the Copenhagen Meeting of the Conference on the Human Dimension of the CSCE, 1990 (Copenhagen Document).

[7] For provisions on equality of the sexes, see, inter alia: the International Covenant on Civil and Political Rights (ICCPR); the International Covenant on Economic, Social and Cultural Rights (ICESCR); the Universal Declaration of Human Rights (UDHR); the European Convention on Human Rights and Fundamental Freedoms (ECHR). See also, the International Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

[8] Council Directive 2000/43 of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin, Official Journal .L 180, 19/07/2000 pp.0022 - 0026.

[9] Ibid., para. 12, Article 3 (1)e, and Article 5.

[10] Ibid., Articles 14 - 16. It is noteworthy that OSCE participating states have also committed themselves, in the Istanbul Summit Declaration, para. 31, to  $B\bar{D}HB\bar{D}_1^1$  ensure that laws and policies fully respect the rights of Roma and Sinti and, where necessary, to promote anti-discrimination legislation to this effect  $B\bar{D}k$ .

[11] See, Human Rights Committee (HRC) General Comment No. 4 on equality between the sexes, Article 2; HRC General Comment No. 18 on non-discrimination, para. 5. The full text of all general comments by UN treaty committees up to April 2001 is given in UN doc. HRI/GEN/1/Rev.5, 26 April 2001, online here: http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/HRI.GEN.1.Rev.5.En?OpenDocument .

[12] See, ICESCR (to which all EU member and accession states, with the exception of Turkey, are party), Article 12(1); and the Convention on the Rights of the Child, Article 24(1). In addition, the (revised) 1996 European Social Charter binds States Parties to guarantee rights to *inter alia* social security and social and medical assistance, without discrimination on medical ground. See, Articles 12, 13 and E.

[13] See, the Committee on Economic, Social and Cultural Rights (CESC), General Comment 14 on the right to the highest attainable standard of health, particularly para. 12 outlining dimensions of accessibility, based on the principle of non-discrimination. See, also, CEDAW, Article 12, which provides that: вЪњStates Parties shall take all appropriate measures to eliminate discrimination against women in the field of healthcare in order to ensure, on a basis of equality of men and women, access to healthcare services, including those related to family planning.вЪќ

[14] CESC General Comment 14, *Ibid.*, para. 43.

[15] HRC, General Comment 28, para. 3.

[16] CEDAW Article 5(a).

[17] See, for example, HRC General Comment No. 18, para. 8.

[18] *Ibid.*, para. 10.

[19] See, in particular, CEDAW, Article 7; and Article 3 of the ICCPR, whereby States Parties undertake to ensure to men and women equally the rights recognized in the Covenant, including the right to take part in public affairs, directly or through chosen representatives, as enshrined in Article 25. The Framework Convention, in Article 15, requires States Parties to вЪњсreate the conditions for the effective participation of national minorities in public affairs affecting themвЪќ.

Paragraph 25 of the Copenhagen Document similarly protects the right of persons belonging to national minorities to effective participation in public affairs.

On minority participation generally see, the *Lund Recommendations on the Effective Participation of National Minorities in Public Life* which were elaborated in September 1999 by independent experts upon request of the OSCE HCNM; for the full text of the Lund Recommendations, *see Helsinki Monitor*, Vol. 11(2000), No. 4, pp. 45-61. See also, the European Roma Rights Center Pamphlet *Political Participation and Democracy in Europe: A Short Guide for Romani Activists* (Budapest: December 2001).

[20] CERD Committee, General Recommendation 27 on Discrimination against Roma (Fifty-Seventh Session, 2000), U.N. Doc. A/55/18, annex V, 16 August 2000, para. 34.

[21] See, CEDAW Committee, General Recommendation No. 23 on Political and Public Life. See also CESCR General Comment 14, Para. 20.

[22] Cemlyn, S., "Traveller Children's Right to be Treated with Common Humanity," *Childright*, Nov 1995, No. 121, p5.

[23] See Committee on Economic, Social and Cultural Rights, General Comment No. 7: The Right to Adequate Housing (Art. 11.1): Forced Evictions: E/C.12/1997/4, para 16.

[24] In this connection, the European Roma Rights Centre has sponsored a conference on вЪњPersonal Documents and Threats to the Exercise of Fundamental Rights among Roma in the Former YugoslaviaвЪќ, from 6-8 September in Igalo, Montenegro.

[25] See, OSCE Conference on Equality of Opportunities for Roma and Sinti: Translating Words into Facts, Bucharest, 10-13 September 2001, Summary of the Working Group RapporteurвЪ™s Reports and Recommendations, p.3. See also: Project on Ethnic Relations, Report on the Roundtable вЪњRoma and StatisticsвЪќ, Strasbourg, France, 22-23 May 2000; and Krizsan, A. (ed.) *Ethnic Monitoring and Data Protection: the European Context*, CPS Books: Central European University Press: 2001.

[26] The CEDAW Committee promotes the mainstreaming of gender issues and contribution of a gender perspective to public policy-making at national and international levels. See, CEDAW Committee, General Recommendation No. 23 on Political and Public Life.

[27] Bitu, N., Presentation on "Living Conditions", Seminar on Roma in the OSCE Area, 14-15 June 2000, Bratislava, The Hague: October 2000.

[28] The Race Directive, in para. 24 and Article 13, requires the establishment of such bodies with competence to analyse problems, study possible solutions and provide concrete assistance for victims.

[29] Primary healthcare is essential healthcare based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation [BTb] It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. Declaration of Alma-Ata, International Conference on Primary Healthcare, Alma-Ata, USSR, 6-12 September 1978, Para. VI. Online here: http://www.who.int/hpr/archive/docs/almaata.html



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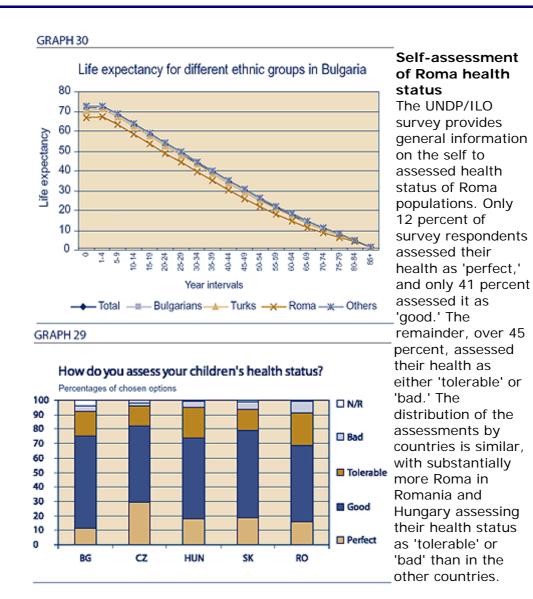
Х	Article
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	Presentations or communications
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## Chapter 6: Health status and trends

The task of monitoring the health status of Roma populations is another area that is negatively impacted by the lack of statistical data, which are disaggregated by ethnicity. At the same time, health aspects are at the core of MDGs 4, 5, and 6.<sup>107</sup> There is much evidence that life expectancy, infant mortality, morbidity, and other major health indicators are substantially worse for Roma than for majority populations in CEE countries. This chapter analyses these problems on the basis of the data produced by the UNDP/ILO survey.

Due to the constraints of the survey,<sup>108</sup> its objectives regarding health issues were rather modest and limited to the self-assessment of the respondents. Another important area investigated was the inclusion in health insurance systems.



Only 18 percent of the Roma think that their children are in perfect health, but 57 percent claim that their children are in good health. As shown in Graph 29, the distribution of these responses by countries is more even, with only Bulgaria showing a slightly lower share of parents assessing their children's status as 'perfect.' But the high morbidity and infant mortality rates reported for Roma children suggest that such optimistic assessments are less a reflection of reality than of low levels of parental health awareness.

Life expectancy is a good proxy for quality of life and for the impact of morbidity levels. Comparisons of life expectancy levels calculated for different ethnic groups at different ages (i.e., the probable number of years that representatives of different ethnic groups and different ages will live) can be very revealing in this respect. Graph 30 summarizes these data for Bulgaria.<sup>109</sup> As seen from the graph, life expectancy of Roma is on average 5 to 6 years lower than for other ethnic groups (for example, the life expectancy at birth for Roma is 66.6, while for ethnic Bulgarians it is 72.3).

The most common chronic diseases reported by Roma are cardiovascular and respiratory ailments, tuberculosis, renal, gastric, enteric, and liver diseases. Neurological and psychiatric diseases, gynecological disorders, and carcinomas are more frequently encountered among Roma than in majority populations, but the persons afflicted by these misfortunes do not always report them. Reference here is to reported diseases, and since these data are not desegregated by ethnicity, monitoring their incidence can be difficult. Infectious and parasitic diseases that are rarely found among majority population are often observed among Roma children. Another big danger is the spread of viral meningitis.

#### Children?s and women?s health status

Roma children are a special risk group in terms of health. Infant mortality data are scarce due to the lack of consistent monitoring by ethnic groups. Still, various, albeit fragmentary, data show large discrepancies between majority and Roma populations. Table 11 presents infant mortality by ethnic groups for Romania in 1999. These data suggest that Roma child mortality rates are 3 to 4 times higher than those for the majority population or other ethnic groups. In the Czech Republic, Slovak Republic, and Hungary, Roma infant mortality rates are roughly double the national averages.<sup>110</sup> In the Czech Republic, Roma children represented 3 percent of all live births and accounted for 5 percent of infant deaths; in Slovak Republic, these figures were 8 percent and 18 percent, respectively.<sup>111</sup> The situation in Bulgaria is even worse: in 1989, the infant mortality rate for Roma children was 240 per 1000, compared to the national average of 40.<sup>112</sup> These figures contrast dramatically with the average infant mortality rates for the five countries (Tables B10 and B11, Annex 3) and are probably among the strongest arguments for more active sub to national MDG monitoring and initiatives in pre to accession countries.

Table 11 Infant and child mortality rates in Romania (infant and child mortality rates deaths by 1000 live births)			
Ethnic group	Infant mortality (0 to 1 year)	Child mortality (1 to 4 years)	Total infant and child mortality (0 to 4 years)
Romanian	27.1	1.1	28.2
Hungarian	19.8	0	19.8
Roma	72.8	7.2	80.0

\*Children born between July 1994 and June 1999. Source: Reproductive Health Survey: Romania (draft, 1999).

Women's health is another area of concern. Problems with women's health reflect both socioeconomic factors (poverty, inadequate nutrition, lack of access to health services) and cultural patterns like early marriages and early births. There is a direct relationship here between frighteningly high infant mortality rates and high fertility rates. Unfortunately, data on the health status of Roma women are fragmentary and not always reliable. Systematic research on this issue is definitely needed, in order to go beyond the national averages and to adequately monitor the health to related aspects of MDGs as well. But even these fragmentary data suggest that promoting reproductive health and rights, including family planning, is indispensable not just for economic growth and poverty reduction, but for decreasing mortality and morbidity rates.<sup>113</sup>

## Major determinants of poor health status

Poor sanitation levels due to inadequate basic infrastructure are a major reason for the poor health status of Roma communities. In Slovak Republic, for example, these factors contribute to the high mortality rates for Roma infants: it is 34.8 per 1,000 children born, while the mortality rate among non-Roma infants is 14.6 per 1,000 children born.<sup>114</sup> These data illustrate the link between sanitation conditions in Roma settlements and the need for sub to national MDG monitoring.

