



NEW NATIONAL HEALTH INSURANCE WILL SAVE LIVES

Life Expectancy and Health
in Kosovo's Roma, Ashkali and
Egyptian Communities

K **sana**

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PUBLISHING DETAILS AND ACKNOWLEDGMENTS

Team

Field Research Coordinator

Mimoza Telaku

Project Advisor

Rand Engel

Research Analyst and Writer

Elsa Raunio

Desk Research / Literature Review

Jacob Perry

Albiona Rashiti

LIVES Film Crew

Arian Mustafa, Writer and Director

Faton Mustafa, Videographer

Avni Mustafa, Journalist

Rrahim Goliqi, Star

Health Economist and Research Adviser

Ilir Hoxha (Solidar Suisse)

Statistical Analyst

Alban Fejza (Solidar Suisse)

Program Coordinator, Solidar Suisse

Syzane Baja

Executive Director, Balkan Sunflowers Kosova

Muhamet Arifi

Financial Officer, Balkan Sunflowers Kosova

Sami Canaj

Field Survey Enumerators

Agon Asllani

Avdullah Shabani

Avdyl Mustafa

Besart Mersula

Demir Osmani

Fridon Lala

Halil Kerellaj

Jetmir Feta

Mexhit Berisha

Mirjeta Gecaj

Samire Bujani

Valdete Osmani

Vera Paqaku

Experts. The following experts agreed to be interviewed:

Ardita Tahirukaj	WHO Kosovo	Public Health Officer
Avnore Morina	Prospect Project, Gjakova/Đakovica	Health Mediator
Faik Hoti	Ministry of Health	Departmental Director
Fridon Lala	Balkan Sunflowers Kosova & UNICEF	Advocate Enumerator
Mimoza Beqiri	Health House, Dubrave, Ferizaj/Uroševac	Family Doctor
Ramiz Beriša	Health House, Plemetina, Obiliq/Obilić	Laboratory Technician
Skender Marolli	Main Health House, Fushë Kosovë	Family Doctor
Slaviša Radosavljević	Health House, Plemetina, Obiliq/Obilić	Otorhinolaryngologist
Teresa Janovic	World Bank & IREX	Research Fellow
Zylfije Bajrami	Health House, Gaqke, Ferizaj/Uroševac	Family Doctor

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Nenad Andric
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LIST OF ACRONYMS

BSFK	Balkan Sunflowers Kosova
CI	Confidence Interval
DRC	Danish Refugee Council
FAO	Food and Agriculture Organization
IDP	Internally Displaced Person
KAS	Kosovo Agency of Statistics
KFOS	Kosovo Foundation for Open Society
LCN	Balkan Sunflowers Learning Centers Network
MoH	Ministry of Health
MICS	Multiple Indicator Cluster Survey
OR	Odds Ratio
OSCE	Organization for Security and Cooperation in Europe
STD	Sexually Transmitted Disease
The Strategy	Strategy for the Integration of Roma, Ashkali and Egyptian Communities in the Republic of Kosovo, 2009-2015
UNDP	United Nations Development Programme
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
WHO	World Health Organization

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1 INTRODUCTION

1.1 Project inception

In 2013-2014, the Balkan Sunflowers Kosova (hereinafter BSFK) together with Solidar Suisse conducted an extensive desk research project on the health situation of the Roma, Ashkali and Egyptian communities in Kosovo. This study was conducted as part of the broader multi-stakeholder project "KOSANA" which aims for establishment of an all-inclusive national health insurance system in Kosovo. At the BSFK we intend to speak for the Roma, Ashkali and Egyptian communities in the process of drafting and implementing the national health insurance system. The findings indicate that the Roma, Ashkali and Egyptian communities are more prone to life-limiting chronic illnesses than the rest of the Kosovo population. Our observations and case study data suggests especially high prevalence of rheumatism, respiratory problems, diabetes and cardiovascular diseases. The poor health situation of the three communities is perhaps best demonstrated by their low life expectancy. For example, in the multiethnic village of Plemetina in the municipality of Obiliq/Obilić, a quick look at the cemeteries reveals that the Roma, Ashkali and Egyptians die, on average, as many as 20 years before their Albanian and Serbian neighbors. This discovery resulted in production of the documentary film LIVES which reveals the alarming health situation of the three communities in Plemetina and beyond.

The desk research helped us to establish a good picture of the overall health situation of the Roma, Ashkali and Egyptian communities. However, what we were still lacking was numerical information about the health situation of the three communities. We argued that without such information, we were unable to provide specific estimations about the amount of funds and other resources required for addressing the health needs of the three minority groups. The second phase of the KOSANA project, conducted in 2014-2015, aimed to address this knowledge gap by gathering information about the health situation, health care needs and life expectancy of the Roma, Ashkali and Egyptian communities. As our main research method, we conducted a health survey with 393 Roma, Ashkali and Egyptian households. The survey was designed to gather information on ten topic areas related to and affecting health situation and health care needs. Additionally, in order to collect information for estimating life expectancy, we asked each household to provide ages and causes of death of their recently perished family members. Furthermore, we conducted ten qualitative interviews with health care professionals who have experience of working with the three communities. This information helped us to triangulate, validate and challenge the survey findings.

We found that the average age of death among these communities is 58.7 years. This is almost 12 years lower than the overall life expectancy in Kosovo at 70.5 years. Little more than one third (34.2%) of the deceased individuals indicated by our survey had reached this age. In more than half of the cases of bereavement, the family was unable to afford full treatment of the disease or condition that was attributed as the cause of death. This finding, along with our other results, reveals that financial constraints significantly reduce the Roma, Ashkali and Egyptian communities' access to health service, which in turn affects negatively in their general health condition.

Our research findings confirm the prevalence of many health problems among the Roma, Ashkali and Egyptian communities. As expected, cardiovascular diseases constitute the most commonly occurring health problem among the three communities. Out of all the respondents aged 30 or over, nearly 30% are affected by one or more types of cardiovascular disease. Additionally, nearly 7% are suffering from bronchitis or other type of disease of the respiratory system, whereas metabolic diseases, mainly diabetes, are affecting 6% of the population. Generally, the health of the Roma, Ashkali and Egyptians begins to deteriorate around the time an individual turns 40 years old. A further significant finding is the disproportionate spending on health care costs among the most low-income households. A universal health insurance system would bring some relief for the households struggling to pay the health-related costs and other necessities. The economically disadvantaged Roma, Ashkali and Egyptian communities would particularly benefit from such a system. Along with the establishment of the health insurance system, the research supports the need for multi-stakeholder health education program to promote health awareness among the three communities.

1.2 What is KOSANA?

KOSANA is a joint project between eight Kosovo non-governmental organizations and the lead partner and donor, Solidar Suisse. The national government of Kosovo is working towards reform of the public health care sector. KOSANA aims to analyze current conditions and lobby for ensuring that national health insurance, when implemented, accommodates the special needs of distinct population groups, such as vulnerable groups, students, sufferers of high impact chronic disease, etc. The KOSANA member organizations and their beneficiary groups are:

ORGANIZATION	MAIN BENEFICIARY GROUP(S)
Action for Mothers and Children	Expectant women, mothers and young children
Balkan Sunflowers Kosova	Roma, Ashkali and Egyptian communities
Association of Infectologists	Whole population
National Autism Association	Adults and children affected by autistic spectrum disorder
National Diabetes Association	Adults and children affected by type 1 or 2 diabetes
Student Resource Hub of the University of Prishtina	Students
Federation of Trade Unions of Health Care Workers	Health care professionals
Southeastern Europe Institute on Nursing and Medical Studies	Whole population

As of 2016, though Kosovo has legally mandated national health insurance, it has not yet been implemented. This situation is especially difficult for economically vulnerable population groups such as ethnic minorities, students and those affected by certain chronic diseases or disabilities. The low utilization of preventive health care services and the treatment costs of common long-term diseases such as diabetes are especially worrisome.

KOSANA consists of three phases implemented in varying ways by each of the organizations: Desk research / literature review, i.e. analysis of existing field research and comparative studies; Field research, i.e. designing and conducting direct quantitative and qualitative research; Advocacy, i.e. use of the research to design and advocate for public policy in the interests of the beneficiary groups in current situations and in implementation of national health insurance.

During the research phase, organizations aimed to develop data and analysis on questions such as: What are the most urgent health needs of the beneficiary group? Are there any obstacles in accessing health care analysis, medication and treatment? What are the financial implications of health care costs for the affected individuals and their households? Should a proportion of health insurance funds be reserved for treatment of specific diseases? In addition to regular allopathic health care services, should other health activities be covered by health insurance? This may include health education, mentoring, and health mediation. When national health insurance is implemented, Kosovo citizens will pay into the health insurance pool. Are there arguments for supporting the exemption of some beneficiary groups from the regular health insurance contributions?

Balkan Sunflowers Kosova assessed the situation of the Roma, Ashkali and Egyptian communities. We argue that the absence of a national health insurance system is having a serious negative impact on the health situation of the three communities. Without national health insurance, there is not guaranteed health care in Kosovo. Ashkali, Roma, and Egyptian communities, along with their economically disadvantaged population groups, cannot access preventive and curative health care services to the extent needed. We further argue that low levels of health awareness affect the health situation of the three communities. Hence, national health insurance including or alongside of allocation of funds for health education are important steps towards improving the health of the three minority groups.

At the time of writing this report, the second phase of KOSANA is completed and we are in the process of implementing an advocacy campaign to address the health needs of the beneficiary communities. The results presented in this report provide markers for making health insurance accommodate the needs of the Roma, Ashkali and Egyptian populations.



Figure 1. Halil Berisha, 55, father of 7 sons and 3 daughters has experienced three heart attacks, and has diabetes says that the Kosovo government is giving him a €65 social assistance per month while he needs at least €80 for his medicines, each month. "I have Serbian health insurance, and that is one of the ways I have been managing to survive" he said. He lives in Plemetina, Obiliç municipality, near Pristina, Kosovo's capital city. The 'Kosova A' and 'B' power plants are also situated in that location. An outcome is that the Plemetina population suffers higher rates of cancer and respiratory diseases than other Kosovo areas.

2 FIELD RESEARCH 2014-2015 - DEVELOPMENT

2.1 Literature review summary

The first phase of the project KOSANA – Health Insurance for All took place between March 2013 and February 2014. As part of this component, the Balkan Sunflowers Kosova research team collected, compiled and reviewed existing data regarding the health situation and life expectancy of the Roma, Ashkali and Egyptian communities. Source materials included academic research papers and reports from organizations and governmental institutions. In addition, a focus group was conducted with community members from Fushë Kosova/Kosovo Polje. The preliminary findings helped us to identify the current knowledge gaps and to design the research aims and objectives for the second phase of the project. This section is a summary. The comprehensive literature review is found in the last section of this report.

2.1.1 Health situation

One of the main challenges of the desk research phase was the lack of large-scale numerical health data on Kosovo's Roma, Ashkali and Egyptian communities. Hence, the preliminary findings are based on studies conducted in other South East European countries or on small-scale studies in Kosovo. As some of our source materials date back to 2002, in many cases we have outdated information. However, despite the flaws, we were able to construct an overview of the health situation and possible health needs of the Roma, Ashkali and Egyptian communities.

What then did we identify as the most urgent health problems of the three communities? According to studies conducted in other Central and Southeast European countries, certain chronic diseases tend to affect the Roma more than non-Roma. These diseases include type-2 diabetes, hypertension, cardiovascular diseases, anemia and rheumatism. Higher prevalence of these diseases in Roma communities is associated with inadequate housing conditions, poor nutrition, high levels of smoking and alcohol consumption, and polluted living environments. In most countries, the Roma tend to have a worse health situation even when compared to the majority population who are in a similar socio-economic position.

As in other Central and Southeast European countries, a large number of the Roma, Ashkali and Egyptian families live below the poverty line with as many as 36% in extreme poverty.¹ Many academic studies have demonstrated the negative impact of poverty on health and life expectancy. People with low-income levels are especially vulnerable to diseases accelerated by improper and imbalanced nutrition. Some case studies suggest high prevalence of hypertension, diabetes, cardio-vascular diseases and anemia in Kosovo Roma, Ashkali and Egyptian communities. The occurrence and aggravation of these diseases could be abated by earlier diagnosis, treatment, and better nutrition.

Dominance of the above mentioned health problems may also be explained by low education levels in the Roma, Ashkali and Egyptian communities. As reported, for instance by Kickbush (2001)², health literacy is strongly linked to general literacy levels. Hence, health awareness among the Roma, Ashkali and Egyptian communities can be presumed to be inadequate. Some case studies have previously raised concern about the low health awareness. One of the most worrisome findings is the relatively low utilization rate of ante and postnatal health services. As a result of poverty and possibly mothers' low health awareness, babies and small children in the three communities are often severely undernourished. Moreover, in addition to poverty, low health knowledge also exacerbates the problem of poor nutrition. Case studies have shown disproportionately high use of salt, sugar, oil and low nutrition value white flour in Roma, Ashkali and Egyptian households.