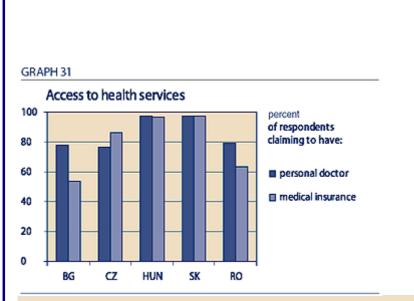
## Box 14: "Hidden impediments" to social services in Romania

Discrimination may have different faces and often is not explicit. In many areas, especially those involving provision of social services, ostensibly neutral legal provisions may in practice have a discriminatory impact.

These "hidden impediments" are apparent in the regulation of health care services. In Romania, the right to health protection (and the state obligation to provide it) are enshrined in the Constitution. Romania embarked on a contribution-based overall health care reform in 1998. Families receiving social support receive health insurance without paying any contribution. Eligibility for non-contributory health insurance is conditional on access to social support, the eligibility criteria for which can be affected by various administrative practices, potential exclusion errors, possible discriminatory denials, and insufficient information. Access to health care for certain social groups-like Roma-can therefore be denied on administrative grounds.

Another theoretically neutral but potentially discriminatory legal provision concerns different definitions of the "family" in different Romanian laws. In the *Law on Social Support*, the "family" is defined as parents and children regardless of the existence of a civil marriage or of the civil status of the child. In the *Health Insurance Law*, two not that imply the existence of a civil marriage have been used, namely "wife" and "husband". Under the social support law couples living in customary-law marriages are eligible for social support, but only the "wife of" or the "husband of" an insured person have the right to non-contributory health insurance. This opens the way for administrative discretion regarding interpretations of eligibility for social support and thus access to health insurance. Since customary-law marriages are more wide-spread among Roma, they are disproportionately affected by these ambiguities.

Romania's social security system also create "hidden impediments" to supplying social services. Access to social support is conditioned on the apparently neutral requirements of permanent residence and possession of appropriate identity documents. Large parts of



the Roma population however do not have identity documents and consequently cannot be registered as permanent residents. Some government employees refuse to cons der the temporary structures in which Roma often live as habitable dwellings and deny Roma permanent resident status on these grounds. Additionally, local governments are given the discretion to decide on the needs, content, and extent of social support. Even though the right to social support is guaranteed by national law, it may be circumscribed by local government decisions to not allocate funds or to delay the distribution of benefits.

Box prepared by UNDP RBEC team based on Zoon, Ina. 2001a.

Limited access to health services is another determinant of poor Roma health status. In many cases it is due to open or hidden discrimination.<sup>115</sup> But even if discrimination were completely abolished, certain systemic factors limiting access are "imbedded" in the reform of old health care systems and transitions to new systems based on health insurance. First, not all of the population is aware of the procedures and the need to have such insurance. Second, the financial contributions required from patients-even if small-are often too high for poor people. Third, large shares of Roma communities lack the new identity cards necessary for inclusion in the system.

The data from the UNDP/ILO survey show that the broadest medical insurance coverage for Roma is in Slovak Republic (where 97 percent of the respondents claimed to have medical insurance), followed by Hungary (96 percent) and the Czech Republic (86 percent). The low levels reported in Bulgaria (54 percent) and Romania (63 percent) seem to reflect the fact that these two countries were among the last in the region to launch their health sector reforms. The same picture emerges if we compare the responses of people who explicitly state that they do not have insurance. In the first three countries the share of this group is between 1 to 4 percent, while in the last two, it is 35 to 36 percent. On the other hand, most respondents in all five countries claim to have a personal doctor (Graph 31). This probably means that significant numbers of respondents in Bulgaria and Romania either do not know how the health system works, or do not have real access to it. In any case, the reality regarding access to health seems to be worse than reported by respondents.

## Box 15: Child morbidity in a Roma settlement: The case of Svinia

In 2001, two Canadian researchers conducted a health survey in Svinia, one of the most destitute and isolated Roma settlements in Slovakia. Although the survey is not representative of all isolated Roma settlement, it gives some idea of the magnitude of the

#### problems.

The total population of the Svinia settlement was estimated at 700 people. The survey counted 352 children under 16; parents and other family members were interviewed about the children's physical health. Of 246 responses, the overwhelming majority (223) felt that their children were healthy. 21 children were reported to be not healthy, and one child was said to "need special care". When asked to identify the season during which children are most likely to get sick, parents were most likely to select summer. This points to a link between morbidity and poor sanitation conditions. The settlement has no sewage infrastructure; the only source of drinking water was a single well; and water from the well did not qualify as potable. Of the settlement's 352 children, 250 were visually inspected, and 28 had distended stomachs (there is usually a link between very distended stomachs and parasites).

The average number of people living in a single household containing children under the age of 16 in the settlement was six. The lowest number was 3, while the highest is 28. The shower facilities that were available in the settlement took the form of a buildir g known as the Dutch Portable, and these were accessed by requesting the key from whoever kept it. Users had to pay for the energy used for their shower. Of 590 respondents, only 172 people were using the showers on a regular basis, while 418 were bathing at home using water heated on the stove. Roughly three quarters of the respondents were not using these shower facilities. 420 respondents were questioned about the management of toilet issues in Svinia. While six people used the regular oilet in their apartment (flushing it with water brought from outside), 269 had their own outhouse, and another 75 shared an outhouse with up to six other families. Of 74 people who did not have access to an outhouse, 52 indicated that they simply use the field.

Box prepared by Sarah Takach based on data from monitoring carried out by Glen Murray and Ruth Mitchell funded by Canadian International Development Agency (CIDA)

#### Poverty and HIV/AIDS

HIV/AIDS has been found to disproportionately affect certain minority groups in Central and Eastern Europe, due to their higher poverty rates and limited access to basic social services. Various sources show that CEE countries are experiencing significant problems associated with drug trafficking and use. The links between drug trafficking and use and commercial sex work (as well as with other high-risk behaviours) have been well documented. Not surprisingly, CEE countries have also seen dramatic increases in the incidence of HIV/AIDS.

Data on the spread of HIV/AIDS in CEE are not very reliable. Figures available from the end of 2000 listed the number of total registered HIV/AIDS cases in Bulgaria (testing began there in 1985) at 357, of which 96 were confirmed AIDS cases with 73 deaths. The actual number of cases is thought to be much higher, however. In Hungary, a 1999 estimate showed a very low (0.05 percent) prevalence of HIV/AIDS, but more recent figures are likely to be noticeably higher. Romania has the dubious distinction of having the largest number of pediatric HIV/AIDS cases in Europe, due to the extensive use of unscreened blood products and repeated use of contaminated needles during the Communist regime. Since 1985 (when the first AIDS case was reported), available data indicate a total of 6,422 registered cases in children and 1,348 adults living with HIV/AIDS. According to data for 2000, less than half of the people requiring anti to retroviral therapy can afford to purchase it.

Due to their difficult socioeconomic circumstances, Roma are disproportionally exposed to risks related to Hepatitis B and C, sexually transmitted diseases, and HIV/AIDS. As poverty and discrimination drive Roma to seek income generating opportunities in the underground economy, reports indicate that growing numbers of Roma (either on their own volition or through forced exploitation) are entering HIV/AIDS to risk industries<sup>116</sup>. These include drug trafficking and drug

use, and commercial sex work. Another possible explanation why young Roma are more at risk than non-Roma for illicit drug use could be related to early to age alcohol and tobacco use by Roma children.<sup>117</sup>

Initial reports indicate that Roma intravenous drug users (IDUs) tend to fall into two age groups: teenagers under 16, and adults in the 35 to 40 age group, most of whom live in urban areas. While this information is helpful, more research regarding the extent to which Roma girls and boys are involved in drug trafficking and use, including links to child commercial sex activities, would be beneficial. UNAIDS reports that, in most CEE countries, child prostitutes and young working women who receive cash payment for their services remain a hidden group. Little information is currently available about these groups, including the extent to which Roma women and children are involved in these activities.

## Main conclusions of Chapter 6

While the insufficient data on health matters limit our ability to draw far to reaching conclusions, it is clear that Roma health status is substantially worse than that of majority populations. Most of the causes of poor health status are related to poverty, poor sanitation conditions, and non to existent basic infrastructure in Roma communities. Projects not directly related to health improvement (such as infrastructure development) can have significant, albeit indirect, effects on health status.

Roma children are a special health risk group, reflected in high levels of infant mortality. Women's health is another area of concern, due both to socioeconomic factors (poverty, inadequate nutrition and lack of access to health services) and to cultural patterns like early marriage and early births.

HIV/AIDS is a new but rapidly growing area of concern for Roma populations. The disease's spread can be linked to poverty and poverty to related issues, including especially drug trafficking and use. An additional risk factor linked to drug trafficking/use is commercial sex work, as well as other high-risk behaviours that are often among the few available survival strategies for Roma.

Problems with access to health services are also important. These are due, in part, to the cash payments required from beneficiaries; although relatively small, they are often too large for many Roma. Limited access to health services is caused in some countries by the lack of the appropriate identity documents and birth certificates necessary for health insurance enrollment.



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	Other:

## Summary (Description of the study and most relevant results):

### Abstract

BACKGROUND The Roma people originated in northern India and have been known in Europe for nearly a thousand years. For much of that time they have been the subjects of discrimination and oppression, culminating in the extermination of half a million Roma in the Nazi death camps. While it is widely believed that the health of Roma people is often poorer than the majority population, these inequalities remain largely unresearched.

*METHODS* Published literature on the health of the Roma people was identified using Medline. Opinion pieces were excluded, as were papers relating to anthropometry and to genetic markers. The resultant papers were analysed by country of study and by disease type or care group. *RESULTS* Some 70% of papers identified related to just three countries; Spain and the Czech and Slovak Republics. Much literature concentrates upon communicable disease or reproductive health. The limited evidence suggests increased morbidity from non-communicable disease, but there is little published on this topic. Evidence on health care, though fragmentary, suggests poorer access to health services and uptake of preventative care.

*DISCUSSION* Published research on the health needs of the Roma population is sparse. The topics that have received attention suggest a focus on concepts of contagion or social Darwinism, indicating a greater concern with the health needs of the majority populations with which they live. There is a need for both further research into the health of Roma people; with particular emphasis on non-communicable disease; and also for interventions that improve Roma health. Such research must, however, be handled with sensitivity, recognising the social and political context of the society concerned. (*J Epidemiol Community Health* 2000;**54**:864-869)



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Author(s):	Isabela Mihalache <sup>2</sup>
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Country:	Romania
Language:	English
Contact address if more information is required: (where applicable)	Tsabela Mihalache holds a BA degree in Philology from Bucharest University and an MA degree in Gender Studies from the Central European University, Budapest. She is a Ph.D. candidate in Romani Linguistics at the Bucharest University. Currently, she works as a program coordinator at the Roma Participation Program, Open Society Institute, Budapest. E-mail: imihalache@osieurope.org.
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	Doctoral thesis
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Summary (Description of the study and most relevant results):

There are very few statistics on Romani women in Central and Eastern Europe. Apart from reports, interviews and discussion papers, one can find very few studies in relation to Romani women. In order to fill the gap on the health-care status of Romani women, the Council of Europe undertook a study in nine European countries on Roma Women and Access to Public Health Care. The report was prepared by Anna Pomykala in May 2002 for the Migration and Roma/Gypsies Division of the Council of Europe. A general lack of information has been further compounded by the reluctance of the Romani community to address certain issues having to do with private life, such as gender relationships, sexuality and some traditional customs. Probably among the most important reasons why there is so little information on women's issues in the Romani community are that Romani women are underrepresented in public life, on the one hand, and that, on the other, the Romani women's rights movement has not been part of the Romani movement as we have known it in the past decade.