¹ Office of the Prime Minister (2008) Strategy for the Integration of Roma, Ashkali and Egyptian Communities in the Republic of Kosovo, p. 8

² Kickbush, Ilona S. (2001) Health literacy: addressing the health and education divide. Health Promotion International 16(3)

There have also been observations of high rates of smoking and low rates of engagement in physical exercise. These findings suggest that the many Roma, Ashkali and Egyptian individuals have limited access to healthy life choices due to poverty or lack of information.

Other societal developments in Kosovo also disproportionately impact the Roma, Ashkali and Egyptian communities. One of these is the repatriation of refugees from foreign countries. As a result of the war of 1998-1999 more than 100,000 individuals from these communities became refugees or displaced.³ The majority of them found refuge in neighboring countries or elsewhere in Europe.⁴ However, the major destination countries of Kosovo refugees including Germany, Austria and France, have been organizing repatriations to Kosovo. Such repatriations, especially from Germany, have soared since 2009. According to a 2010 report by the United Nations High Commissioner for Refugees (UNHCR), the number of repatriated Roma, Ashkali and Egyptian individuals may be as high as 12,000. According to the recent report by the Society for Threatened Peoples, nearly 4,000 Roma, Ashkali and Egyptian individuals have returned to Kosovo from Western Europe since 2010. However, as this includes only the registered returnees, the real figure is believed to be higher.⁵ The 2011 Kosovo Census puts the number of citizens from these communities as more than 35,000. Hence, a significant portion of Kosovo Roma, Ashkali and Egyptian citizens may have a history of forced or voluntary repatriation.

Other organizations have discovered numerous cases of psychological and physiological health problems affecting returnee communities. According to a UNICEF study conducted among potential Roma, Ashkali and Egyptian repatriates in Germany, the majority of the consulted families had at least one member suffering from a long-term disease such as cardiac disorders, respiratory disease or diabetes.⁶ The UNICEF study found a high prevalence of psychological disorders such as post-traumatic stress disorder and depression among the repatriated children.⁷ Since many of these families have by now been repatriated forcibly or voluntarily, we can assume especially serious occurrence of psychological and physiological health problems among repatriated Roma, Ashkalis and Egyptians.

2.1.2 Life expectancy

An effective way to compare the health situation of different population groups is to look at the differences in life expectancy. Various studies have identified striking differences in the life expectancy of Roma and non-Roma populations in other Central and East European countries. A 2014 study by the European Commission in the 27 European Union member states revealed up to twenty years life expectancy difference between the Roma and non-Roma populations.⁸ Similarly, in neighboring Serbia, the Roma are estimated to live, on average, ten to twelve years less than the rest of the population.⁹

³ OSCE-ODIHR (2010). Sustainable Solutions for Displaced Roma, Ashkali and Egyptians and Policies to Improve the Reintegration of Repatriated Roma (Report of the OSCE-ODIHR Roundtable. Organized in co-operation with the Serbian Ministry of Human and Minority Rights). Retrieved from <http://www.osce.org/odihhr/75578?download=true>

⁴ *ibid*

⁵ The Society for Threatened Peoples (2015) Lost in Transition: The Forced Migration Circle of Roma, Ashkali and Balkan Egyptians from Kosovo. Retrieved from http://assets.gfbv.ch/downloads/lost_in_transition.pdf

⁶ UNICEF Kosovo and the German Committee for UNICEF (2010). Integration Subject to Conditions: A report on the situation of Kosovan Roma, Ashkali and Egyptian Children in Germany and After Their Repatriation to Kosovo, p. 41. Retrieved from http://www.unicef.org/kosovoprogramme/RAEstudy_eng_web.pdf

⁷ UNICEF Kosovo in Cooperation with Kosovo Health Foundation (2012) Silent Harm: A Report Assessing the Situation of Repatriated Children's Psychosocial Health. Retrieved from http://www.unicef.org/kosovoprogramme/SILENT_HARM_Eng_Web.pdf

⁸ European Commission (2014) Roma Health Report: Health status of the Roma population. Data collection in the Member States of the European Union. Retrieved from http://ec.europa.eu/health/social_determinants/docs/2014_roma_health_report_en.pdf

⁹ Bogdanovic, Dragan et al (2007) Mortality of Roma Population in Serbia, 2002-2005. Croatian Medical Journal 28(5), pp. 220-226 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2205976/>

In the absence of comprehensive birth and death data regarding Ashkali, Roma, and Egyptians, we cannot determine their life expectancy according to international standards. We have some indicators. As an example, graves in the Islamic cemetery in the ethnically diverse village of Plemetina in Obiliq/Obilić municipality, of the deceased Roma, Ashkali and Egyptians are separate from the Albanian graves. A non-scientific comparison of the death ages suggests about ten years of difference in the life expectancy between Albanian and the minority communities. The household survey included questions to further focus on life expectancy.

2.1.3 Problems with health care services

The existing studies have identified numerous obstacles preventing the Egyptian, Roma, and Ashkali communities from using and accessing health care services. One of the main problems of the three communities has been a large number of persons not registered as residents of the Republic of Kosovo.¹⁰ Those lacking identity documentation (IDs) are unable to benefit from social assistance or free public health care services. In the Serbian-majority localities, which are home for a large number of the Kosovo Roma residents, children's birth certificates are also essential for school enrolment. The absence of IDs is said to be a particularly urgent problem among repatriated families.

We have come across evidence suggesting that the Roma, Ashkali, and Egyptian communities are not using health care services as much as they should. According to a study conducted in Fushë Kosova/Kosovo Polje municipality, many Ashkali, Egyptian and Roma citizens are avoiding the use of health services because of the high costs of medication and treatment. Often, people from the three communities are not aware of the importance of regular health checks. When it comes to antenatal services, over 60% of the Roma, Ashkali and Egyptian women are not visiting a gynecologist during their pregnancy. The corresponding figure is less than 3% for the other ethnic groups of Kosovo. At certain localities there have also been reports about home births without a midwife.

Furthermore, ethnically based discrimination is affecting the Roma, Ashkali and Egyptian communities in all societal sectors including health care services. According to a study by Bloom (2007) and his team, all over the country Roma, Ashkali and Egyptians face discriminative attitudes and behavior by health care personnel. In order to address this problem, Kosovo Open Society Foundation ran a health mediator program in Gjakova/Đakovica, Prishtina and Klina municipalities. One of the main purposes of this program was to facilitate dialogue between the communities and the health care personnel and in this way increase the communities' utilization of health care services.



Figure 2. Sherfie Beka, who is 34, has suffered from asthma for five years. When she came to the health center she was coughing badly and hardly breathing.

¹⁰ Op cit., The Strategy

2.1.4 Knowledge gaps

Our preliminary findings reveal serious shortcomings in the health situation and health care among the Roma, Ashkali and Egyptian communities. These include prevalence of certain chronic diseases accelerated by poor nutrition, inadequate housing conditions and low health awareness. Utilization of health care services is limited because of health care costs, discrimination, and low utilization of medical check-ups. Anecdotal and case study evidence indicates reduced life expectancy of the three communities but in the absence of mortality data, we cannot determine which diseases cause the early deaths. Hence, as part of the second phase of the *KOSANA sponsored* project, we aimed to gather *numerical* data on our three main topics of interest: health care access, health care needs, and life expectancy of the Roma, Ashkali and Egyptian communities.

2.2 Research aims and objectives

The previous chapter treated the findings and knowledge gaps identified as part of the desk research. We concluded that we have sufficient observations and case studies regarding the health situation, and life expectancy of the Roma, Ashkali and Egyptian communities. However, we were still short of quantifiable data on these issues. Numerical data was needed to provide reliable a picture of the occurrence and frequency of different diseases and other health problems. Further, reliable data is necessary to calculate the funds required for adequate treatment of diseases prevailing among the Roma, Ashkali and Egyptian communities.

With these findings and knowledge gaps in mind, we defined the key research themes as follows:¹¹

1. Life expectancy;
2. Incidence and prevalence of diseases and health conditions;
3. The potential for increased use of health services resulting from access to national health insurance, and the potential for preventive and ameliorative impacts;
4. Economic implications of increased access to health services.

The research process was guided by the following objectives:

1. Gathering data about life expectancy, incidence and prevalence of diseases, and the current utilization rates of health care services;
2. Gathering confirmatory qualitative data to support or challenge the numerical findings;
3. Estimating the potential for increased use of preventive health care services if covered by the national health insurance
4. Estimating the amount of funding required to provide adequate preventive and curative treatment for the most common health problems affecting the Roma, Ashkali and Egyptian communities.

2.3 Research methods

2.3.1 Household survey

The primary data collection method was a household survey of 394 Roma, Ashkali and Egyptian households in nine Kosovo municipalities. The final sample included 1592 individuals age 12 and over. The survey questionnaire was designed to collect information concerning the following topic areas:

1. Demographic information
2. Employment, education and income
3. Housing conditions and living environment

¹¹ The original project proposal also considered study of the psychosocial health problems and needs of Roma, Ashkali and Egyptian returnees. This was left to consider at a later time due to both costs and challenges that would be required.

4. Residential history
5. Health awareness
6. Nutrition and life choices
7. Diseases or health conditions during the past 12 months
8. Use of health care services during the past 12 months
9. Obstacles in using health care services
10. Family members deceased during the past 10 years

The sampled households are located in all regions of Kosovo except Gjilan/Gnjilane and the four northern municipalities.¹² The survey aimed for a sample with a representative proportion of each ethnic group: 43% Ashkali, 33% Egyptian and 24% Roma. The survey came close to this as the final proportions were: 158 (40%) Ashkali, 142 (36%) Egyptian, and 94 (24%) Roma households. About two thirds of the sampled households are in urban and one third in rural areas, which approximates the distribution of the communities. A full sampling summary with municipalities and sublocalities is provided in Table 1.

Municipality	Urban/ Rural	Sub-Locality	Ashkali	Egyptian	Roma
Ferizaj/Uroševac	U	Sallahane	23	0	2
	R	Halit Ibishi	20	0	0
	R	Dubrava	20	0	0
Fushë Kosova/ Kosovo Polje	U	Neighborhoods 028 and 029	39	7	4
	U	Mahalla e Sefës	0	20	0
Gjakova/ Đakovica	U	Piskota/Dardania	1	19	0
	U	Kolonia/Ali Ibraj	0	16	0
	R	Brekoc	0	13	1
Gračanica/ Graçanicë	U	Town Center	1	1	12
	R	Preoce & Laplje Selo	0	0	12
Kline/Klina	R	Shtupel	0	11	0
	U	Town Center	10	0	0
Lipjan/Lipljan	R	Gadime	9	0	1
	R	Medvec	10	0	0
Obiliq /Obilić	R	Plemetina Village	0	0	17
	R	Plemetina Buildings	5	2	8
Peja/Peć	U	7 Shtatori	0	37	7
	R	Treboviq	0	16	0
Prizren	U	Terzi Mahalla	0	0	15
	U	Lakuriq	0	0	15
Shtime/Štimlje	U	Town Center	20	0	0
Total Sample			158	142	94

Table 1. Research locations

¹² We excluded the four Northern municipalities as the majority of the residents in that area are already covered by the Serbian national health insurance. Should Kosovo adopt a national health insurance system, it is unlikely to be implemented in the North as long as the parallel systems are in place.

Before beginning the full data collection, a pilot survey with 20 households in two municipalities was conducted. Some adjustments were then made to the main survey. The survey was conducted in Albanian language in all areas except the Serbian-majority localities in Gračanica/Graçanicë and Obiliq/Obilić.

A team of fourteen enumerators was trained to carry out the data collection process. In a majority of the cases, the enumerators conducted the survey interviews in their own home localities. In the large urban localities, the enumerators were instructed to make contact with every fifth house, and in the smaller localities, with every third house. In the rural and mixed localities, the enumerators were asked to use their own knowledge to find the eligible Roma, Ashkali or Egyptian households.

The data collection process was generally smooth, on time, and without major disruptions. In Plemetina (Obiliq/Obilić municipality) and 7 Shtatori (Pejë/Pec), the enumerators reported refusals by some households. As these localities have been frequented for research on Roma, Ashkali and Egyptian communities, some residents have become frustrated with “endless surveys but absence of concrete help.” Another challenge resulted from the mass emigration from the summer of 2014. It is estimated that over 100,000 Kosovo citizens left the country by March 2015, many of whom are from the Roma, Ashkali and Egyptian communities. Survey enumerators in Ferizaj/Uroševac, Lipjan/Lipljan and Fushë Kosova/Kosovo Polje reported many houses vacant due to emigration. In some localities, the enumerators had to divert from the sampling instructions in order to achieve the quota. At the end of the data collection process, we were six short of our target of 400 households. Still, with 394 households we were within the 95% confidence level required for a representative sample.

2.3.2 Qualitative interviews

After the completion of the data gathering and entry for the household survey, we conducted qualitative interviews with ten health care professionals, whose names and positions are provided in Table 2. All our informants had many years of experience of working with the Roma, Ashkali and Egyptian communities. The purpose of the interviews was firstly, to provide information to support or challenge the survey findings. Secondly, with the interviews we were able to gather information on issues that are sensitive or stigmatized in the Roma, Ashkali and Egyptian communities. Such problems include, for example, certain skin diseases, sexually transmitted disease, personal hygiene and improper administration of medication. Thirdly, the interviews provided us with valuable recommendations on how to improve health policies and practices for advancement of the health situation of the three communities.

Name and surname	Institution/Organization	Position	Ethnicity
Ardita Tahirukaj	WHO Kosovo	Public Health Officer	Albanian
Avnore Morina	Prospect Project, Gjakova/Đakovica	Health Mediator	Albanian
Faik Hoti	Ministry of Health	Departmental Director	Albanian
Fridon Lala	Balkan Sunflowers Kosova & UNICEF	Advocate Enumerator	Egyptian
Mimoza Beqiri	Health House, Dubrave, Ferizaj/Uroševac	Family Doctor	Albanian
Ramiz Beriša	Health House, Plemetina, Obiliq/Obilić	Laboratory Technician	Roma
Skender Marolli	Main Health House, Fushë Kosovë	Family Doctor	Albanian
Slaviša Radosavljević	Health House, Plemetina, Obiliq/Obilić	Otorhinolaryngologist	Serb
Teresa Janovic	World Bank & IREX	Research Fellow	USA
Zylfije Bajrami	Health House, Gaqke, Ferizaj/Uroševac	Family Doctor	Egyptian

Table 2. Interviewees

3 FIELD RESEARCH 2014-2015 – GENERAL FINDINGS

3.1 Demographics and living conditions

3.1.1 Basic demographics

Age. The median age of our sample is 30 years. This is higher than the Kosovo average of 27.8 years because we excluded children under 12 years of age from our sample. Figure 1 below shows the proportion of household members by age group. As we can observe, nearly half (48.9%) of the household members are less than 30 years of age.

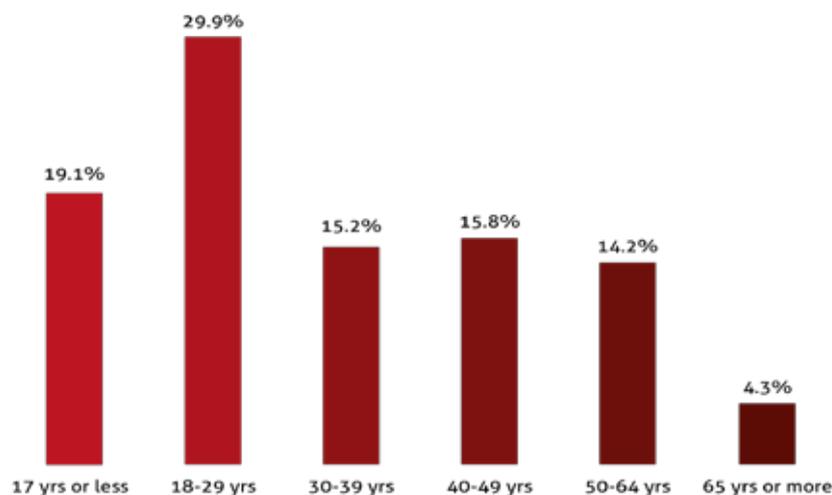


Figure 3. Survey age distribution

Gender. As for gender, we have an almost equal sample of male and female members with males comprising 50.2% (799) of the household members and females the remaining 49.8% (793). Regarding survey interviewees, in 70.4% of the households, the interviewee was of male gender with females constituting the remaining 29.6%. We left it up to the interviewee to decide whether s/he considers him/herself as the head of the household. In cases where the interviewee was a self-declared head of the household, males constitute 74.5% and females 25.5% of the interviewees.

Identity documents. The research has yielded conflicting information about the proportion of Roma, Ashkali and Egyptian citizens lacking identity documentation (hereinafter ID). As many as 40% of individuals from the three communities lacked IDs, according to Human Rights Watch.¹³ However, our survey found that 95.2% of those over 18 years of age possess a Kosovo ID card. We can assume that the registration and documentation of the Roma, Ashkali and Egyptian communities has improved significantly during the past five years. In addition, 10.3% of the respondents possess a Serbian health insurance card.

Marital status. Early marriage and pregnancy at a young age among Roma, Ashkali and Egyptians constitutes a significant physiological and psychological risk for the adolescent women whose bodies are not yet ready for such processes. The problem becomes even more acute if we consider that with or before the early marriage or pregnancy, the young women usually drop out of school. Those who leave school early are more likely to have low awareness of how to take care of their own and their children's health.

Considering these health risks, the survey gathered data about each household member's marital status, their age at their first marriage and women's age at the birth of their first child. Regarding marital status, a majority (56.8%) of the sampled individuals are married or cohabiting. 37.8% are single and the remaining 7.3% are either separated, divorced or widowed. 93.6% of those living as singles are less than 29 years of age.

¹³ Human Rights Watch (2010) Rights Displaced: Forced Returns of Roma, Ashkali and Egyptians from Western Europe to Kosovo. Retrieved from <https://www.hrw.org/report/2010/10/27/rights-displaced/forced-returns-roma-ashkali-and-egyptians-western-europe-kosovo>

Current Age	Mean ¹⁴ age at marriage	Cases
17 or less	15.73	11
18-29	19.37	201
30-39	20.17	215
40-49	20.73	236
50-64	20.15	209
65 or more	18.89	56
Total	20.01	928

Table 3. Respondents' age at first marriage

The age of first marriage ranges from 12 years at the lowest to 42 years at the highest. The average age at time of marriage for the whole sample is 20 years with 18 years for females and 21 years for males. 27.3% have married before reaching age 18. There is no significant difference between the age groups in the age of first marriage. This means that early marriage has hardly reduced over time: the average marriage age of men and women now in their 50s and 60s was almost exactly the same as the average marriage age of men and women now in their twenties. On the other hand, there is a significant positive correlation between education and age of first marriage: the more education one has, the later they are likely to get married.

Mother's age at first childbirth. The average age at birth of the first child (or abortion) is 20 years. As with the case of first marriage, we have not observed significant differences in the age at birth of the first child between different age groups (i.e., those who are in their 20s now compared to those who are now in their 30s, or 40s, or 50s, etc.). However, as with the age of marriage, what we do observe is significant positive correlation between the level of education and age at birth of the first child (or abortion). This finding supports our previous observation that on average, those who are least educated are also most likely to get pregnant at an early age.

3.1.2 Education, employment and income

Education. The education levels are of significance because of the strong correlation between health awareness and years spent in formal education. Therefore, the survey asked the highest education level of each family member. The results for the household members aged 18 and above are presented in Table 5.¹⁵ As we can observe, more than half (52.2%) of the sample have not finished compulsory education up to the end of lower secondary school. More than one quarter (26.1%) completed less than four years of primary education. Even though we can observe some advancement in the education levels of the younger age groups, the levels are still disproportionately low compared to the Kosovo average. For example, according to the recent UNICEF Multiple Indicator Cluster Survey (MICS), the primary school completion rate for the rest of the Kosovo population is 97.3%.¹⁶

Current age	Mean	Cases
17 or less	16.50	2
18-29	19.56	87
30-39	20.47	108
40-49	21.38	120
50-64	20.56	95
65 or more	18.14	28
Total	20.39	440

Table 4. Age of first childbirth or abortion

¹⁴ "Mean" and "average" are synonyms. Mean is used in more formal contexts such as mathematics and research.

¹⁵ We have excluded household members under aged 17 or less because we cannot be sure whether they are still attending school or have dropped out.

¹⁶ The Kosovo Agency of Statistics (2014) 2013-2014 Kosovo Multiple Indicator Cluster Survey, p. vii Retrieved from <http://mics.unicef.org/surveys>

	Frequency	Proportion %
Primary school incomplete	319	26.1
Finished primary school	170	13.9
Unfinished lower secondary school	149	12.2
Finished lower secondary school	282	23.1
Unfinished upper secondary school	57	4.7
Finished upper secondary school	193	15.8
Attended or finished university studies	53	4.2
Total	1223	100.0

Table 5. Education

Employment. The problem of low employment levels of the Roma, Ashkali and Egyptian communities is well recognized. Without employment, income generation opportunities are very limited. Those out of work are eligible for social assistance, which as of 2015, is €75 monthly if they have a child under six years of age. This is one of the criteria to receive social assistance, among many others. Poverty is known to have significant negative impact on people’s health and well being; Inadequate living conditions, low quality food, closer proximity to environmental pollution, and inability to pay medical treatments and medication are just a few of the many health risks associated with poverty. With these problems in mind, the survey queried each family member’s employment situation. The results for the population aged 18 and above are presented in Table 6. As we can see, just above one fifth (21.7%) of our sample is in any kind of employment. To clarify, “self-employed” and “employed” often means recycling and other very low income and irregular forms of income, so even the two thirds (68.0%) of the sample currently unemployed may dramatically underestimate the lack of work.

Table 7 below presents the employment situation according to the educational level. As we can observe, almost half of the unemployed respondents (46.5%) have not attended school beyond primary education. In contrast, those who have finished upper secondary education constitute only 11.5% of the unemployed and those with university education (completed or uncompleted), only 1.6%. Those with the highest level of education also tend to be the best employed. Out of those in employment, 43.0% have upper secondary school education or higher even though they constitute only 20.0% of the overall sample. Of 16364 central level public sector employees, only 78 (0.48%) were from Roma, Ashkali and Egyptian communities.¹⁷

	Frequency	%
Employed	201	16.1
Self-employed	70	5.6
Student or at school	47	3.8
Unemployed	849	68.0
Pensioner	82	6.6
Total	1249	100.0

Table 6. Employment (age 18 and over)

Household Income. Employment levels are of high interest for us because usually the employment situation determines the household’s income level. As part of the survey, we asked the informant about the level and sources of household income. The mean monthly household income among our sample is €201 while the median income is €150. We argue that the median income of €150 is closer to the average, as our sample includes a number of households with a monthly income of over €1000. These households are skewing the mean income upwards.

¹⁷ Ministry for Public Administration.

	Employed	Selfemployed	Pupil / Student	Unemployed	Pensioner
Unfinished primary school	7.1%	13.2%	4.3%	32.0%	36.4%
Finished primary school	11.1%	8.8%	4.3%	14.5%	24.7%
Unfinished lower secondary school	13.6%	13.2%	6.4%	12.4%	10.4%
Finished lower secondary school	20.7%	32.4%	2.1%	24.4%	16.9%
Unfinished upper secondary school	4.5%	4.4%	27.7%	3.6%	2.6%
Finished upper secondary school	30.3%	22.1%	31.9%	11.5%	9.1%
University studies	12.7%	5.9%	23.3%	1.6%	

Table 7. Employment correlated to education level

The 2015 Kosovo average monthly household income is €440.¹⁸ In our sample, only 6.9% of households have an income equal to or higher than the Kosovo average. UNICEF uses €1.147 per person per day as the poverty line in Kosovo, equaling a monthly income of €42.50.¹⁹ However, in 67.60% of the sampled Roma, Ashkali and Egyptian households, the monthly income per person is less than €42.50. The rural situation is even more severe with an average per person income of €35.10.

As part of the survey we also investigated the most common sources of income among the Roma, Ashkali and Egyptian communities. The results are presented in Table 6. As we can see, formal work in the private, public or non-governmental sectors generates the highest average monthly income, which is €224.10. This category also includes formal self-employment such as running of private business. Less than half (46.5%) of the households have at least one member earning income from formal work. Yet, formal work is still the most common individual source of income.

Remittances and other non-state assistance constitute the second highest source of income with a mean of €155.70. A total of 57 households (14.6%) are receiving this type of income. Another source of income is informal work that typically involves collecting and selling recyclable trash or temporary work at construction sites. On average, this sector generates a monthly income of €126.00. Seventy five households (19.2%) have at least one member making income from informal work.

Social assistance from the state generates the lowest average monthly income of €102.80. This finding is worrying because social assistance from the state is the only source of income for 82 households (21.5% of the sample). In total, 148 households (38%) are in receipt of one or more types of social assistance.

¹⁸ Kosovo Agency of Statistics cited in Trading Economics: Kosovo Average Monthly Wages. Retrieved from <http://www.tradingeconomics.com/kosovo/wages>

¹⁹ UNICEF (2010) "Child Poverty in Kosovo: Policy Options Paper and Synthesis Report" http://www.unicef.org/kosovoprogramme/Child_Poverty_ENG%282%29.pdf

3.1.3 Living and housing conditions

Life satisfaction. Numerous existing studies have established a link between life satisfaction and good health. For example, a multi-country study by Grant and his colleagues demonstrates a strong correlation between life satisfaction and healthy life choices among young adult population.²⁰ Bearing these findings in mind, we asked each interviewee about their perceived level of life satisfaction. Firstly, we asked to what extent they agree with the statement “The conditions of my life are excellent”. The results, as illustrated in Figure 2 reveal 54.5% of the respondents rather disagree with the statement as opposed to 32.6% who rather agree with the statement.