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Summary (Description of the study and most relevant results):

The article focuses on analyses of programs on health care for Roma people in Slovakia and Czech Republic and on Healthcare policies.

#### Roma Rights 3-4/2004: Health Care

Editorial

 Undiagnosed: The Impact of Racial Discrimination on Roma Health Savelina Danova/Russinova

### **Field Report**

• "Gypsy Rooms" and Other Discriminatory Treatment Against Romani Women in Hungarian Hospitals Rita Izsák

### Notebook

- Differences in Access to Primary Healthcare Structures, Equal Opportunity and Prejudice The Results of an Empirical Study
- Healthcare Policy and Provision for Roma in Slovakia and the Czech Republic James Grellier and Katarína Šoltésová
- Reflections on the Access of Roma to Health Care Ivan Ivanov
- Improving Access of Roma to Health Care through the Decade of Roma Inclusion Heather Doyle
- The Health of Foreign Romani Children in Italy: Results of a Study in Five Camps of Roma from Macedonia and Kosovo Lorenzo Monasta
- Roma in Finland Janette Grönfors

### Women's rights

• Discrimination against Romani Women in Spain: European Roma Rights Center Submission to the UN Committee on the Elimination of Discrimination Against Women Cristi Mihalache

### Legal defence

- Strasbourg Court Finds Hungary in Breach of Human Rights Standards in a Roma Police Brutality Case Branimir Pleše
- Strategic Litigation Undertaken by the ERRC and Local Partners Prompt Bulgarian Courts to Sanction Racial Discrimination against Roma

#### Advocacy

- Breakthrough: Challenging Coercive Sterilisations of Romani Women in the Czech Republic Claude Cahn
- Response of the Czech Government Commissioner for Human Rights to ERRC Action
   on Coercive Sterilisations of Romani Women in the Czech Republic
- International Concerns about Forced Sterilisations of Romani Women Prompt Amendments to the Slovak Health Care Act
- Written Comments of the European Roma Rights Center to European Commission "Green Paper: Equality and Non-Discrimination in an Enlarged European Union"



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	Doctoral thesis
	Other:

Summary (Description of the study and most relevant results): Reaction on the article "The health of gypsies" (see doc. 13).



	Publication Details	
Title:	The health of Gypsies, Lack of understanding exemplifies wider disregard of the health of minorities in Europe	
Author(s):	Martin McKee Professor of European Public Health a a European Centre on Health of Societies in Transition, London School of Hygiene and Tropical Medicine, London	
Publication date:		
Country:		
Language:	English	
Contact address if more information is required: (where applicable)	http://bmj.bmjjournals.com/cgi/content/full/315/7117/1172?ijkey=f2bda75f618 2dced7eff8d75761f93f8b5cd73fa&keytype2=tf_ipsecsha	
Published by:	BMJ.com	
Bibliography: <sup>(1)</sup>		

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

## Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

Summary (Description of the study and most relevant results):



Publication Details	
Title:	On the Margins – Slovakia (Roma and Public Services in Slovakia)
Author(s):	Ina Zoon
Publication date:	2001
Country:	USA
Language:	English
Contact address if more information is required: (where applicable)	OSI, 400 West 59 <sup>th</sup> Street, New York 10019 USA
Published by:	Open Society Institute (OSI)
Bibliography: <sup>(1)</sup>	Chapter Lack of Adequate Health Care, page 49 - 76

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

	Article
Х	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

## Summary (Description of the study and most relevant results):

General status of Romani Health in Slovakia, Health care rights and Access to health Care Insurance, Access to health care, Direct discrimination, Attitudes of medical personnel, Segregation in health care facilities, Access to emergency services.



Publication Details	
Title:	Body and Soul: Forced Sterilization and Other Assaults on Roma Reproductive Freedom <b>And</b> The Slovak Government's Response to Reproductive Rights Violations against Romani Women: Analysis and Recommendations
Author(s):	Centre for Reproductive Rights and Poradna pre obcianske a ludske prava
Publication date:	January 2003, May 2003
Country:	
Language:	English
Contact address if more information is required: (where applicable)	http://www.crlp.org/pub_bo_slovakia.html#report (PDF format) http://www.crlp.org/pdf/report_slovakiafollowup_0603.pdf (follow up, PDF)
Published by:	Centre for Reproductive Rights and Poradna pre obcianske a ludske prava
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
Х	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

## Summary (Description of the study and most relevant results):

"Body and Soul: Forced Sterilization and Other Assaults on Roma Reproductive Freedom": report from interviews on topics including the sterilization practices, treatment by health care professionals in maternal health care facilities and access to reproductive health care information.

The other paper "The Slovak Government's Response to Reproductive Rights Violations against Romani Women: Analysis and Recommendations" summarizes the government of Slovakia's response to Body and Soul: Forced Sterilization and Other Assaults on Roma Reproductive

Freedom in Slovakia, as of May 15, 2003. It also provides recommendations on further action the Slovak government must take. It begins with a summary of the findings of Body and Soul and key developments since the report's launch. It then describes international support for the report, details flaws in the government's investigation and ends with a discussion of ongoing civil proceedings.



## **Publication Details** Sexual and Reproductive Health in Multicultural Europe Title: Author(s): 1/ Margareta Ackerhans "Health Issues of Ethnic Minority and Migrant Women", page 9 2/ Corinne Packer "Roma Women and Public Health Care", page 20 Publication date: 2003 Country: Language: English Contact address http://www.euro.who.int/document/ens/en55.pdf (PDF format) if more information is required: (where applicable) Published by: Entre Nous, The European Magazine for Sexual and Reproductive Health, No. 55 - 2003 Bibliography:<sup>(1)</sup>

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

Summary (Description of the study and most relevant results):

1/ article based on results of literature review focusing on health issues of immigrant women living in Scandinavia and includes reproductive health, domestic violence and HIV/AIDS. 2/ article on poor health status of Roma across the European Region, inadequate access to health care.



	Publication Details	
Title:	Gypsy Mothers and the Hungarian Health Care System	
Author(s):	Maria Nemenyi	
Publication date:	01/1999	
Country:		
Language:	English	
Contact address if more information is required: (where applicable)	http://www.geocities.com/~patrin/health-hungary.htm	
Published by:	The article is reproduced by the Patrin Web Journal	
Bibliography: <sup>(1)</sup>		

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

The author argues that perceptions, misperceptions, and cultural differences between health case providers and traditional Roma affects the quality of health care provided by the Hungarian health care system.



	Publication Details	
Title:	Cross-cultural medicine: A decade later	
Author(s):	Anne Sutherland	
Publication date:	1992	
Country:		
Language:	English	
Contact address if more information is required: (where applicable)	http://www.geocities.com/~patrin/healthus.htm	
Published by:	The Western Journal of Medicine The article is reproduced by the Patrin Web Journal	
Bibliography: <sup>(1)</sup>		

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

Article on Roma in the United States, Roma ideas about health and illness related to notions of good and bad fortune, purity and impurity, and inclusion and exclusion from the group. How these basic concepts affect everyday life, including the way Roma deal with eating and washing, physicians and hospitals, the diagnosis of illness, shopping around for cures, and coping with birth and death.



#### **Publication Details**

Title:	Litigating Discrimination in Access to Health Care
Author(s):	Alan Anstead
Publication date:	2003
Country:	
Language:	English
Contact address if more information is required: (where applicable)	http://www.errc.org/cikk.php?cikk=1989&archiv-1
Published by:	European Roma Right Centre
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

Short stories / cases: Challenging Segregation on racial Grounds in Health Care Establishments, Challenging Discrimination in the Provision of Health Care Benefits, Contesting the Barriers for Roma Access to Health Care and Treatment, Including the Emergency Services, Combating the Informal and Illegal Payments for Services, Most Prevalent at Public Hospitals.



	Publication Details	
Title:	Health Care Systems in Transition, Slovakia	
Author(s):	Svatopluk Hlavacka, Dagmar Skackova (2000) Svatopluk Hlavacka, Róbert Wágner, Anette Riesberg (2004)	
Publication date:	2000, 2004	
Country:		
Language:	English	
Contact address if more information is required: (where applicable)	http://www.euro.who.int/observatory/Hits/TopPage (PDF format)	
Published by:	European Observatory in Health Care Systems	
Bibliography: <sup>(1)</sup>		

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

	Article
	Book
	Program
Х	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

Delivery of Health Care, Evaluation Studies, Financing and Health, Health Care Reform, Health Systems Plans – country based report that provides an analytical description of each health care system and of reform initiatives in progress or under development.



Publication Details	
Title:	Genetic structure of the Greek gypsies.
Author(s):	C.S. Bartsocas, C. Karayanni, P. Tsipouras, E. Baidas, A. Bouloukos & C. Papadatos.
Publication date:	1979
Country:	Denmark
Language:	English
Contact address if more information is required: (where applicable)	C.S. Bartsocas M.D. Second Department of Pediatrics University of Athens "A. Kyriakou" Children's Hospital Athens, Greece.
Published by:	
Bibliography: <sup>(1)</sup>	Clinical Genetics 1979 15:5-10

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results):** Data are presented on several polymorphic genetic markers in 200 Greek Roma people. Polymorphic loci studied were: the ABO, MN, Rhesus, Kell and Duffy blood groups, hemoglobin and ceruloplasmin. Fifty out of 174 persons (28%) were considered heterozygous for b- thalassemia



Publication Details		
Title:	Determination of Antibody Titres for Borrelia burgdorferi in the serum of Gipsies living in Attica, Greece.	
Author(s):	S.Chatzipanagiotou, P. Papandreou – Rakintzis, H. Malamou –Ladas & P.Antoniou.	
Publication date:	1992	
Country:		
Language:	English	
Contact address if more information is required: (where applicable)	S.Chatzipanagiotou. Department of Clinical Microbiology, Pendeli Children's Hospital, Pendeli,15236,Greece.	
Published by:		
Bibliography: <sup>(1)</sup>	European Journal of Clinical Microbiology and Infectious Diseases Vol.11 477-478, 1992.	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

Summary (Description of the study and most relevant results): The sera of 271 Roma people were tested for antibodies to Borrelia burgdorferi in order to find out the prevalence of Lyme disease in the Roma population in greater Athens area.



#### Publication Details

Title:	Risk factors for childhood burn injuries: a case – control study from Greece
Author(s):	E. Petridou, D. Trichopoulos, E. Mera, Y. Papazoglou, A. Marantos and C.Scontras.
Publication date:	March 1998
Country:	
Language:	English
Contact address if more information is required: (where applicable)	Eleni Petridou, Dept of Epidiomology, Athens University Medical School, 75 M.Asias str. Goudi, Greece. Tel: +3017773840 Fax: +3017773840 e-mail: epetrid@atlas.uoa.ariadne-t.gr
Published by:	Elsenier Science Ltd.
Bibliography: <sup>(1)</sup>	Burns, Vol. 24 (2),March 1998, pages 123-128
(1)	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

Summary (Description of the study and most relevant results):

During a 12-month period 239 children who presented with a burn injury at the Emergency Ddepartment of a teaching children's hospital in Athens, with city-wide coverage, and age matched controls with minor non- injury ailments were interviewed. The questionnaire covered sociodemographic characteristics of the children and their families , information allowing the construction of a burn avoidance index in their homes and items from the Achenback scale that were synthesized into a child activity score. The data were analyzed through conditional logistic regression. In general, socio-demographic variables were not of overwhelming importance, although some of the findings indicate that supervision lapses and barefoot walking of gypsy children increase the risk of burn injuries. The kitchen in an inherently high risk place for injuries and the powerful inverse association of the burn avoidance index with burn injure risk points towards steps that could be easily taken and impart substantial protection. There was no evidence in this study of burn injury proneness or that hyperactivity of the child increased the risk of burn injury proneness or that hyperactivity of the child increased the risk of burn injuries are largely environmentally conditioned and, accordingly, easily preventable.