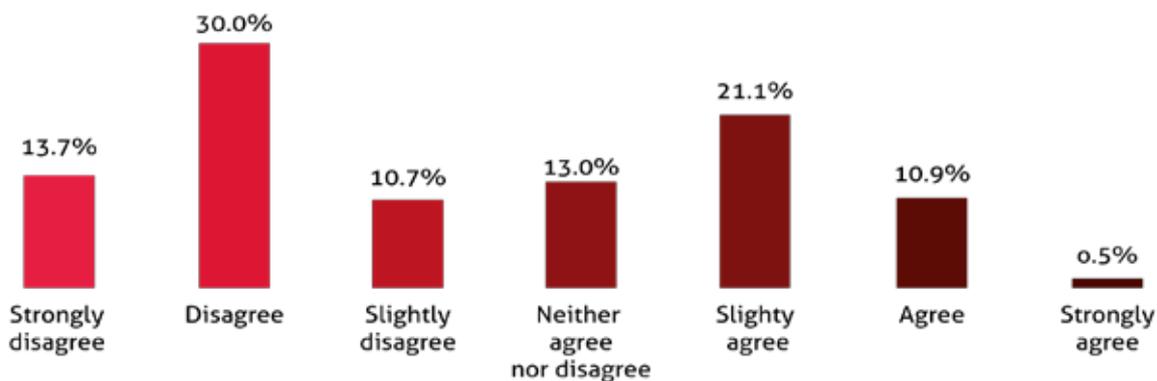


Figure 4. The conditions of my life are excellent.

The survey confirms a strong correlation between life satisfaction and the per capita household income. The results are presented in Figure 3. We can observe that life satisfaction is significantly lower among households where the average per capita income is less than the median of €28 per month. Those who agree that the conditions in their life are excellent tend to have much higher per capita household income than those who disagree. For example, those who “Agree” that their life conditions are excellent have an average per capita household income of €70 per month.

Secondly, we asked the respondent to what extent they agree with the statement “I am satisfied with my life.” The results, illustrated in Figure 4, are highly similar with the statement on life conditions. However, we can observe that those who agree being satisfied with their life constitute about the same proportion of the sample (41.2%) as those who disagree (43.9%).

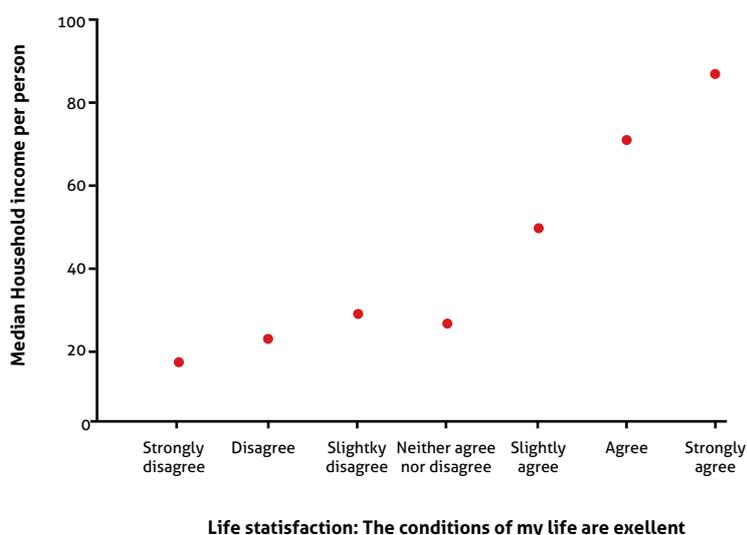


Figure 5. Correlation of household income and perceived life satisfaction.

²⁰ N Grant, J Wardle, A Steptoe (2009). “The Relationship Between Life Satisfaction and Health Behavior: a Cross-Cultural Analysis of Young Adults”. International Journal of Behavioral Medicine. 16(3). 259-268.

Figure 5 shows a slight but still statistically significant correlation between perceived life satisfaction and per capita household income. On average, those who disagree being satisfied with their life have a per capita household income less than the overall median of €28. In contrast, those who agree have a median household income higher than €28. Housing Conditions. Along with nutrition and other life choices, housing and living conditions are demonstrated to have strong effect on human health.²¹ Previous studies connect the poor health situation of Roma, Ashkali and Egyptian communities to inadequate housing and living conditions.

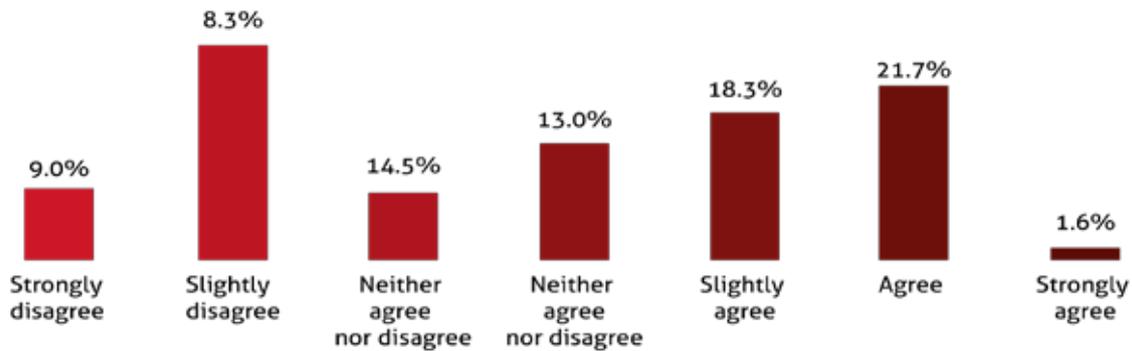


Figure 6. I am satisfied with my life.

A household survey aim was to find out to what extent housing and living conditions have changed since the other studies were conducted. We were also hoping to be able to do correlation tests between living conditions and certain diseases such as hepatitis or respiratory diseases.

Each respondent was asked in what type of household they live and what amenities they have. The results reveal that 96.4% of the households reside in a house and the rest in apartments. No household in our sample is living in a special form of dwelling such as a container or barrack. 84.2% of the households own the property that they inhabit. 8.6% live in their homes on a temporary basis but do not pay rent. The remaining 7.2% are either renting their home or living in municipal social housing.

Even more important than the type of housing is the availability of different household amenities. Presence or absence of certain amenities can make a significant difference in the residents' health. For example, availability of piped water and bathing facilities is important for personal hygiene. Presence of proper sanitation facilities is essential for prevention of waterborne diseases. Furthermore, refrigerators and freezers can reduce incidence of diseases associated with poor food hygiene.

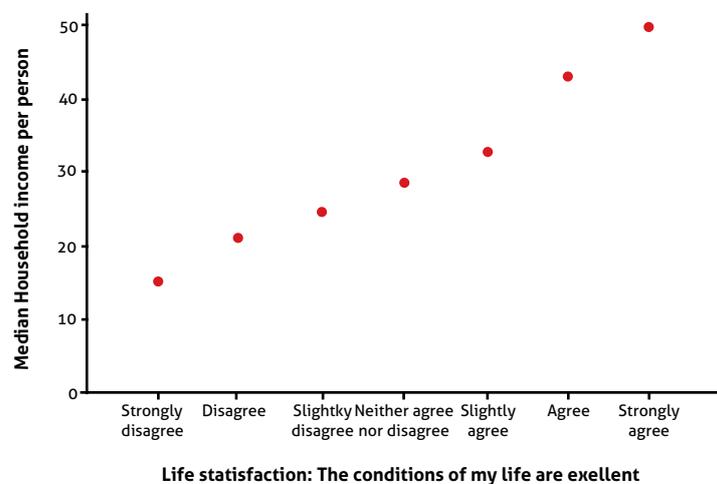


Figure 7. Correlation of household income and perceived life satisfaction

²¹ Krieger, James & Higgins, Donna L. (2002) "Housing and Health: Time Again for Public Health Action." American Journal of Public Health 92(5), pp. 758-768

The percentage of households lacking certain amenities is presented in Figure 6. As we can observe, nearly all surveyed Roma, Ashkali and Egyptian households have electricity and piped water inside their dwellings. Hence, the situation has improved dramatically from year 2004, when nearly 25% of the families belonging to these communities lacked access to piped water.²² However, in some municipalities, tap water is not available on a 24-hour basis. For example, in Obiliq/Obilić, Gračanica/Graçanicë and Fushë Kosova/Kosovo Polje municipalities, water availability can be as short as four hours per day.

Of households, 18.1% do not have an indoor toilet. This is a major improvement from 2000, when reportedly as many as 60% of Roma, Ashkali and Egyptian households lacked an indoor toilet.²³ The advancement in house sanitation is also supported by the MICS results, which show that 89.1% of the dwellings of the three communities have improved sanitation facilities.²⁴ On the other hand, 18.1% percent of the dwellings are not connected to the sewage system. This is particularly a problem in some of the neighborhoods in Pejë/Peć, Gjakova/Đakovica, Gračanica/Graçanicë and Kline/Klina. Further, our qualitative interviews with health care professionals reveal that in a number of neighborhoods in Gjakova/Đakovica, Fushë Kosova/Kosovo Polje and Obiliq/Obilić, the sewage network is overflowing.



Figure 8. Halil Berisha

Living Environment. Previously conducted studies among the Roma, Ashkali and Egyptian communities have discovered high prevalence of diseases caused and accelerated by a polluted living environment. Most notable cases include the internally displaced persons camps close to the lead-contaminated slag of Mitrovica, and the village and social housing buildings of Plemetina close to the extremely polluting power plants and coalmine. In this survey, we aimed to discover to what extent the living environment impacts the health of the Roma, Ashkali and Egyptian communities. The survey asked about the prevalence of certain types of air, water, soil and noise pollution.

As illustrated in Figure 7, the most reported environmental problems for the Roma, Ashkali and Egyptian communities include dust in the air (63.4% of the sample), garbage in the air, i.e. burned garbage smell, 48.1%, and odor of household waste (42.5%). There are also other commonly occurring problems such as odor of human waste (32.1%), noisy road or train traffic (30.3%) and water polluted with garbage (22.1%). Problems such as bad odor caused by household or human waste are occurring in a majority of the sampled localities. These findings reflect poor communal waste collection and inadequate sewage treatment in many of the localities with high number of Roma, Ashkali and Egyptian households.

²² UNDP Human Development Report for Kosovo (2004) cited in the Strategy, p. 33

²³ Ibid.

²⁴ MICS. According to the UNICEF definitions, improved sanitation facilities include: a. Flushing toilet connected to sewage network or septic tank; b. Pit toilet with a slab.

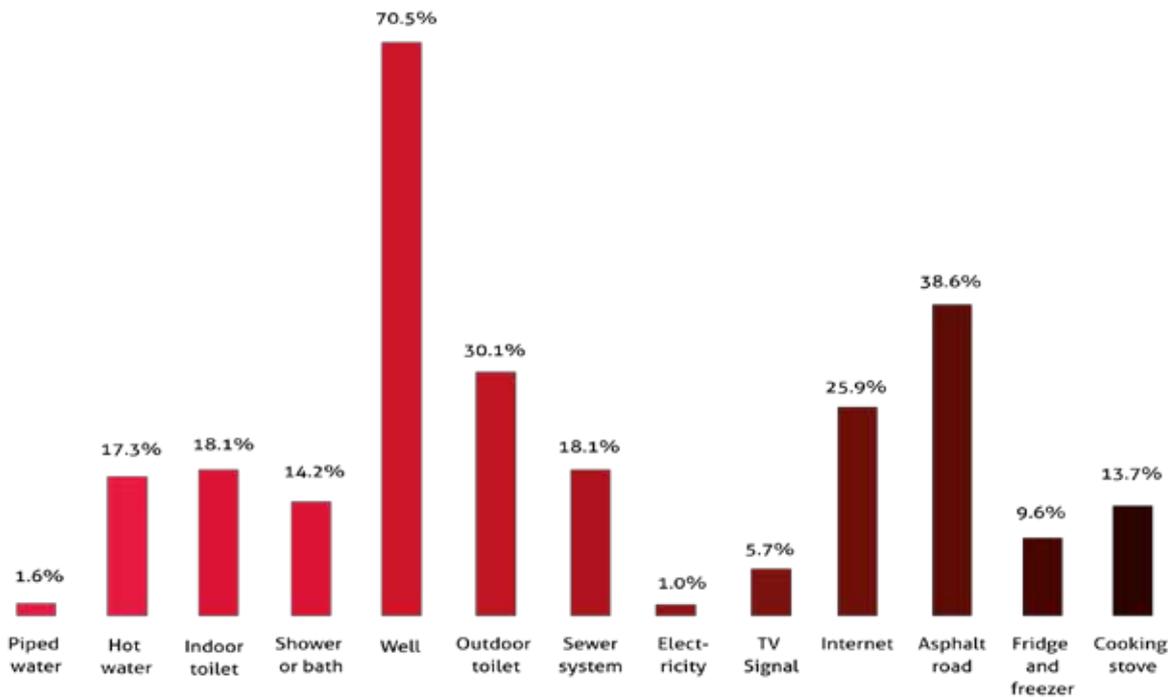


Figure 9. Percentage of households without amenities

In contrast, some environmental hazards appear to be concentrated in certain localities. For example, in addition to the village of Plemetina (Obiliq/Obilić municipality), air pollution appears to be a major problem in 7 Shtatori of Pejë/Pec and Neighborhoods 28 and 29 of Fushë Kosova/Kosovo Polje. In addition, many of the households in Gjakova/Đakovica and Klina complain about dust and garbage in the air. As for water pollution, Neighborhoods 28 and 29 of Fushë Kosova/Kosovo Polje and Plemetina of Obiliq/Obilić are the worst affected localities. Especially worrying is the high number of households affected by sewage pollution. Similar problems are also occurring in neighborhoods of Mahalla e Sefës and Piskota in Gjakova/Đakovica and parts of 7 Shtatori of Pejë/Peć.

Polluted living environments contribute to the prevalence of many commonly occurring diseases such as diseases of the respiratory and genitourinary system. Also, many gastrointestinal and skin diseases can be connected to unsanitary living environments. In addition, development of some types of cancers is strongly connected to air, water and soil contamination. Detailed information about the impact of environmental factors on incidence of diseases can be found in Chapter 4.2: Occurrence and Prevalence of Diseases.

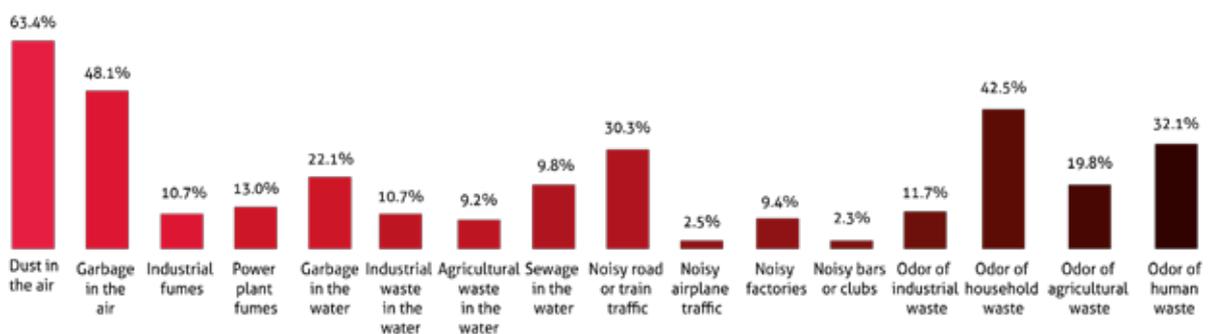


Figure 10. Environmental problems.

Housing History. Displacement and forced repatriation are demonstrated to have strong effect on psychological health. Since psychological and physical health is closely connected, we predict that individuals with a history of displacement or forced repatriation are also suffering from physical diseases to a higher extent than those never displaced. During the war in Kosovo between 1998-1999, as many as 100,000 Roma, Ashkali and Egyptians were displaced.²⁵ Many of them left Kosovo for other countries but up to 50,000²⁶ remained as internally displaced persons (IDPs) in Kosovo or Serbia. Even more people from these communities became displaced after the civil disturbances of March 2004. For the past ten years, Germany, France and other European Union countries have organized systematic returns of immigrants originating from Kosovo. Out of the 21,500 returnees, around 18% are estimated to belong to the Roma, Ashkali and Egyptian communities.²⁷

We asked each household whether any of the household members have a history of displacement or forced repatriation. Out of all households, 79.3% are permanently settled and have never been displaced. A further 14.3% have a history of displacement but are now permanently settled. The remaining 7.1% continue to live in internal displacement. In total, in 74.8% of households not one member has ever been displaced. However, 22.6% of the households have at least one member with a history of displacement and in 2.6%, all household members have been displaced. In 90.4% of the households no members have been forcibly repatriated. In the remaining 9.6%, at least one member of the household has been forcibly repatriated. Notably, out of eight households with a history of forced repatriation, six are in Gjakova/Đakovica.



Figure 11. Housing History

The figures on displacement and repatriation are, to a large degree, lower than suggested by the previous studies. The following are a few possible explanations for these findings:

- Many families may have been displaced during 1998-1999 but have afterwards resettled. Those who consider their new locality as their new home may no longer regard themselves as internally displaced.²⁸

²⁵ OSCE-ODIHR, p. 2

²⁶ Minister of Human and Minority Rights (Serbia) cited in UNHCR (2007) Analysis of the Situation of Internally Displaced Persons from Kosovo in Serbia: Law and Practice, p. 11. Retrieved from <http://www.refworld.org/pdfid/4704bff72.pdf>

²⁷ STP Report, p. 44

²⁸ Here we also come across with the problem that there is no precise internal definition on the period of time after which the "IDP" status comes to an end.

- A number of former IDPs are currently residing in the North of Kosovo, which was not included in our sample. There is also a large IDP settlement in the southern part of Mitrovica, which was also not included in our sample. Therefore, as a result of our sampling procedure we may have missed a considerable number of households with a history of displacement or repatriation.
- When data collection was taking place in September 2014, a large number of people had recently left Kosovo. A high proportion of these recent emigrants were Roma, Ashkali and Egyptians. Our enumerators in Ferizaj/Uroševac, Lipjan/Lipljan and Fushë Kosova/Kosovo Polje reported a large number of dwellings in their localities being vacant because of emigration. There have been reports that in many cases, those who have recently left Kosovo have earlier been repatriated from Germany, Austria or other countries. Thus, the current emigration wave can partially explain the low presence of households with a history of forced repatriation.

With the low number of households with a history of forced repatriation, we are thus unable to identify any specific health problems concerning the repatriate population. Identifying the health and psychosocial needs of the repatriate citizens will thus be a matter of the future research projects.



Figure 12. Halil Berisha, house.

3.2 Health perceptions and awareness

3.2.1 Self-perceived health status

A simple but helpful way to estimate the health situation of a population segment is to ask the survey respondents how they perceive their own health. Comparison of subjective (self-perceived health status) and objective (presence of diagnosed diseases) can also help to estimate the levels of health awareness among the population.

In our survey, we asked each respondent to rate their own and their household members' health situation. Table 8 gives the results for the whole sample and Table 9 for the adult-aged population aged 18 and over. In both cases, those who see themselves in "very good" health constitute over half (56.7% and 50.3%) of the sample. About one fifth (19.0% and 20.6%) are said to be in "fairly good" health. Those in a "fairly bad" or "very bad" health constitute about one eighth (11.1 % and 13.2%) of the sample.

According to our data, 86.8% of the Roma, Ashkali and Egyptian individuals have a positive perception of their health status. This finding is in line with results of health studies in other countries of Southeast Europe. For example, according to a 2012 UNDP study, 84.0% of the Roma in Serbia, 86.0% in Macedonia and 88.0% in Albania, Croatia, and Bosnia and Herzegovina have a positive self-perception of their health.²⁹

3.2.2 Limitations in daily activities

However, as emphasized in the UNDP Roma Inclusion Working Papers, the positively self-perceived health status should not be interpreted to mean good general health situation among less educated communities.³⁰ Another way to investigate the subjective perceptions of the health situation is to ask about the level of limitations on daily activities because of a disease or health condition. As part of our survey, we asked about each household member's diseases during the past 12 months. (More information is available in Chapter 4.2: Occurrence and Prevalence of Diseases). In addition, we asked the respondents to assess to what extent the household member is limited in his/her daily activities because of a disease.

Very good	56.7
Fairly good	19.0
Neither good nor bad	13.2
Fairly bad	7.1
Very bad	4.0

Table 8. Self-perceived health whole survey population

Very good	50.3
Fairly good	20.6
Neither good nor bad	15.9
Fairly bad	8.3
Very bad	4.9

Table 9. Self-perceived health survey population age 18 and over

²⁹ UNDP Europe and the CIS (2012), The health situation of Roma communities: Analysis of the data from the UNDP/World Bank/EC Regional Roma Survey, p. 16. Retrieved from <http://www.undp.org/content/dam/rbec/docs/The-health-situation-of-Roma-communities.pdf>

³⁰ *ibid*, p. 16

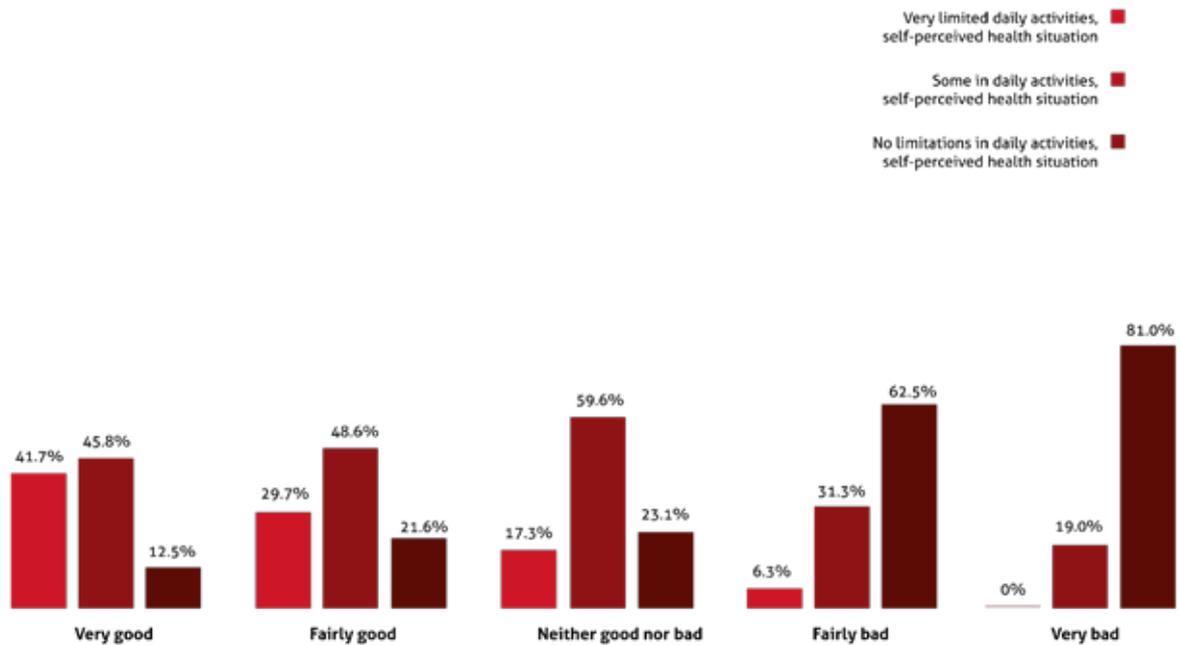


Figure 13. Self-perceived health situation vs. Limitation in daily activities

The comparison between the self-perceived health situation and self-assessed level of limitations in daily activities is presented in Figure 13. Even though for most part we can observe a correlation between the self-perceived health situation and level of limitations, we can also notice some remarkable discrepancies between the two. For example, 45.8% of those with a self-perceived health situation as “very good” have assessed themselves as “Somewhat limited” in their daily activities. Similarly, of those with a “fairly good” health situation, 48.6% are self-evaluated as “somewhat limited” and even more strikingly, 21.6% as “very limited.”

3.2.3 Subjective vs. objective state of health

Considering the findings above, should we now be able to identify discrepancies between objective and subjective states of health? In order to explore this issue, we have taken a look at the number of household members with diagnosed diseases and their self-perceived health status as evaluated by the survey respondent. What we notice is dramatic discrepancies between in the objective and subjective evaluations of health status. For example, out of the 625 household members (14.8%) with a self-perceived health status of “very good”, 69 have been diagnosed with a disease. This includes individuals with serious long-term diseases such as diabetes, hypertension and cardiovascular diseases. A further 25.3% of those with a “fairly good” self-perceived health have a diagnosed disease. Again, this includes individuals with dangerous longterm diseases such as cancer and heart diseases.

Qualitative interviews with health care professionals may help explain why people with serious chronic diseases could have a positive perception of their own health. For example, according to Dr. Slaviša Radosavljevic of Plemetina, Obiliq/Obilić, individuals from the Roma, Ashkali and Egyptian communities generally wait to seek medical treatment until seriously suffering because of the symptoms.³¹ Hence, it is common in these communities not to consider a person “sick” as long as s/he is not limited in everyday activities. Similarly, Gjakova/Đakovica Health Mediator Avnore Morina has observed that many people stop taking prescribed medication as soon as the symptoms begin to disappear. Practices such as late seeking of health care and inadequate administration of medication suggest that in the Roma, Ashkali and Egyptian communities, there is a high threshold for considering a person to be in need of treatment.