Publication Details	
Title:	Lung funcion in Gypsies in Greece
Author(s):	Konst.I. Gourgoulianis, P. Tsoutsou , N. Fotiadou, K. Samaras, D. Dakis & P.A. Molyvdas
Publication date:	November / December 2000
Country:	
Language:	English
Contact address if more information is required: (where applicable)	K.I. Gourgoulianis, M.D., Pulmonologist, Ass. Professor of Physiology, 22 Papakyriazi, 41222 Larissa, Greece .
Published by:	Heldref publications
Bibliography: <sup>(1)</sup>	Archives of Environmental Health, Nov . 2000, Vol.55(6) pp.453-454

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results):** The relationship between lung function and smoking and dietary habits was examined in 121 Gypsies (62 males, 59 females) who were 14-70 y of age and who lived Greece. All were examined clinically, after which they all participated in spirometry tests. Half of the study group had abnormal (<80% of predicted) forced vital capacity, 36.4% had abnormal (<80% of predicted) forced expiratory volume in 1 sec, and 5% had serious lung function disturbances (forced vital capacity <50% of predicted). Approximately 70% of subjects were smokers, and their diets were rich in alcohol and meat they ate very few salads and oranges. Consequently, decreased lung function might be a mayor health problem in Gypsies in Greece. Organization of preventive health strategies should improve the overall health of this study group.



#### Publication Details

Title:	Political clientilism and social exclusim. The case of Gypsies in the Greek town of Sofade.
Author(s):	N. Marantzidis G. Mavrommatis
Publication date:	December 1999
Country:	
Language:	English
Contact address if more information is required: (where applicable)	N. Marantzidis, University of Macedonia 156 Egnatia street. 54006 Thessaloniki, Greece.
Published by:	SAGE
Bibliography: <sup>(1)</sup>	International Sociology, December 1999, Vol.14(4): 443-456

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results):** The article relates to two much- discussed concepts in the field of social sciences: clientage relations and social exclusion. Using the city of Sofades in central Greece – where about 2000 Gypsies live – as their empirical research field, the authors attempt the analysis of the following : (1) whether the socially excluded Gypsies of the area form clientage relations (2) whether their political clientage relations and (3) whether political clientage relationships help socially excluded groups surmount their exclusion or not. Even though the dominant theories about clientage relations associate the evolution of those relations with the evolution of a particular society, the study of the clientage relations in Sofades shows that within a society there may coexist more than one type of clientage relationships – from the most traditional to the most modern.



### **Publication Details**

Title:	Report on Greece to the OSCE Review Conference 1999
Author(s):	Co – operating organizations for the rights of tent- dwelling Roma in Greece (Drom Network for Roma Social Rights, European Roma Rights Center, Greek Delegation of Doctors of the world, Greek Helsinki Monitor and Minority Rights Group – Greece)
Publication date:	22 September 1999
Country:	Greece
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
Х	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results):** This document is a report of the above mentioned co-operating organizations for the rights of tent- dwelling Roma in Greece. It refers to the housing and health conditions, the education and human rights of the Roma in Greece. With respect to housing it recites the main Roma settlements throughout Greece that were abandoned or often percecuted destitute.



	Publication Details	
Title:	The State of Roma in Greece	
Author(s):	Assistant Professor Lena Divani.	
Publication date:	March 2005	
Country:	Greece	
Language:	English	
Contact address if more information is required: (where applicable)	http://www.nchr.gr/category.php?category_id=99	
Published by:	National Commission for Human Rights	
Bibliography: <sup>(1)</sup>		
(1) in the case of a r	nagazing article, include name, number, volume and date. If it is a chapter of	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

	Type of document (mark with an X):
	Article
	Book
	Program
Х	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results):** This document refers to the state of Roma in Greece and examines the social problem, the housing problem, the state of health of the Roma, the education problem, the problem of employment, the reaction of local communities and finally to the policy and the rights of Roma. More specifically the part concerning the state of health of Roma mentions that the state of health of this population, particularly of the tent-dwellers, is perilous because of their deplorable living conditions and because of the widespread use of narcotic substances. According to the World Doctors' enquiry in 1999, in some tent-dweller communities, up to 99% were infected with the hepatitis A virus. Fifty per cent had also been exposed to the hepatitis B virus.

Seventy-seven per cent of the Roma are entirely without social security. The only treatment available to them is that for people without means, that is, they can resort to public hospitals - where they are not welcome and are not treated like the rest of the patients. But even a certificate of being without means is difficult to obtain. In these cases, hospitals demand certain fees, which they attempt to extract by seizing the Roma's police identity cards. The result is that that even those Roma who had them are deprived of their identity card, which is essential for their transactions.



### **Publication Details**

Title:	Roma Suffer Discrimination in Access to Health Care in Greece
Author(s):	ERRC, Greek Helsinki Monitor
Publication date:	
Country:	Greece
Language:	English
Contact address if more information is required: (where applicable)	Email: office@errc.org Web page: http://www.errc.org/
Published by:	EUROPEAN ROMA RIGHTS CENTRE
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results):** On April 13, 2002, the Greek Helsinki Monitor (GHM) and the ERRC received testimony from Mr Christos Chrisikos, a 33-year-old Romani man, that on April 9, 2002, his 3-year-old daughter Maria had been denied medical assistance at the office of a private physician in Kiato, in northwestern Peloponnese. At approximately 8:00 PM, Mr Chrisikos, his wife, Mrs Panayota Chrisikos, 27, and his mother-in-law, Mrs Maria Karagiannis, 46, brought Maria to the office of Dr C., and after receiving the consent from other patients to allow Maria to be seen before them, Mr Chrisikos was reportedly told by Dr C. that he should have made an appointment. Mr Chrisikos then informed Dr C. that it was an emergency, but she reportedly stated: "I will not examine your children." According to Mr Chrisikos reported to GHM/ERRC that this was not the first time Dr C. had refused to examine Romani patients. Previously, according to Mr Chrisikos, Dr C. refused to examine the sick one-month-old daughter of his brother-in-law



### **Publication Details** Title: The Roma Minority of Greece, The situation of Roma in Greece Author(s): Cia Rinne Publication date: 2002 Country: Greece Language: English Contact address http://www.domresearchcenter.com/journal/16/index.html if more information is required: (where applicable) Published by: KURI, Journal of the Dom Research Center Bibliography:<sup>(1)</sup>

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results):** The article is based on the information and experience gathered during a two months stay with Roma in Greece. The work is part of a book on the Roma of Asia and Europe that photographer Joakim Eskildsen and Cia Rinne have been working on for two and a half years. The article refers generally to the way of Greek Roma's way of living and to the prejudice they face. A paragraph of the article mentions that: Since the normal refuse collection does not apply to Gypsy settlements, remaining garbage attracts rats, and in many places the water has to be transported from far away. The rough circumstances under which half of the Romani population live are alarming, and a threat to health in every respect. Effectively, almost 90% of the tent-dwelling Roma have hepatitis, and suffer from other illnesses that result from the unsanitary and rough conditions they live in, and 60 out of 1000 Roma children die before the age of one.



Publication Details	
Title:	Problems in Roma settlements throughout Greece: "Hepatitis"
Author(s):	
Publication date:	23/11/2000
Country:	Greece
Language:	English
Contact address if more information is required: (where applicable)	http://www.greekhelsinki.gr/pdf/roma-press-nov-00.PDF
Published by:	"Eleftherotypia" Daily newspaper
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results):** A large percentage of Gypsies living in the settlement of Sageika of Achaia, are carriers of hepatitis B. According the results of tests carried by the hospital in the Patras area 6,7% out of 90 Gypsies living in that settlement are carriers. The hospital recommended that the Municipal Authorities must undertake the vaccination of all inhabitants in that settlement.



	Publication Details	
Title:	INTEGRATED ACTION PROGRAMME FOR THE GREEK ROMA	
Author(s):	MINISTRY OF INTERIOR AFFAIRS	
Publication date:	2001	
Country:	GREECE	
Language:	ENGLISH	
Contact address if more information is required: (where applicable)	Web page: http://www.ypes.gr/ Email: info@ypes.gr	
Published by:	MINISTRY OF INTERIOR AFFAIRS	
Bibliography: <sup>(1)</sup>		

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

	Article
	Book
Х	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results):** The interior-ministerial Commission, aiming at the improvement of Greek Roma's living conditions, has developed an **Integrated Action Programme**, enduring six years (2002-2008), which refers to the following sectors: HOUSING TRAINING-EMPLOYMENT, EDUCATION, HEALTH-WELFARE, CULTURE, ATHLETICS. More specifically, the targets of HEALTH-WELFARE SECTOR are to 1. inform the Roma about public health issues, 2. to assume their regular medical examinations, 3. to carry out projects regarding preventive medicine, health education, vaccinations, etc.



#### **Publication Details**

Title:	RACIAL DISCRIMINATION AND VIOLENCE AGAINST ROMA IN GREECE
Author(s):	
Publication date:	July 31, 2000
Country:	Greece
Language:	English
Contact address	GREEK HELSINKI MONITOR (GHM) MINORITY RIGHTS GROUP – GREECE (MRG – G)
if more information is	Address: P.O. Box 60820, 15304 Glyka Nera
required:	Telephone: (+30-1) 347.22.59. Fax: (+30-1) 601.87.60.
(where applicable)	e-mail: office@greekhelsinki.gr website: http://www.greekhelsinki.gr
Published by:	GREEK HELSINKI MONITOR (GHM)
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
Х	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

Summary (Description of the study and most relevant results): An international survey by the Doctors of the World (ROMEUROPE Program, Medecins du Monde, Juin 1999) directly associates the odious living conditions in the settlements with the poor health of Roma tentdwellers. The results of hepatitis tests in Nea Liosia and Aspropyrgos are significant: 99% of the population has been exposed to hepatitis A. The same percentage for Hepatitis B is 50%; 18% are carriers while the healthy remainder of 32% are adolescents aged 10-18, most of which go to school. These percentages are high in comparison to the rest of the population. Comparative data from other European cities show that percentages of Roma tentdwellers in Greece with health problems are higher (42% for the women, 32% for the men). The Roma's access to the health system is insignificant. The Doctors of the World have found the Roma were living completely lack of first aid, vaccination and medical information. Roma do not trust hospitals and First Aid Services, and they find it impossible to follow the pace and procedures in practice in these institutions (except for cases when the doctor has created an atmosphere of trust). Only 15% of them receive benefits. Out of the 40% of Roma who have social security, only 30% are fully covered. These percentages are less than half of the equivalent average for Roma in other European cities. Based on research conducted by the Doctors of the World-Greece in Athenian camps, the average age of the Romani woman who gives birth for the first time is 16 years old.