³¹ Interview, November 2014.

3.2.4 Health awareness

Poor health awareness commonly correlates with low education levels. Limited knowledge of factors affecting human health is one of the reasons behind the worse than average health situation of the Roma communities across Europe. That lower education levels of Kosovo Roma, Ashkali and Egyptian populations impact health awareness also negatively affects the general health of these communities.

In order to evaluate the health awareness among our sample, we asked respondents to what extent they agree that the following factors are harmful to health:

- i. Smoking
- ii. Overweight
- iii. Lack of physical exercise
- iv. Polluted living environment
- v. Limitations on body and hand washing

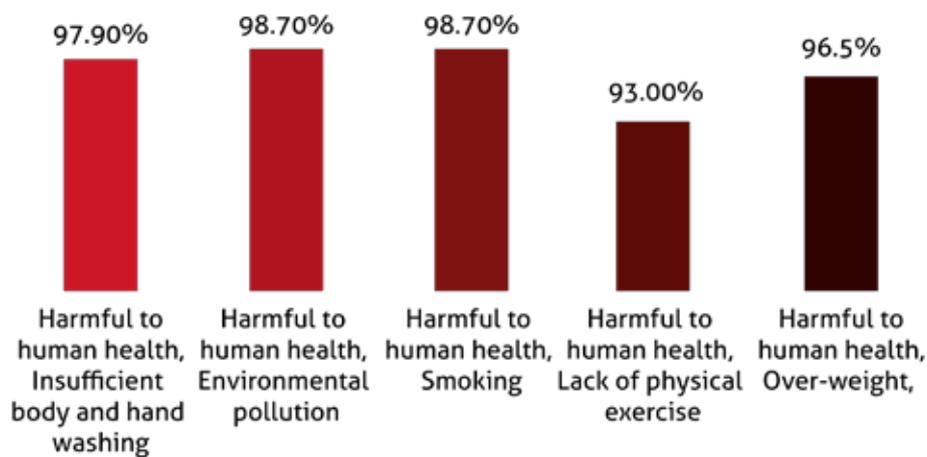


Figure 14. What is harmful to human health?

As illustrated in Figure 15, nearly all respondents agree that each of these factors is harmful to human health. Still, there is a discrepancy between health beliefs and actual health practices. As illustrated in Figure 15, 48.9% of those smoking daily “Strongly agree” that smoking is harmful to human health of whom 29.0% smoke 20 or more cigarettes per day.

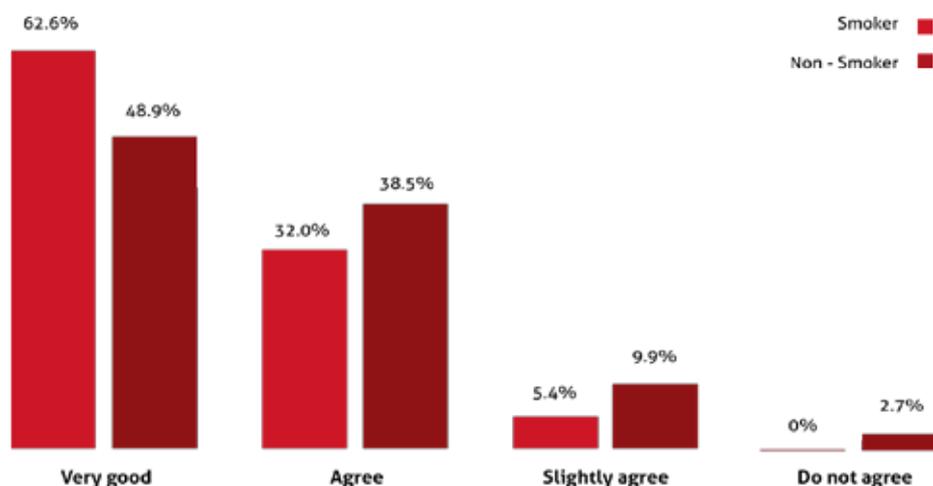


Figure 15. Smoking is harmful to human health

Figure 16 shows that 53.7% of those who are engaged in physical exercise “less than weekly or never” “Agree” that lack of physical activity is harmful to human health.³² Overall, 92.7% of those engaged in physical exercise “less than weekly or never” agree at least slightly with the statement. Accordingly, as with smoking, despite awareness of the harmful health effects resulting from lack of physical activity, the engagement in such activities remains low in the Roma, Ashkali and Egyptian communities.

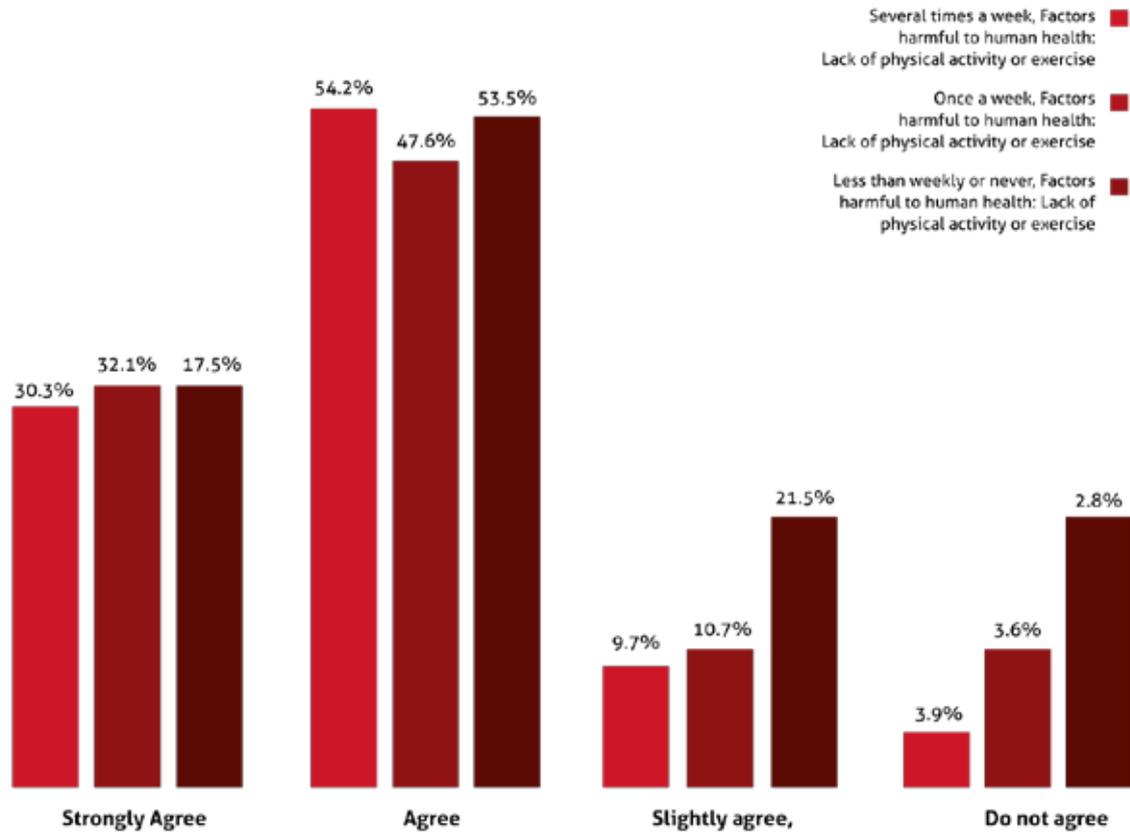


Figure 16. Lack of physical exercise is harmful to human health

Despite the awareness of health risks, Roma, Ashkali and Egyptian communities like most everyone everywhere are slow to change life style. For instance, Dr. Radosavljevic has advised many of his patients to lose weight to ease their disease.³³ However, patients do not have information or resources on how to lose weight. Other informants expressed concern about the poor home and communal hygiene. According to Dr. Mimoza Beqiri of Dubravë, Ferizaj/Uroševač, gastrointestinal diseases are commonplace in her community as a result of inadequate kitchen and food hygiene.³⁴ Survey and interview findings suggest that the knowledge problem is not so much the connection of nutrition, exercise, smoking, etc. to health, but rather of the strategies or resources to support making changes.

³² Households in Shtime/Štimlje and Gračanica/Gračanicë municipalities have been excluded from these statistics due to inconsistencies in the data

³³ Interview, December 2014.

³⁴ Interview, December 2014.



Figure 17. As expected, cardiovascular diseases constitute the most commonly occurring health problem among the three communities. Out of all the respondents aged 30 or over, nearly 30% are affected by one or more types of cardiovascular disease. Additionally, nearly 7% are suffering from bronchitis or other type of disease of the respiratory system, whereas metabolic diseases, mainly diabetes, are affecting 6% of the population. Generally, the health of the Roma, Ashkali and Egyptians begins to deteriorate around the time an individual turns 40 years old.

4. FIVE POLICY FOCUS AREAS

4.1 Life expectancy

4.1.1 Background

Currently, there is not reliable statistical data available on the life expectancy of the Kosovo Roma, Ashkali and Egyptian communities. As part of our preliminary research, we took a look at other types of data that could indicate the lower life expectancy of the three communities compared to the Kosovo population as a whole. In the absence of death statistics in Kosovo, we took a look at the situation in the neighboring countries³⁵. For example, according to a 2007 study in Serbia, the Roma population on average dies 10-12 years earlier than the other people.³⁶ This gives strong suggestion that the Roma, Ashkali and Egyptian populations of Kosovo also die considerably younger than people from the other communities.

Kosovars' life span is around 70 years.... I started getting more interested in this subject. I was surprised to find out that the average life span of our communities of Roma, Ashkali and Egyptians doesn't exceed 55 years. Living 15 years less than my Albanian and Serbian neighbors! I didn't receive it well; the classroom started spinning around in my head. I ask myself, why my community has such a short life? Why should I live such a short life!?

**Rrahim
Student in Plemetina
LIVES Film, 2014**

As part of our survey, we asked the respondents information about their family members and close relatives who were deceased during the past ten years.³⁷ In the process of data analysis, we took a look at the descriptive statistics on age of death, regional differences in the age of death and mean differences between the three ethnic groups.

³⁵ The most reliable life expectancy analysis includes a minimum population size, and comprehensive reporting of births and deaths to legal institutions – all of which are insufficient in this case.

³⁶ Dragan Bogdanović, Dragana Nikić, Branislav Petrović, Biljana Kocić, Jovica Jovanović, Maja Nikolić, and Zoran Milošević. "Mortality of Roma Population in Serbia, 2002-2005." *Croatia Medical Journal* 48 (2007): 720-726

³⁷ For the questions regarding the deceased family members and relatives, refer to Annex 2

Following this, we also produced descriptive statistics on the causes of death. We also investigated to what extent the deceased individuals were receiving medical treatment and whether this is having any impact on the age of death. For further explanations for the low life expectancy, we have also taken a look at the qualitative interviews in order to find out the health care professionals' opinion on the issue.

4.1.2 Average age of death

As part of the household survey, we gathered information about 312 Roma, Ashkali and Egyptian individuals who had died during the past ten years. The mean age of death for this sample is 58.7 years and the median 63 years. For the male population, the mean age of death is 57.4 years and for the female population, 59.9 years. Based on these numbers, we can postulate that the life expectancy for the three minority communities is 13.1 years lower than the Kosovo average of 70.5 years. However, this must be considered at best a rough estimate. Internationally accepted practices in determining life expectancy include calculations based on statistically complete records of live births, and complete reporting of deaths. Neither complete reporting of live births nor of deaths takes place in the Ashkali, Egyptian and Roma communities in Kosovo.

The complete distribution of the ages of death is depicted in Figure 18.

Out of the 312 deceased family members, ten individuals have died as infants before reaching their first birthday. The oldest age of death is 93 years with a total of two individuals having reached the age of 90 or above. About one third (34.2%) of the sample reached age 70, the average age of death for the general population of Kosovo. We have been unable to identify significant differences in ages of death between the Roma, Ashkali and Egyptian communities. Thus, holding the other factors constant, all three communities can be assumed to have a similar life expectancy regardless of their ethnicity.

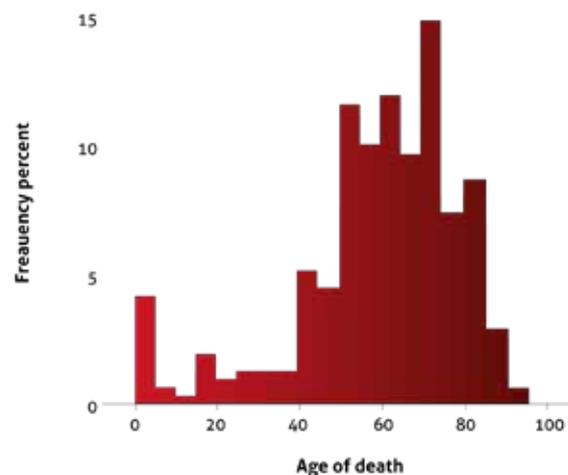


Figure 18. Distribution of the ages of death

The survey identified considerable regional differences in the ages of death. For example, rural Ashkali, Egyptian and Roma populations live, on average, six years less than their urban coethnics.³⁸ The highest average age of death at 70 years is in Prizren city where all the sampled households are located in urban settings. In contrast, in Gračanica/Gračanicë municipality, the average age of death at 49 is more than 20 years less than in Prizren. We can only speculate if this difference is due to different economic levels, urban vs. rural, level of pollution, health care services, or other cause.