Publication Details		
Title:	REPORT ON FIELD VISITS TO ROMA COMMUNITIES IN GREECE: AUGUST 2001	
Author(s):	Carried out by monitors Theodore Alexandridis, Apostolos Stragalinos, in the framework of the regular GHM monitoring in cooperation with the European Roma Rights Centre and of the MRG-G' partnership in Minority Rights Group International (MRGI)'s RomaSEE (Roma in South East Europe) Project.	
Publication date:		
Country:	Greece	
Language:	English	
Contact address if more information is required: (where applicable)	GREEK HELSINKI MONITOR (GHM) MINORITY RIGHTS GROUP – GREECE (MRG – G) Address: P.O. Box 60820, 15304 Glyka Nera Telephone: (+30-1) 347.22.59. Fax: (+30-1) 601.87.60. e-mail: office@greekhelsinki.gr website: http://www.greekhelsinki.gr	
Published by:		
Bibliography: <sup>(1)</sup>		
(1)		

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
х	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results):** The report refers to the results derived from planned and carried out visits to the following Roma settlements, in Greece. Some of the settlements that have been visited are: Halandri camp, Spata camp, Aspropyrgos camp, Kalogreza settlements, Aghia Paraskevi, Kalamata (Messinia) camps, Vlichos (Megara, Attica region) camps, Kamari/Melisi (Corintia) camps, Zevgolatio (Corinthia) camp, Examilia (Corinthia) camp, Nea Kios, (Karakaxa, Argos) camp, Aghia Triada (Argos), Glikia (Nea Tirintha, Argos) cams and many other. The survey showed that in most cases the settlements lack access to electricity, garbage collection, sewage system and provision of running water. The last one is the main reason why Roma children are forced to drop out of school, as they are embarrassed by their being dirty, due to the lack of water.



Publication Details	
Title:	Assessment for Roma in Greece
Author(s):	
Publication date:	December 31, 2000
Country:	Maryland
Language:	English
Contact address if more information is required: (where applicable)	http://www.cidcm.umd.edu/inscr/mar/assessment.asp?groupId=35002
Published by:	University of Maryland
Bibliography: <sup>(1)</sup>	Lexis/Nexis: US Department of State Human Rights Reports for 1990, 1991, 1993 and 1994 (all published the February following the year which they cover.) Lexis/Nexis: All news files: 1990-2000.

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
Х	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results)**: As is the case elsewhere there is considerable prejudice against the Roma in Greece. They are considered lazy, dirty and prone to crime. Also, their refusal to assimilate is not well received in Greece's nationalistic society. The Roma of Greece face harsh demographic disadvantages due to both their higher birth rates and their declining health conditions. The group faces exclusionary policies by the government politically, and face numerous restrictions. Most of these restrictions are due to the policy not to grant the Roma citizenship. Some municipalities attempt to prevent settlement by Gypsies in their area by refusing to register them as citizens (all Greek citizens have to be registered in a municipality). Without such a registration, Gypsies are not allowed to vote, cannot obtain the papers required to start a business and are excluded from a range of government services. Access of the Roma to state services including education and medical care is very low due to their nomadic lifestyle.



Publication Details		
Title:	Genetic studies of the Roma (Gypsies)	
Author(s):	Luba Kalaydjieva <sup>*1,2</sup> , David Gresham <sup>1</sup> and Francesc Calafell <sup>3</sup>	
Publication date:	2 April 2001	
Country:		
Language:	English	
Contact address if more information is required: (where applicable)	Web page: http://www.pubmedcentral.gov/pi.PDF Web page: http://www.biomedcentral.com/1471-2350/2/5 Address: <sup>1</sup> Centre for Human Genetics, Edith Cowan University, Perth, Australia, <sup>2</sup> Western Australian Institute for Medical Research, Perth, Australia and <sup>3</sup> Unitat de Biologia Evolutiva, Facultat de Ciencies de la Salut i de la Vida, Universitat Pompeu Fabra, Barcelona, Spain E-mail: Luba Kalaydjieva* - L.Kalaydjieva@ecu.edu.au; David Gresham - D.Gresham@ecu.edu.au; Francesc Calafell - francesc.calafell@cexs.upf.es *Corresponding author	
Published by:	BMC Medical Genetics 2001	
Bibliography: <sup>(1)</sup>	magazina articla, includo nomo, numbor, volumo and dato. If it is a chapter of	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
Х	Other: Review

**Summary (Description of the study and most relevant results): Background:** Data provided by the social sciences as well as genetic research suggest that the 8-10 million Roma (Gypsies) who live in Europe today are best described as a conglomerate of genetically isolated founder populations. The relationship between the traditional social structure observed by the Roma, where the Group is the primary unit, and the boundaries, demographic history and biological relatedness of the diverse founder populations appears complex and has not been addressed by population genetic studies.

**Results:** Recent medical genetic research has identified a number of novel, or previously known but rare conditions, caused by private founder mutations. A summary of the findings, provided in

this review, should assist diagnosis and counselling in affected families, and promote

future collaborative research. The available incomplete epidemiological data suggest a

non-random distribution of disease-causing mutations among Romani groups.

**Conclusion**: Although far from systematic, the published information indicates that medical genetics has an important role to play in improving the health of this underprivileged and forgotten people of Europe. Reported carrier rates for some Mendelian disorders are in the range of 5 -15%, sufficient to justify newborn screening and early treatment, or community-based education and carrier testing programs for disorders where no therapy is currently available. To be most productive, future studies of the epidemiology of single gene disorders should take social organisation and cultural anthropology into consideration, thus allowing the targeting of public health programs and contributing to the understanding of population structure and demographic history of the Roma.

Among all the above the review contains a figure (figure4) that shows the distribution of reported mutations in Europe and is based on available information referring to several disorders. The figure help us to derive the fact that Greek Roma suffer basically from congenital myasthenia.



	Publication Details
Title:	MODEL ACTION FOR THE ECONOMIC AND SOCIAL INTEGRATION OF THE LEAST PRIVILEGED GROUPS IN THE DISTRICT OF ELEFTHERIO/KORDELIO-EVOSMOS-MENEMENI (E./K.EM.) POVERTY-3
Author(s):	
Publication date:	1991
Country:	Greece-, Thessaloniki
Language:	English
Contact address if more information is required: (where applicable)	Web page: http://www.eled.auth.gr/reds/p3/p3keimena/description.htm
Published by:	
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

	Article	
	Book	
Х	Program	
	Study / Public administration report	
	Study / NGO report	
	Presentations or communications	
	Doctoral thesis	
	Other: Review	

**Summary (Description of the study and most relevant results**): This project aims to the maximum economic and social integration of the least privileged groups in the western part of Thessaloniki. The project involves the groups of single-parent families, Roms, repartriated Greek-Pontians and families with individuals with special needs, as target groups and is a part of the European Programme POVERTY-3. It represents a joint effort of various social and public agents and adopts a multi-dimensional approach of combating poverty.

A large number of Gypsies have settled in Dendropotamos, a damp, often flooded, overcrowded, poorly serviced, highly-polluted area of Menemeni. This group suffers greatly from poverty, health problems, social marginalization and educational improverishment Romany is the mother tongue of the Gypsies but almost half are illiterate and the quality of spoken Greek varies highly from person to person. Children who do attend school drop out early to help provide income for

#### the family.

In order to serve the general objectives of the Programme an information Centre has been established in the district to inform individuals on different subjects related to health, welfare, education, jobs, insurance and social services. With the creation of this Centre the Programme aims at overcoming the problems that result from the inadequacies of the civil service in Greece, to utilise knowledge and information that are of interest to our target groups and to confront the phenomena of ignorance and passivity that characterise these marginalised minority groups. One of the main project objectives is the improvement of health conditions and of standard of living (financial dimension of poverty) as well as the creation of workshops and consultation on health issues, nutrition and preventive health care

The approach of the Project is a multi-dimensional one, trying to incorporate and address all the factors contributing to poverty. Thus, the arranged actions address financial, educational, health and social problems in the target groups.



Publication Details	
Title:	Policies to Integrate and Protect the Greek Gypsy Community
Author(s):	George Papandreou
Publication date:	20 Februry, 2004
Country:	Greece
Language:	English
Contact address if more information is required: (where applicable)	Web page: http://media.papandreou.gr/media/content/articlepage.aspx?articleid=568
Published by:	George Papandreou-Media Centre
Bibliography: <sup>(1)</sup>	nagazina artiala, includa nama, number, valuma and data. If it is a chapter of

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
х	Other: document of G.Papandrou personal Web page

**Summary (Description of the study and most relevant results**): Mr George Papandreou, Presisent of Greek Axiomatic Opposition is looking back to the achievements of 2000-2004 and mentions that aiming to significantly improve the quality of life and social integration of Greek gypsies, special programmes were implemented in 76 gypsy communities nationwide, for housing, education, healthcare etc. Healthcare was improved with the use of mobile medical units which have vaccinated kids and provided check-ups for women and children in 70 gypsy communities. Furthermore he mentions that medical/social centres are being founded in 40 communities. Looking ahead Mr G. Papandreou mentions the goals for 2004-2008 suggesting the implementation of a national plan aiming to improve gypsies' living conditions and guarantee their social integration. Concerning housing he proposes the increase of loans for the construction of conventional – style permanent housing. Concerning healthcare he proposes the introduction of a general plan for preventive medicine (vaccination, gynaecological check-ups, blood tests, etc) via mobile medical units in all gypsy communities. Furthermore he proposes the establishment of medical/social centres in all organised communities, staffed with doctors, nurses, social workers, gym instructors and special needs teachers.



#### **Publication Details**

Title:	CLEANING OPERATIONS, Excluding Roma in Greece
Author(s):	The following ERRC and GHM researchers, consultants, interns and staff members contributed significantly to the production of this report: Dimitris Angelides, Tara Bedard, Anita Danka, Maria Dimitriou, István Fenyvesi, Orestis Georgiadis, Demetra Kassimis, Georgios Kloudas, Spyros Kloudas, Angeliki Kotsantoni, Mariana Lenkova, Sophia Nikolaidou, Antonia Papadopoulou, Nafsika Papanikolatos, Terry Platis, Christina Rougheri, Demi Sakellaropoulou, Apostolis Stragalinos, Orsolya Szendrey, Sundy Topidou, Georgia Tsaklaganos, and Mary Elen Tsekos. Mayra Gomez of the Center on Housing Rights and Evictions (COHRE) read the chapter on residential segregation of Roma in Greece and provided comments on it in light of international housing rights provisions. Historians Elena Marushiakova and Vesselin Popov, specialists in Romani history and
Publication date:	culture, commented on the history chapter. April 2003
Country:	Greece
Language:	English
Contact address if more information is required: (where applicable)	E-mail: office@errc.org Web page: http://www.errc.org
Published by:	ERRC and the Greek Helsinki Monitor
Bibliography: <sup>(1)</sup>	Chapter 7

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
Х	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results**): The report aims at emphasising at several patterns of human rights abuse against Roma in Greece. Such patterns are: Cruel and Inhuman or Degrading Treatment of Roma in the Field of Housing, Police Violence Against Roma, Exclusion of Roma from the Educational System, Barriers to Access to Health Care and Other Social Support Services. More Specifically chapter 7 refers to barriers to access to healthcare and social benefits.