³⁸ The regional differences in the ages of death should be treated with some caution since in 51.7% of the cases, the deceased individual did not live in the same household with the survey respondent.

4.1.3 Causes of death

We asked survey respondents about the causes of death of their deceased family members. The most common individual cause of death was brain infarction (stroke) with 68 cases, 21.8% of the sample. The second most common cause at 14.4% was cancer. Heart diseases constituted the third highest cause of death at 10.2%. 41 respondents (13.1%) were reported as dying of "old age" or "natural causes".

	Frequency	Percent
Brain infarction	68	68
Cancer	45	45
Natural	41	41
Heart diseases	33	33
Hypertension	19	19
Respiratory diseases	18	18
Other	16	16
Multiple diseases	13	13
Diabetes	12	12
Kidney diseases	12	12
Accident	11	11
Gastrointestinal diseases	11	11
Not known	7	7
Thrombosis	3	3
Tumor	3	3

Table 10. Causes of death

85.2% had been receiving full and 9% partial treatment for their disease.

We also asked, whether the treatment was affordable for the family of the deceased individual. In 46.5% of the cases, treatment was perceived as fully affordable for the family. A further 38.7% were able to afford the treatment partially. The respondents in 15.3% of the cases considered treatment unaffordable. We did not observe any significant difference in the affordability of treatment between localities or ethnic groups.

Based on these findings, we are unable to conclude that the low life expectancy of the Roma, Ashkali and Egyptian communities results mainly from lack of treatment or inaccessibility of health care services. To a certain degree, inability to afford medical treatment can help to explain low life expectancy. In 54% of the cases, the deceased person was unable to afford full medical treatment for the disease or other problem that caused the death.

Qualitative interviews helped identify possible other reasons for the low life expectancy. Many of our informants agree that problem is not the absence of treatment as such but failure to seek medical treatment at the early stage of a disease. In such cases, treatment of the disease is usually more difficult, more expensive, and with less positive outcomes.

Another serious problem that might affect life expectancy is the inadequate adherence to the medication regimen or other treatment. For instance, according to Dr. Radosavljevic of Obiliq/Obilić, it is common that his patients stop taking the prescribed treatment as soon as the symptoms begin to disappear. As a result, the symptoms may ease for a while but the disease will continue to persist. At some point, it will be too late to treat the disease with the limited resources available at a community health house. Of course, from the limited number of interviews, we cannot be sure, to what extent the inadequate or late treatment constitute a problem in all Kosovo Roma, Ashkali and Egyptian communities.

57.8% of those who died of cancer were deceased between 40 and 59 years old. Infarction appears to be more fatal in the older age groups as 75.6% have died of infarction between 50 and 79 years of age. This age group is also most affected among those who have died of various heart diseases.

4.1.4 Treatment coverage

As one hypothesis, we assumed that the low life expectancy of the Roma, Ashkali and Egyptians is related to these communities' lack of access to health care services. The survey explored to what extent this is the case among the deceased family members of the survey respondents. In 86.4% of the cases, full medical treatment was reported as available for the disease that is believed to have caused the death. Of the deceased,

4.1.5 Discussion and recommendations

Our findings support the observation that Roma, Ashkali and Egyptian individuals have more than ten years lower life expectancy than their neighbors from other communities. The low life expectancy provides evidence that the Roma, Ashkali and Egyptian communities are unable to enjoy “the highest attainable standard of health” as declared in the WHO Constitution.³⁹ Accordingly, we consider the low life expectancy and the poor health situation of the three communities as a human rights issue that needs urgent intervention from the Kosovo authorities. Addressing the low life expectancy requires further research about the factors that lead to early mortality. To take cost-effective action towards reducing premature deaths, we need further investigation.

Since life expectancy is closely connected to the state of health, we urge all relevant actors to take action towards improving the health of these communities. Recommendations for the national government, local governments, international organizations, non-governmental organizations and the community actors follow here and are included in the other four chapters of this section.

Concerning life expectancy as such, we still need more accurate information about the ages when people die. Currently, many and perhaps the majority of the deaths in Roma, Ashkali and Egyptian communities tend to remain unreported. Therefore, more precise, scientifically backed estimates not only about life expectancy but also about the causes of death among the three communities are unavailable. In order to address this issue, we recommend the following activities:

1. The national government together with local authorities and non-governmental organizations should determine the extent of death registration of Roma, Ashkali and Egyptians and identify the reasons for non-reporting of deaths.
2. The abovementioned actors should act to ensure universal reporting of mortality. The national government and other relevant actors should consider means such as financial incentives for families of deceased persons tied to reporting,⁴⁰ and increased data requirements linking health institutions, municipalities, and parties involved in burials to the Kosovo Statistical Agency.
3. Policies or practices implemented to increase reporting of deaths should also to the extent possible record the cause of death.
4. National health institutions should undertake wide, or at least exploratory, screenings for some of the most common mortal diseases to assess the possibility to increase early detection and intervention.



Figure 19. Halil Berisha

³⁹ Constitution of the World Health Organization, 1954.

⁴⁰ Some countries pay out a final pension payment equal to multiple months of a regular pension when a pensioner dies. Besides helping families cope with expenses, it can also act as an incentive for reporting.

4.2. Occurrence and prevalence of diseases

4.2.1 Most common diseases

A primary research aim was to find the magnitude of various diseases among the Roma, Ashkali and Egyptian communities. Hence, the survey asked about each family member's diseases during the past 12 months. We found that disease affected 494 household members (31% of the sample) over 12 years of age during this period. A doctor diagnosed the disease in 95.4% of the cases. A vast majority (89.7%) of those with a diagnosed disease are currently under full medication or other treatment. Seven most commonly occurring disease groups are presented in Table 11.

Disease	Count	% Of Affected	% Of Grand Total
Circulatory system diseases	162	33	10
Nervous system diseases	63	13	4
Respiratory system diseases	55	11	3
Endocrine, nutritional and metabolic diseases	41	8	3
Musculoskeletal system and connective tissue diseases	40	8	3
Genitourinary system diseases	37	7	2
Digestive system diseases	33	7	2

Table 11. Most common diseases

The most prevalent diseases are presented in Table 11 according to the International Classification of Diseases (ICD) codes. Circulatory system diseases are the most prevalent diseases in the Roma, Ashkali and Egyptian communities. This type of disease has affected a total of 162 household members, which is 10% of the total sample and 33% of those affected by any disease during the past 12 months. The most commonly occurring disease in this group is hypertension that affects 127 household members. The second most common diseases are those of the nervous system. This includes diseases such as stroke, epilepsy and migraine and the most frequent of these is a brain stroke with 25 identified cases. Respiratory system diseases are the third most common type of health problem. The disease was described generally as a "problem with respiration", but we also captured some cases of bronchitis, asthma and tuberculosis. As expected, endocrine, nutritional and metabolic diseases, mainly diabetes, are also highly prevalent. There is also a high occurrence of diseases of the genitourinary and digestive systems.

However, these figures do not reveal a picture of the whole situation. Generally, the most prevalent diseases such as hypertension, cardiovascular diseases and type 2 diabetes rarely occur before age 30. On the other hand, nearly half (48.9%) of our sample are less than 30 years of age.⁴¹ As 408 individuals or 82.5% of those affected by any disease are over 30 years old, we must look at the disease occurrence among those aged 30 or more. The results for this age group are summarized in Table 12.

⁴¹ For diabetes, see for example: Centers for Disease Control and Prevention: Diabetes Public Health Resource: Distribution of Age at Diagnosis of Diabetes Among Adult Incident Cases Aged 18–79 Years, United States, 2011. Retrieved from <http://www.cdc.gov/diabetes/statistics/age/fig1.htm>
For hypertension see Center for Diseases Control and Prevention: Centers for Disease Control and Prevention: High Blood Pressure Facts.

Disease Classification	Count	% of all over 30s	% of affected age 30 and over
Diseases of the circulatory system	162	20.58%	39.71%
Diseases of the nervous system	63	8.01%	15.44%
Diseases of the respiratory system	55	6.99%	13.48%
Endocrine, nutritional and metabolic diseases	41	5.21%	10.05%
Diseases of the musculoskeletal system and connective tissue	40	5.08%	9.80%
Diseases of the genitourinary system	37	4.70%	9.07%
Diseases of the digestive system	33	4.19%	8.09%

Table 12. Disease occurrence over age 30.

As we can see, out of those aged 30 or older, 20.5% are suffering from circulatory system diseases, 8.0% from nervous system diseases and 6.9% of respiratory system diseases. Figure 5.4.1 presents the general trend of disease occurrence in each age group. The findings reveal a dramatic proportional increase in the occurrence after 30 years of age. Even more remarkable change happens in the 40-49 age group, as disease has affected over half (50.6%) during the past 12 months. Statistical analysis reveals that, on average, the odds for being sick for those over 30 years of age are 10 times higher than for those younger than 30 years (OR= 9.82, CI=95%, P < 0.01).

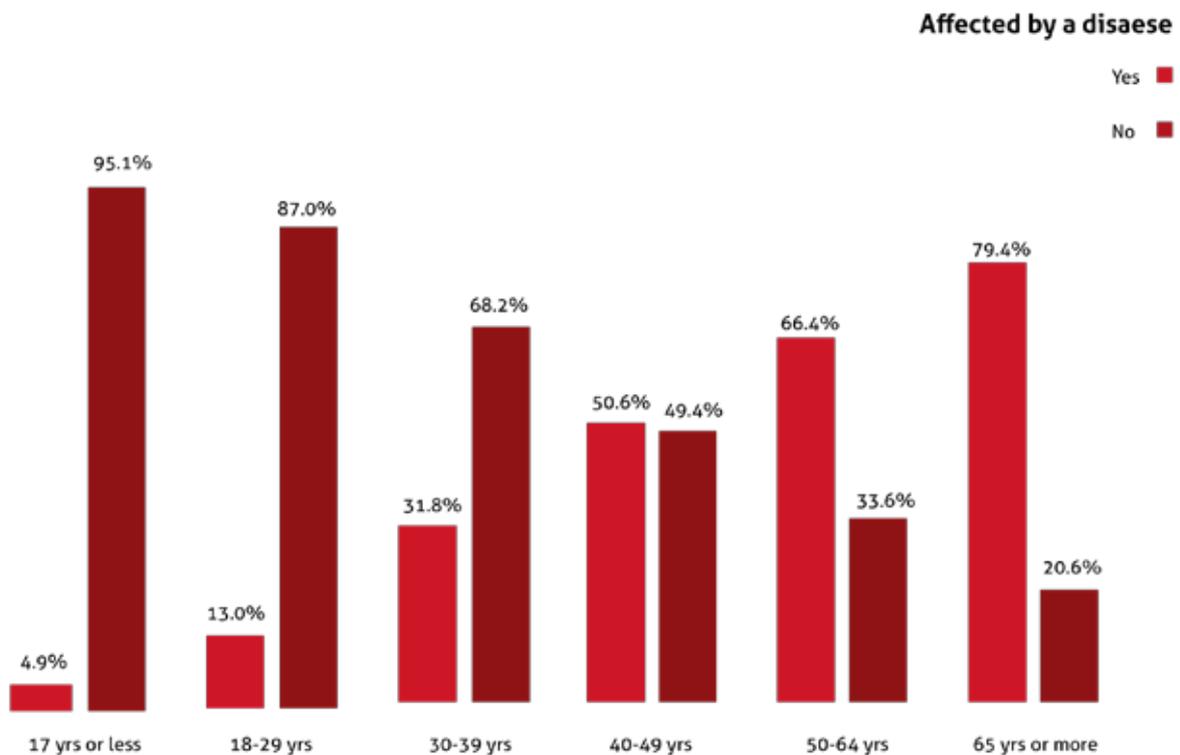


Figure 20. Percentages by age affected by disease

In our sample, 330 individuals have been affected by a chronic disease three months or longer during the past 12 months. This is 20.7% of the total sample and 66.8% of those affected by any disease during the past 12 months. Moreover, 305 respondents (19.1% of the total sample and 61.7% of those affected by a disease) have suffered from a chronic disease for one year or longer. As demonstrated in Figure 14, chronic diseases commonly last from one to ten years, with an average duration of 7.9 years.