### **Publication Details** Title: REPORT BY MR ALVARO GIL-ROBLES, COMMISSIONER FOR HUMAN RIGHTS ON HIS VISIT TO THE HELLENIC REPUBLIC 2-5 JUNE 2002 Author(s): MR ALVARO GIL-ROBLES, COMMISSIONER FOR HUMAN RIGHTS Publication date: 17 July 2002 Country: Greece Language: English (original version in French) Contact address Web page : http://www.nchr.gr/downloads/CO.PDF if more information is reauired: (where applicable) OFFICE OF THE COMMISSIONER FOR HUMAN RIGHTS Published by: Bibliography:<sup>(1)</sup>

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

-	
	Article
	Book
	Program
	Study / Public administration report
х	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:
E	Doctoral thesis

**Summary (Description of the study and most relevant results**): Mr Alvaro GIL-ROBLES, COMMISSIONER FOR HUMAN RIGHTS accepted the invitation addressed by the Foreign Affairs Minister for an official visit from the 2<sup>nd</sup> to the 5<sup>th</sup> of June 2002 and travelled to Athens with the director of his office and a member of his staff. Among other contacts he did during his visit in Athens he went on his own initiative to the Roma/ Gypsy district of Aspropyrgos on the outskirts of Athens and made a point of visiting the premises of the Attica General Police Directorate in Alexandra's Avenue where unsuccessful foreigners awaiting expulsion are detained on the 7<sup>th</sup> floor. As far as his visit to Aspropyrgos district is concerned he made several remarks. His remarks refer to sever programmes that have been undertaken for the improvement of Roma's living conditions as well as to all things he observed by himself. He was astonished by the perilous living conditions among rubbish, without running water and electricity. Mr Alvaro GIL-ROBLES also mentions, to his report, the fact that Roma are highly vulnerable ad at a disadvantage in many areas such as access to healthcare, housing, employment and education. Finally it is remarkable to refer that he refers to the indifference of local authorities to whatever concerns Roma and the improvement of their living.



	Publication Details	
Title:	GHM 1998 ACTIVITY REPORT OF THE GHM ROMA OFFICE	
Author(s):	Sofia Nikolaidou	
Publication date:	June 1998	
Country:	Greece	
Language:	English	
Contact address if more information is required: (where applicable)	Web site: http://www.greekhelsinki.gr/english/reports/GHM%20report%20to%ERRC- June98	
Published by:		
Bibliography: <sup>(1)</sup>	GHM REPORT TO ERRC NO 38: 31/7/1998	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
Х	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results**): The report is an almanac of visits, observations and events have taken place to Roma Settlements in Greece, including also elements for the Roma's living conditions.



	Publication Details
Title:	Denied a future?
Author(s):	
Publication date:	
Country:	Greece
Language:	English
Contact address if more information is required: (where applicable)	Web page: http://www.see-educoop.net/educ.PDF
Published by:	
Bibliography: <sup>(1)</sup>	Chapter 4 volume 2

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
Х	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

**Summary (Description of the study and most relevant results**): The report contains generally information about Roma population in Greece. It refers to demographical data, a historical overview, the legal status of Roma/ Gypsies, The socioeconomic situation of Roma/ Gypsies, Interethnic relations, National Legislation and Minority Rights, What happens in practice, Governments initiatives, Rocommendations and others. Concerning the matter of health their rights to access healthcare system, the topic refers to socioeconomic situation of Roma mentions that apart from the bad living conditions, it is widely recognised among health specialists that certain groups, such as Roma are seriously underserved in relation to social welfare in Greece. The document mentions also the difficulties Roma face in their attempt to exercise these rights.



### **Publication Details** Title: Traveller Gypsies and primary health care in Est London, (manuscript); Degree of MD, St. Bartholomew's Hospital Medical College. Author(s): Feder, G. **Publication date:** 1993 Country: G.B. Language: English Contact address if more information is required: (where applicable) Published by: Bibliography:<sup>(1)</sup> (manuscript)

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
Х	Other: manuscript

### Summary (Description of the study and most relevant results):

As in the article 'Gipsies' in *Medline*, the author observes that 1/3 of the studies devoted to the topic of Gipsies' health in the years 1979-1992 is related to Genetics, with a consequent lack of analysis of other risk factors such as housing, uneasy access to health -care system, and so on.



#### **Publication Details**

Title:	Mortality, morbidity and marital features of Traveller in the Irish Midlands
Author(s):	Flynn, M.
Publication date:	1986
Country:	Ireland
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	"Irish Medical Journal", 79: 308-10

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

Based on a 30-year research on a group of 180 families of Irish Travellers, this paper displays the distribution of death cases by age, and also observes marriage and reproduction dynamics. Due to the original solution it gives to the problem of sampling and to the unusually positive conclusions it offers to that of death rate, it has surprisingly been almost ignored in later scientific publication on the topic.



### **Publication Details**

Title:	The health of Travellers' children in Northern Ireland
Author(s):	Gordon, M. Gorman, D.R. Hashem, S. and Stewart, D.G.T.
Publication date:	1991
Country:	Ireland
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	"Public Health", 105: 387-391.

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

Travellers are here identified as autochthones, and the sample has been chosen under suggestion of sanitary assistants, which, in absence of an identified control group, makes the results of this research confused and unaffordable.



### **Publication Details**

Title:	
	What does blood tell ?
Author(s):	Gropper, R.C.
Publication date:	1981
Country:	North America
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	"Newsletters of the Gypsy Lore Society", North American Chapter, Vol. 4, Number 2-3-4, New York.

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

Summary (Description of the study and most relevant results):

After a critical analysis, the author explains how difficult is to find reliable sampling criteria for gipsy population, and how this makes the mathematical model of genetic studies uneasy to be applied to this research field.



### **Publication Details**

Title:	Risk factors for childhood burn injuries: case-
	control study from Greece.
Author(s):	Petridou, E. Trichopoulos, D. Mera, E. Papadatos,
	Y. et al.
Publication date:	1998
Country:	Greece
Language:	English
Contact address if	
more information	
is required:	
(where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	"Burns", 24 (2): 123-128

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

A study showing environmental factors improving Greek children's risk of being scalded, based on documents from an Hospital in Athens (Greece).



### **Publication Details**

Title:	An unknown risk group of lead poisoning: the gypsy children
Author(s):	Redondo, M.J. Guisasola, F. J. A.
Publication date:	1995
Country:	
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	"European Journal of Pediatrics", 154: 197-200.

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

A study about environmental risk factors (especially lead intoxication) that most strongly affect life conditions of gipsy children in Valladolid (Spain).



### **Publication Details**

Title:	Genetic markers in Welsh gypsies.
Author(s):	Harper, P.S. Williams, E.M. and Sunderland, E.
Publication date:	1977
Country:	G.B.
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	"Journal of Medical Genetics", 14: 177-182

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

#### Summary (Description of the study and most relevant results):

The authors' attempt to characterize a sample of "true Gipsies" is in conflict with the results they obtain in their attempt to reconstruct family trees. Nobody -they say- can say the true origins of Gipsies, because different communities around Europe are genetically heterogeneous, even if often different from local population (except for the case of Wales, which is in fact the object of their study). Two assumptions are provided: 1) Gipsies could descend from different ancestors' groups (some of whom not from India): but this couldn't be possible, due to linguistic evidence; 2) All Gipsies originate from India, and some groups have had their genetic patrimony mixed with local populations: the distinction would in this case be constituted by the time factor. This study shows how incorrect a scientific argumentation can be: the original hypothesis denied by the research results is in fact transformed in an indisputable matter of fact.



#### **Publication Details**

Title:	Prevalence of congenital anomaly syndromes in a spanish gypsy population.
Author(s):	Martinez-Frias, M.L. Bermejo, E.
Publication date:	1992
Country:	Spain
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	"Journal of Medical Genetics", 29 (7): 483-6.

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

#### Summary (Description of the study and most relevant results):

The only diffuse and statistically relevant research on congenital syndromes and to compare the situations of Gipsies and the rest of population. The high rate of consanguine marriages among Gipsies (16 to 19.5 times higher than the rest of population) is considered the most relevant factor of their SINDROMI RECESSIVE. Some doubts are to be expressed about how the criteria of consanguinity are chosen and the data collected: where a real familiar relationship can't be defined, the criteria chosen are those of the surname (in Spain, a child inherits both the father's and the mother's), which doesn't fit with the practice of declaring marriages and births among Gipsies.



#### **Publication Details**

Title:	Size at Birth and some sociodemographic factors in Gypsies in Hungary
Author(s):	Joubert K.
Publication date:	1991
Country:	Hungary
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	1991
Bibliography: <sup>(1)</sup>	"Journal of Biosocial Science", 23: 39-47.

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

#### Summary (Description of the study and most relevant results):

Here are the results of researches conducted about baby and infantile mortality rate in Hungary on important samples of Gipsy population, where the low rate of births has been related to the high rate of those. Some of the researchers' explanation of the causes concerning this relationship are affected by distorted and pre-conceptual points of view on the Rom communities observed (e.g. the ethno-centric choice by which the author chooses the school level as a turning point).



### **Publication Details**

Title:	
	Health care needs of Travellers
Author(s):	Van Cleemput, P.
Publication date:	2000
Country:	G.B.
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	In "Arch. Disabled Children", 82: 23-37.

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

The author shows how difficult is for British Travellers to get into the health system services, focusing on: a) the danger and unhealthy conditions of equipped "parking areas"; b) discriminations of which members of gipsy communities suffer in their everyday relationships with social and sanitary services and their operators; c) their different point of view about disease and its danger.

The author urges for specific professional ("specialist health visitors") specifically intended for Traveller population and in charge of their health.



### **Publication Details**

Title:	Travellers Gypsies and primary care
Author(s):	Feder, G
Publication date:	1989
Country:	G.B.
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	"Journal of the Royal College of General Practitioners", 39: 425-429.

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

## Summary (Description of the study and most relevant results):

The author makes a summary of the health problems of Traveller Gipsies and evaluates the experience of "Travellers' health visitors", explaining how this professional figure should be able not only to follow Traveller population, but also to mediate between them, medical officers, and health social structures.



#### **Publication Details**

Title:	Traveller Children and the State: Welfare or Neglect?,
Author(s):	Cemlyn, S.
Publication date:	1995
Country:	
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	"Child Abuse Review", Vol. 4: 278-290.

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

The author focuses on the interesting topic of how a majority-based society (and particularly health and social operators) is not able to understand that State social politics are part of the causes of gipsy children lack of health and forsaking, which are usually ascribed to their parents.



### **Publication Details**

Title:	Health and health care among Travellers
Author(s):	Phal , J., Vaile, M.
Publication date:	1986
Country:	Canterbury
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	University of Kent, Health Research Unit.
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

	Article
Х	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

Phal & Valle's research in the Kent region, represents one of the few studies on the health of the English gypsies restricted to the pre-natal period. The research shows a connection between the infant mortality and the translocations due to evacuation orders. The results from the interviews were never verified.



#### **Publication Details**

Title:	The Health of Travellers' children in Northern Ireland
Author(s):	Gordon, M., Gorman, D.R., Hashem, S. and Stewart, D.G.T.
Publication date:	1991
Country:	
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	Public Health, 105:387-391

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

	Article
	Book
	Program
Х	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

#### Summary (Description of the study and most relevant results):

The text gives a medical documentation on the health status of the Travellers of Northern Ireland analysing a sample of 350 children. The survey was conducted using a standard questionnaire and family interviews. The results show a high rate of congenital anomaly and identify the Travellers as being a high-risk group blaming their poor health on intermarriages and the urban decline in the place of settlement.



### **Publication Details**

Title:	Gypsies and American medical care
Author(s):	Thomas, J.D.
Publication date:	1985
Country:	
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	Annals of Internal Medicine, 102: 842-845

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

## Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

## Summary (Description of the study and most relevant results):

This study describes the etiological picture of the principal pathologies seen in a kaiderasa community of Boston and examines a group where 50% is made up of endogamous marriages. The results show a very low life expectancy outlining the distance between the community and the medical infrastructure. The emphasis is on finding strategies that can facilitate the relationship between the gypsy group and the health service.



### **Publication Details**

Title:	Travellers Gypsies and primary care
Author(s):	Feder, G.
Publication date:	1989
Country:	
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	Journal of the Royal College of General Practitioners, 39:425-429

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

## Summary (Description of the study and most relevant results):

In the article Feder develops firm criticisms on the ways that the research was carried out on the medical-anthropological type, carried out on some Travellers communities of the United Kingdom and analyzes the unfriendly attitude of the medical staff towards the gypsy patients.



## **Publication Details**

Title:	Gypsies and the health professions
Author(s):	Gropper, R. C.
Publication date:	1982
Country:	North America
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	North American Chapter
Bibliography: <sup>(1)</sup>	Newsletters of the Gypsy Lore Society, 5 (4), pp. 1-8

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

The author, after an acknowledgement of the medical literature concerning the gypsy community, outlines a statement of pathologies more widespread between the groups, without considering the existing results and without critically looking at the meaning attributed to the health/sickness concept.



#### **Publication Details**

Title:	The body as a social symbol among the Rom
Author(s):	Sutherland, A.
Publication date:	1977
Country:	London
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	Academy Press
Bibliography: <sup>(1)</sup>	J. Blaching (ed) The anthropology of the body, , pp. 375-390

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article	
	Book	
	Program	
	Study / Public administration report	
	Study / NGO report	
	Presentations or communications	
	Doctoral thesis	
	Other:	

#### Summary (Description of the study and most relevant results):

The authoress, during her researches on Kalderasa and Macwaja in California, analyses the theories concerning the body and the concept of "impurity" in the Gypsy communities, connecting it to the creation of a symbolism based on the somatic opposition between pure and impure parts, which regulates the relationships with the Gage' world and determines a group identity.



## **Publication Details** Title: Gypsies: the hidden Americans Author(s): Sutherland, A. **Publication date:** 1975 Country: London Language: English Contact address if more information is required: Published by: **Tavistock Publications** Bibliography:<sup>(1)</sup>

(1) In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.
Type of document (mark with an X):

	Type of document (mark with an X).	
	Article	
Х	Book	
	Program	
	Study / Public administration report	
	Study / NGO report	
	Presentations or communications	
	Doctoral thesis	
	Other:	

### Summary (Description of the study and most relevant results):

The text, by proposing an anthropological study on Kalderash Machwaya and Kunesti in California, offers a well-constructed explanation of the modality through which Rom people use the concept of "impurity" to build up their social and moral order, setting it against gage's one. There are many testimonies about the dangerousness of some public spaces considered as impure; the hospital is one of the most risky places, as it is associated to a perception of the disease like the highest grade of "impurity".

The state of health/disease strictly depends on the conception of the body which, from the Roma's point of view, is composed by a pure part which is that from the waist upward, and by an impure part which is that from the waist downward. The latter is considered responsible for numerous diseases, especially the infectious ones. Moreover, a lot of pathologies are ascribed, not only to the incapacity to keep separated the top part from the low part of the body, but also to a sort of opposition: luck/bad luck, considering that a social behaviour, which does not go with the group rules, can provoke a general state of ill-luck, revealed by the appearance of the disease, in a subject responsible for breaking those rules.



#### **Publication Details**

Title:	Gypsies and health care
Author(s):	Sutherland, A.
Publication date:	1992
Country:	
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	The Western Journal of Medicine, Sep. 157: 276:280

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

#### Summary (Description of the study and most relevant results):

The text highlights how the concept of disease, among the Gypsies, springs from a representation of life and death, from the relationships they establish with the Gage, and by all those aspects of everyday life, such as cleanness, food, way of clothing, which are within this worldview.

According to the authoress, diseases can be grouped into two categories: those which come from the Gage world, and those internal to the group, which are considered curable through the only intervention by the oldest Romni. Yet, this distinction doesn't sometimes exist and they turn to any possible cure in order to recover from the disease.



#### **Publication Details**

Title:	The Traveller Gypsies
Author(s):	Okely, J.
Publication date:	1983
Country:	Cambridge
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	Cambridge University Press
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

	Article
Х	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

. The text may be considered one of the more important research on the Traveller in England. What follows is an examination of the strategy through the group defines the own identity and symbolic borders regarding the dominant society. According to the Okely, Traveller mark the belongings to the group avoiding relationship with no gypsies and not attending places considered impure and dangerous. The hospital is, therefore, a particularly dangerous place because in the structures hospitals worker the body is exposed to highly contaminating situations.



### **Publication Details**

Title:	The health of Traveller mothers and children in East Anglia
Author(s):	Linthwaite, P.
Publication date:	1983
Country:	London
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	Save The Children Fund

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

#### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

## Summary (Description of the study and most relevant results):

Linthwaite's study is one of a series of anthropological surveys on the "health condition" of the United Kingdom's Traveller-Gypsies. In the survey, where over 200 women were interviewed, a very high pre-natal and infant mortality rate was found, even though the results were contested by the Travellers themselves for the methodology used and the conclusions which seem to stigmatize their life style.



## **Publication Details**

Title:	"Breaking the barriers-Romani Women and Access to Public Health Care"
Author(s):	OSCE HCNM
	Council of Europe
	EUMC
Publication date:	2003
Country:	International
Language:	English, French
Contact address	www.eumc.eu.int
if more	www.osce.org/hcnm
information is	www.coe.int/T/E/Social_Cohision/Roma_Gypsieis
required:	
(where	
applicable)	
appricasic)	
Published by:	
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

	Type of document (mark with an X):
	Article
	Book
	Program
	Study / Public administration report
Х	Study / report
	Presentations or communications
	Doctoral thesis
	Other:

## Type of document (mark with an V).

## Summary (Description of the study and most relevant results):

The report is based primarily on interviews conducted by the author in few countries including Romania. In each country, interviews were held with representatives of governments, nongovernmental organization and other institutions working on behalf of Roma, and with Romani women themselves.

The report aims to contribute analysis and policy options to eliminate discrimination in and to improve access to health care for Roma women and their communities.



## **Publication Details**

Title:	"Health care" – no 3 and 4
Author(s):	European Roma Rights Centre-ERRC
Publication date:	2004
Country:	International
Language:	English
Contact address if more information is required: (where applicable)	www.errc.org
Published by:	ERRC
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

inc	lude the title and references.
	Type of document (mark with an X):
	Article
	Book
	Program
	Study / Public administration report
	Study / report
	Presentations or communications
	Doctoral thesis
х	Other: Newsletter

- Differences in access to primary healthcare
- Healthcare policy and Provision for Roma in Slovakia and Czech Republic
- Reflections on the access of Roma to health care
- Improving access of Roma to health care through the Decade of Roma Inclusion
- The health of Foreign Romani children in Italy: result of a study in 5 camps
- Roma in Finland



## **Publication Details**

Title:	Report on the situation of Roma and Sinti in the OSCE area
Author(s):	OSCE/ High Commissioner on national Minorities
Publication date:	2000
Country:	
Language:	English
Contact address if more information is required: (where applicable)	www.osce.org
Published by:	
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

## Type of document (mark with an X): Article Book

	Program
	Study / Public administration report
Х	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:

Summary (Description of the study and most relevant results):

The report contain a chapter on health situation(page 117)of Roma population in different countries, and more important has a focus on Roma women health situation.



## **Publication Details**

Title:	"Health care reform in Central and eastern Europe and the Former Soviet Union"
Author(s):	Hernan I. Fuenzalida- Puelma Open Society Institute/ Local Government and Public Service Reform INITIATIVE
Publication date:	2002
Country:	Hungary
Language:	English
Contact address if more information is required: (where applicable)	E-mail: lgprog@osi.hu Web: www.lgi.osi.hu
Published by:	OSI
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
Х	Study / report
	Presentations or communications
	Doctoral thesis
	Other:

## Summary (Description of the study and most relevant results):

The study includes a chapter about the challenges faced by Roma in their access to health system .



### **Publication Details**

Title:	Highlights on Health, Romania
Author(s):	World Health Organisation, Regional Office for Europe
Publication date:	1999
Country:	Romania
Language:	English
Contact address if more	Dr Victor Stefan Olsavszky
information is required:	WHO Liaison Officer
(where applicable)	WHO Liaison Office UN House
(where applicable)	48A Primaverii Blvd.
	011975 Bucharest 1 Romania
	Tel: +402 1 2017872-6
	Fax: +402 1 2017889
	E-mail: wholoro@who.eunet.ro
Published by:	
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

	Type of document (mark with an X):
	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
Х	Other: International organisation report

#### Summary (Description of the study and most relevant results):

Country Highlights give an overview of the health and health-related situation in a given country and compare, where possible, its position in relation with other countries in the region. The Highlights have been developed in collaboration with Member States for operational purposes and do not constitute a formal statistical publication. They are based on information provided by Member States and other sources as listed. For Romania, the reference countries are ten central and eastern European candidate countries for accession to the EU (Bulgaria, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Romania, Slovakia and Slovenia).

The report contains the following chapters:

- the country and its people
- health status
- lifestyles
- environment and health

## health care system



## **Publication Details** Title: "Body and soul"- Forced Sterilization and Other Assaults on Roma Reproductive Freedom in Slovakia Ina Zoon Author(s): Publication date: 2003 **Country:** Romania Language: Romanian and English Contact address E-mail: inazoon3@worldonline.es if more On the Margins online: www.soros.org/romaandpublicservices information is required: (where applicable) Published by: Center for Reproductive Rights in consultation with Ina Zoon Bibliography:<sup>(1)</sup>

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

Type of document (mark with an X):

	Article
	Book
	Program
	Study / Public administration report
Х	Study / report
	Presentations or communications
	Doctoral thesis
	Other:

### Summary (Description of the study and most relevant results):

The study is a human rights fact-finding mission involving in-depth, private interviews with more than 230 women in almost 40 Romani settlements throughout eastern Slovakia, the region with the highest concentration of Roma, on topics including sterilization practices, treatment by health-care professionals in maternal health-care facilities and access to reproductive health-care information.

It also includes interviews with Slovak hospital directors, doctors, nurses, patients, government officials, activists, and non-governmental organizations regarding these same issues.



## **Publication Details**

Title:	Origins and divergence of the Roma (Gypsies)
Author(s):	Gresham D., B. Morar, P. Underhill, G. Passarino, A. Linn, C. Wise, D. Angelicheva, F. Calafell, P. Oefner, P. Shen, I. Tournev, R. de Pablo, V. Kucinskas, A. Perz-Lezaun, E. Marushiakova, V. Popov, L. Kalaydjieva
Publication date:	2001
Country:	Bulgaria
Language:	English
Contact address if more information is required: (where applicable)	Foundation "Health Problems of Minorities" 81 V, A. Stamboliiski Blvd, floo1, ap. 4 Tel/fax: (+359-2) 981-68-66 email: emhpf@techno-link.com Contact person: Ivailo Tournev, MD
Published by:	Am. J. Hum. Genet., 2001, 69, 1314-31
Bibliography: <sup>(1)</sup>	Am. J. Hum. Genet., 2001, 69, 1314-31

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

## Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:



## **Publication Details**

Title:	Spinal muscular atrophy among the Roma (Gypsies) in Bulgaria and Hungary
Author(s):	Jordanova A, Kargaci V, Kremensky I, Litvinenko I, Uzunova M, Tournev I, Ishpekova B, Herzegfalvi A, Simeonova I, Kalaydjieva L.
Publication date:	2002
Country:	Bulgaria
Language:	English
Contact address if more information is required: (where applicable)	Foundation "Health Problems of Minorities" 81 V, A. Stamboliiski Blvd, floo1, ap. 4 Tel/fax: (+359-2) 981-68-66 email: emhpf@techno-link.com Contact person: Ivailo Tournev, MD
Published by:	Disord, 2002, 12:378-385
Bibliography: <sup>(1)</sup>	Disord, 2002, 12:378-385

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:



# **Publication Details**

Title:	High Levels of Sexual HIV/STD Risk Behavior among Roma Men in Bulgaria: Patterns and Predictors of Risk in a Representative Community Sample
Author(s):	Kabakchieva, E., Amirkhanian, Y., Kelly, J., McAuliffe, T. & Vassileva, S.
Publication date:	2002
Country:	Bulgaria
Language:	English
Contact address if more information is required: (where applicable)	Health and Social Development Foundation http://www.hesed.bg/
Published by:	International Journal of STD & AIDS, 13, p. 184-191, 2002
Bibliography: <sup>(1)</sup>	International Journal of STD & AIDS, 13, p. 184-191, 2002

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:



# **Publication Details**

Title:	Clinical, electrophysiological and neuropathological studies of hereditary motor and sensory neuropathy type Lom
Author(s):	Kalaydjieva L., A. Nikolova, I. Tournev, B. Ishpecova, J. Petrova, A. Shmarov, & S. Stancheva, L. Middleton, R. King, P.K. Thomas
Publication date:	1998
Country:	Bulgaria
Language:	English
Contact address if more information is required: (where applicable)	Foundation "Health Problems of Minorities" 81 V, A. Stamboliiski Blvd, floo1, ap. 4 Tel/fax: (+359-2) 981-68-66 email: emhpf@techno-link.com Contact person: Ivailo Tournev, MD
Published by:	Brain, 121, 399-408,1998.
Bibliography: <sup>(1)</sup>	Brain, 121, 399-408,1998.

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

## Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:



## **Publication Details**

Title:	A founder mutation in the GK1 gene is responsible for galactokinase deficiency in Roma (Gypsies)
Author(s):	Kalaydjieva L., A. & Perez-Lezaun, D. Angelicheva, S. Onengut, D. Dye, N. Bosshard, A. Jordanova, A. Savov, P. Yanakiev, I. Kremenski, B. Radeva, J. Hallmayer, A. Markov, V. Nedkova, I. Tournev, L. Aneva and R. Gitzelmann
Publication date:	1999
Country:	Bulgaria
Language:	English
Contact address if more information is required: (where applicable)	Foundation "Health Problems of Minorities" 81 V, A. Stamboliiski Blvd, floo1, ap. 4 Tel/fax: (+359-2) 981-68-66 email: emhpf@techno-link.com Contact person: Ivailo Tournev, MD
Published by:	Am.J.Hum.Genet., 65 (5), 1999, 1299-307
Bibliography: <sup>(1)</sup>	Am.J.Hum.Genet., 65 (5), 1999, 1299-307

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:



## **Publication Details**

Title:	Social and biological history of the Roma (Gypsies)
Author(s):	Kalaydjieva L., B. Morar, D. Gresham, P. Underhill, G. Passarino, A. Lin, C. Wise, D. Angelicheva, F. Calafell, P. Oefher, P. Shen, I. Tournev, R. de Pablo, V. Kucinskas, A. Perez-Lezaun, E. Marushiakova, V. Popov
Publication date:	2001
Country:	Bulgaria
Language:	English
Contact address if more information is required: (where applicable)	Foundation "Health Problems of Minorities" 81 V, A. Stamboliiski Blvd, floo1, ap. 4 Tel/fax: (+359-2) 981-68-66 email: emhpf@techno-link.com Contact person: Ivailo Tournev, MD
Published by:	Acta Myologica, 2001, vol. XX, 3, 181-187
Bibliography: <sup>(1)</sup>	Acta Myologica, 2001, vol. XX, 3, 181-187

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

## Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:



## **Publication Details**

Title:	Gender Roles and HIV Sexual Risk Vulnerability of Roma (Gypsies) Men and Women in Bulgaria and Hungary: An Ethnographic Study	
Author(s):	Kelly, J., Amirkhanian Y., Kabakchieva, E., Csepe, P., Seal, D., Antonova, R., Mihailov, A. & Gyukits, G.	
Publication date:	2004	
Country:	Bulgaria	
Language:	English	
Contact address if more information is required: (where applicable)		
Published by:	AIDS CARE, Vol. 16, No. 2, p. 231-245, 2004	
Bibliography: <sup>(1)</sup>	AIDS CARE, Vol. 16, No. 2, p. 231-245, 2004	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

### Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:



## **Publication Details**

Title:	Homogeneous phenotype of the Gypsy Limb-girdle Muscular Dystrophy with the gamma-sarcoglycan C283Y Mutation	
Author(s):	Merlini L., A. Barois, A. Monte, B. Echenne, L. Jarre, L. Kalaydjieva, A. Levi-Gomes, C. Navarro, A. Toutain, I. Tournev, A. Urtizberea, J. Vallat, T. Voit, J. Warter, J. Kaplan	
Publication date:	on date: 2000	
Country:	Bulgaria	
Language:	English	
Contact address if more information is required: (where applicable)Foundation "Health Problems of Minorities" 81 V, A. Stamboliiski Blvd, floo1 , ap. 4 Tel/fax: (+359-2) 981-68-66 email: emhpf@techno-link.com Contact person: Ivailo Tournev, MD		
Published by:         Neurology, 2000, 54, 1075-1079		
Bibliography: <sup>(1)</sup> Neurology, 2000, 54, 1075-1079		

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

## Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:



## **Publication Details**

Title:	Hereditary motor and sensory neuropathy - Russe: new autosomal recessive neuropathy in Balkan Gypsies	
Author(s):	Thomas P., Kalaydjieva L., Youl B., Rogers T., Angelicheva D., King R., Guergueltcheva V., Colomer J., Lupu C., Corches A., Popa G., Merlini L., Shmarov A., Muddle J., Nourallah M., Tournev I.	
Publication date:	2001	
Country:	Bulgaria	
Language:	English	
Contact address if more information is required: (where applicable)Foundation "Health Problems of Minorities" 81 V, A. Stamboliiski Blvd, floo1, ap. 4 		
Published by:	Ann. Neurol. 2001, 50 (4): 452 -457	
Bibliography: <sup>(1)</sup>	Ann. Neurol. 2001, 50 (4): 452 -457	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

## Type of document (mark with an X):

Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:



## **Publication Details**

Title:	The Congenital Cataracts Facial Dysmorphism Neuropathy (CCFDN) syndrome: a novel complex genetic disease in Balkan Gypsies	
Author(s):	Tournev I., L. Kalaydjieva, B.Youl, B. & Ishpekova, V. Guergueltcheva, O. Kamenov, M. Katzarova, Z. Kamenov, M. Raicheva-Terzieva, R.H.M. King, K. Romanski, R. Petkov, A. Schmarov, G.Dimitrova, N.Popova, M.Uzunova, S.Milanov, J. Petrova, I.Petkov, G.Kolarov, L.Aneva, O.Radeva & P.K.Thomas	
Publication date:	e: 1999	
Country:	Bulgaria	
Language:	English	
Contact address if more information is required: (where applicable)Foundation "Health Problems of Minorities" 81 V, A. Stamboliiski Blvd, floo1 , ap. 4 Tel/fax: (+359-2) 981-68-66 email: emhpf@techno-link.com Contact person: Ivailo Tournev, MD		
Published by:	Annals of Neurology, 1999 Jun; 45 (6): 742-750.	
Bibliography: <sup>(1)</sup>	Annals of Neurology, 1999 Jun; 45 (6): 742-750.	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

	Type of document (mark with an X):
Х	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:



## **Publication Details**

Title:	Congenital Myasthenic Syndrome in southeastern European Roma (Gypsies)	
Author(s):	Veronika Karcagi, Ivailo Tournev, Carolin Schmidt, Agnes Herczegfalvi, Velina Guergueltcheva, Ivan Litvinenko, In-Ho Song, Angela Abicht, and Hanns Lochmüller	
Publication date:	date: 2001	
Country:	Bulgaria	
Language:	uage: English	
Contact address if more information is required: (where applicable)Foundation "Health Problems of Minorities" 81 V, A. Stamboliiski Blvd, floo1, ap. 4 Tel/fax: (+359-2) 981-68-66 email: emhpf@techno-link.com Contact person: Ivailo Tournev, MD		
Published by:	Acta Myologica, 2001, vol. XX	
Bibliography: <sup>(1)</sup> Acta Myologica, 2001, vol. XX		

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

## Type of document (mark with an X):

$\mathbf{v}$	Article
<u> </u>	Article
	Book
	Program
	Study / Public administration report
	Study / NGO report
	Presentations or communications
	Doctoral thesis
	Other:



## Publication Details

Title:	The Roma in central and eastern Europe : avoiding the dependency trap : a Regional Human Development report
Author(s):	different
Publication date:	2002
Country:	Prague, Czech
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

	Article	Type of document (mark
	Book	with an X):
	Program	, í
Х	Study / Public administration report	
	Study / NGO report	
	Presentations or communications	
	Doctoral thesis	
	Other:	
	<b>Immary (Description of the study and most relev</b> e egional Human Development report	ant results):



**Publication Details** 

Title:	The Roma and Europe
Author(s):	different
Publication date:	1998
Country:	Prague, Czech Republic
Language:	English
Contact address if more information is required: (where applicable)	
Published by:	
Bibliography: <sup>(1)</sup>	conference proceedings : Štiřín Castle, December 10-13

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

	Article	Type of document (mark		
	Book	with an X):		
	Program	,		
х	Study / Public administration report			
	Study / NGO report			
	Presentations or communications			
	Doctoral thesis			
	Other:			
Summary (Description of the study and most relevant results): Anthology of text from the conference in Štiřín castle that was focused on Roma population in Europe from all points of view.				



**Publication Details** 

Title:	1959- Body and soul : forced sterilization and other assaults on Roma reproductive freedom in Slovakia	
Author(s):	Zoon, Ina	
Publication date:	2003	
Country:	New York, USA	
Language:	English	
Contact address if more information is required: (where applicable)		
Published by:	Center for Reproductive Rights Slovakia	
Bibliography: <sup>(1)</sup>		

<sup>(1)</sup> In the case of a magazine article, include name, number, volume and date. If it is a chapter of a book, include the title and references.

	Article	Type of document (mark with an X):		
х	Book			
	Program			
	Study / Public administration report			
	Study / NGO report			
	Presentations or communications			
	Doctoral thesis			
	Other:			
Summary (Description of the study and most relevant results): Study on forced sterilization of Roma women in Slovakia during communistic				
	riod.	and an ing communistic		