Qualitative interviews support the survey findings. Nearly all of our ten informants expressed concern regarding the prevalence of hypertension, cardiovascular diseases and type 2 diabetes among Roma, Ashkali and Egyptians. Some informants also mentioned high occurrence of other, more stigmatized diseases such as scabies and other skin diseases. Dr. Sylfije Bajrami, working in Gaqke village, Ferizaj/Uroševac, reports that those engaged in informal waste collection are especially vulnerable to scabies. Doctors state many cases of gastrointestinal diseases occur because of housing and food hygiene challenges. Dr. Radosavljevic (Plemetina, Obiliq/Obilić) notes occurrence of sexually transmitted diseases (STDs) among his patients. The survey identified a low number of skin diseases and STDs. The reason for this could be the stigma associated with these diseases. As a result of such stigma, emphasized Bajrami, affected people are reluctant to report these diseases even to a doctor.

4.2.2 Comparative findings

Normally, statistics present only diagnosed cases of diseases. Studies in other countries have identified high numbers of undiagnosed cases of diabetes, hypertension, and high cholesterol. For example, Beljić Živković and her colleagues studied the prevalence of diabetes among adult-aged Roma in Serbia.⁴² 5.9% of the sampled individuals had been diagnosed with diabetes. However, blood sugar level tests conducted as part of the study revealed an additional 5.2% of the sample were unknowingly suffering from diabetes. The number of previously undiagnosed cases was almost as high as the number of diagnosed cases. In our sample, 3.9% of the household members over 18 years of age have been diagnosed with diabetes.⁴³ Considering the Živković findings we may presume a high number of undiagnosed cases. However, as the mean age of 37.6 years in our sample is 4.8 years less than the mean age of 42.4 years of the participants in the Živković study, a lower level in the prevalence of diabetes is possible.

As with diabetes, many people suffer from hypertension without knowing it. According to a 2006 study in Serbia, 42% of participants with high blood pressure were previously unaware of their condition.⁴⁴ The findings revealed that nearly half (47%) of the surveyed population over age 20 is suffering from hypertension.⁴⁵ This is a high number comparing to our total sample where only 11% have been diagnosed with the disease. However, an important issue to take into account is that hypertension strongly correlates with age and rarely occurs among those under 40 years of age.

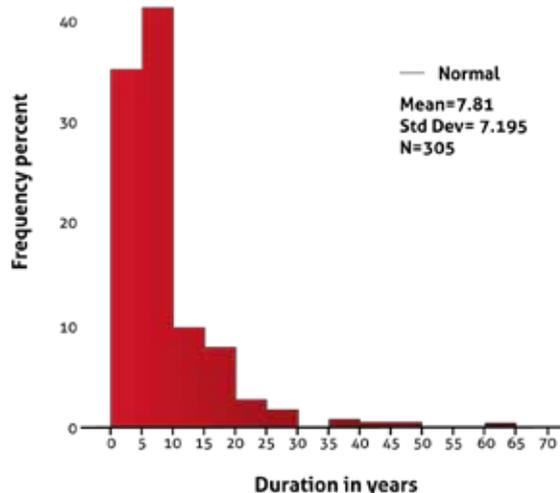


Figure 21. Duration of diseases

⁴² T Beljić Živković, 1 M Marjanović, 1 S Prgomelja, 2 I Soldatović, B Koprivica, 4 D Acković, R Živković (2010) "Screening for Diabetes Among Roma People Living in Serbia", *Croatian Medical Journal*, 51(2), 144-150.

⁴³ Ibid.

⁴⁴ V Grujić, N. Dragnić, S Kvrđić, S Šušnjević, J Grujić, S Travar (2012) "Epidemiology of Hypertension in Serbia: Results of a National Survey", *Journal of Epidemiology*, 22(3), 261-265.

⁴⁵ Ibid.

The mean age of participants in the Serbian study was 51 years for women and 49.5 for men, whereas in our study the corresponding figures are 40.1 years for women and 39.0 years for men. Still, the findings by Grujic et al suggest that over four in ten of those with hypertension are unaware of having the disease. Considering low education levels and utilization of preventive health care,⁴⁶ we may find that the proportion of undiagnosed cases of hypertension is even higher among the Roma, Ashkali and Egyptian populations of Kosovo.

4.2.3 Locality-specific health issues

Environmental factors such as air and water pollution or lack of sewage connection impact the occurrence of diseases. Therefore, the survey looks at locality-specific differences in the occurrence and prevalence of certain diseases. We did not identify any significant deviation from a normal distribution of hypertension, cardiovascular diseases or diabetes. In contrast, 25.5% of the 55 cases of respiratory diseases occur in Obiliq/Obilić municipality, which has only 7.1% of the sample population. We assume the high prevalence of respiratory diseases is caused by the Obiliq/Obilić power plants and coal mine. Further, residents of Fushë Kosova/Kosovo Polje also appear to be strongly affected by air pollution as 19.0% of the cases of respiratory diseases appear in this municipality.

Likewise, we identified 37 cases of genitourinary diseases, mainly kidney stones. Almost half of them (48.9%) occur in Gjakova/Đakovica municipality. Again, this is disproportionately high as only 19.1% of the overall sample is from this municipality. Moreover, 30.3% of the 33 cases of digestive system diseases are located in Gjakova/Đakovica. Our informants suggest these diseases can be associated with low quality drinking water and poor household and communal hygiene in some of the neighborhoods. Clearly, this is a theme for further research.

4.2.4 Impact of diseases and limitations

As stated by the WHO Constitution (1946), "Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity." With this principle in mind, the study explored the impact of disease on everyday activities including the extent of limitations the diseases cause Roma, Ashkali and Egyptians and the extent that disease-affected individuals regard themselves as limited in their daily activities. The results, as expected, in Figure 15 show that limitations caused by disease are significantly correlated with age. For instance, less than 8% of those aged 29 or less are "Some what limited" or "Very limited" because of a disease. In contrast, out of those aged 50-64 years, 34.1% are regarded as "Somewhat limited" and 22.1% as "Very limited".

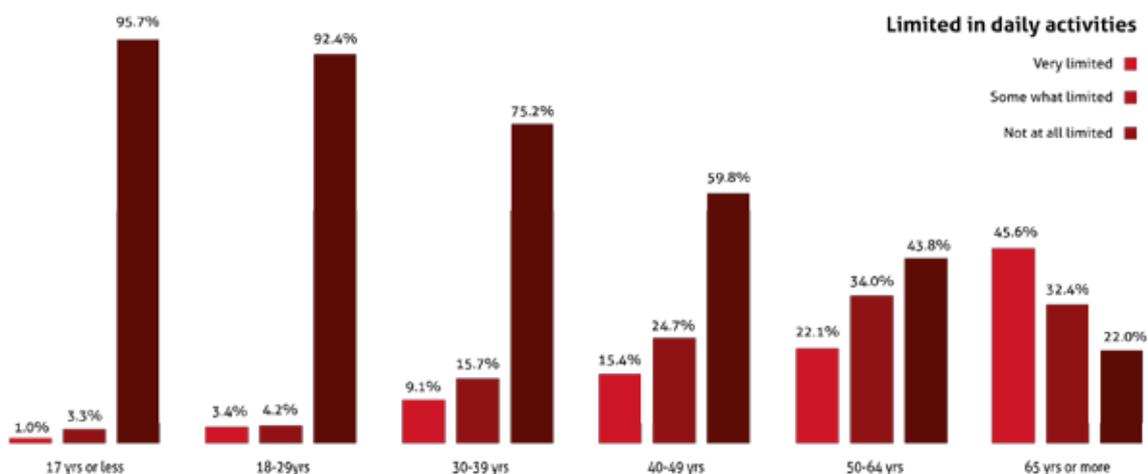


Figure 22. Disease correlation with age

⁴⁶ For more information, check section 4.3: Access to and use of health care services.

There is a high prevalence of limitations among those aged 40 and over. This is troubling as limitations in daily activities generally mean reduced working capacity. The findings for the working age (18-64 year old) individuals support this hypothesis. Of those "Not at all limited", 25.0% are employed or self-employed. In contrast, only 18.1% of those self-evaluated as "Somewhat limited" and 10.4% of those who are "Very limited" are employed. Overall, 81.0% of those regarded as "Somewhat limited" and 88.8% of those regarded as "Very limited" are unemployed or on disability.

Limitations also impact household income. The average income is €208.30 in households where the respondent declares him/herself as "Not at all limited". In contrast, the corresponding figure is €181.64 for households where the respondent considers him/herself as "Very limited".⁴⁷ We can see that on average, every step increase in the degree of limitations increases the probability of receiving social assistance 1.7 times (OR 1.7, CI 95%, P < 0.01). Of households with a "Not at all limited" respondent, 32.1% are receiving social assistance, whereas the corresponding proportion is 59.0% for households with a "Very limited" respondent. Age is not making a difference to the results. Clearly, higher limitations mean higher dependence on social assistance. Reduced working capacity is problematic for the financial situation of the affected household and society as a whole.

4.3 Access to and use of health care services

4.3.1 Background

As of 2015, Kosovo is the only country in the Southeast Europe without a national health insurance system, so Kosovo citizens lack access to guaranteed free health care. We look at how this affects economically disadvantaged communities' access to health services. Previous evidence suggests that the Roma, Ashkali and Egyptian communities are experience consequent harms. For example, OSCE has expressed concern about these communities' inability to afford health services, medication and treatment.⁴⁸

Like with other topic areas covered by our research, we needed numerical information about the use of health services among the Roma, Ashkali and Egyptian communities. In addition, we did not have quantitative data about the reasons why using health care services was avoided. To address these knowledge gaps, the survey included questions around the following topic areas:

- Use of preventive health care services;
- For those affected by a disease: number of times visited a doctor during the past 12 months;
- For those affected by a disease: number of days spent in in-patient hospital treatment;
- Types of health care services used: Kosovo public, Serbian public, alternative and/or private;
- Distance and form of transport to the most used family medicine center, hospital and pharmacy;
- Reasons for not visiting a doctor more often.

4.3.2 Preventive health care services

We asked if each female household member has ever been screened for the most commonly occurring cancers or sexually transmitted diseases (STDs). Table 13 shows that screening rates are extremely low with only 22 women (3.0% of the female sample) among the Roma, Ashkali and Egyptian communities have been screened for breast cancer, and 13 women (1.9%)

⁴⁷ These numbers should be treated with caution as the respondent was not the main breadwinner in about one third of the interviewed households.

⁴⁸ OSCE (2010) Kosovo Communities Profiles, pp. 10-12, 18-19; <http://www.osce.org/kosovo/75450?download=true>, <accessed 10/03/2015>.

for cervical cancer. A total of 7 male household members (1.0% of the male sample) have undergone a screening for prostate cancer. Only one household member had ever been tested for STDs.

	Count	Proportion
Mammography	22	3.0% of females
Screening for cervical cancer	13	1.9% of females
Screening for prostate cancer	7	1.0% of males
Screening for STDs	1	0.1% of both genders

Table 13. Early screening percentages for diseases

4.3.3 Use of health care services

Of sampled households, 493 members affected by a disease have visited a doctor at least once during the past 12 months. 95.5% of those who have visited a doctor during the past 12 months have a medical diagnosis for their disease. The number of visits range from once (15 cases) to 20 times (3 cases) with an average of 4.8 visits. Moreover, 151 (9.4% of the total and 30.5% of those disease affected) household members have spent at least one day in inpatient hospital treatment. Those who have received inpatient treatment have spent an average of 14 days hospitalized. 13.2% have been hospitalized for a period of one month or longer.

What do these numbers tell us? We have already identified very low utilization of preventive health services among the Roma, Ashkali and Egyptian communities. Furthermore, the findings above confirm that nearly everyone who have visited a doctor during the past 12 months have a medical diagnosis for their disease. This is further evidence that the Ashkali, Roma, and Egyptian communities are utilizing health care services almost exclusively for curative rather than preventive purposes.

An additional problem of concern is failure to seek health care during early stages of a disease. The preliminary research anecdotal and case study evidence suggested health care is often not sought until the disease is causing unbearable pain or serious limitations in everyday activities. At this stage, successful treatment of a disease can be significantly more difficult and expensive than it would have been in an early stage.

To learn about the scope of the problem we asked how many days after first symptoms appeared did the disease-affected household member first seek health services. The results are summarized in Table 14. Health care was sought by 177 (39.1%) on the same day the symptoms first appeared. Nearly one third (31.3%), however, waited for two weeks or longer before seeking health care. About one in eleven (8.6%) waited for at least two months, and 21 individuals (2.4%) for more than one year. Despite many seeking health care on the first day of symptoms, we can also observe a high number of individuals not seeking health care on time.

One day	39.1
Two days	9.3
Three days to one month	19.0
One week to one month	20.3
One to three months	6.4
Three months to one year	3.5
More than one year	2.4

Table 14. After how many days sought health care

Many serious, commonly occurring diseases such as hypertension and diabetes do not necessarily cause any symptoms at early stages, argues for wider use of available screening practices. Dr. Slavisa Radosavljevic of Plemetina, Obiliq/Obilić, in many cases finds the patients come to seek help only when experiencing unbearable symptoms.⁴⁹ Radosavljevic further highlights that often, people from these communities do not consider themselves “sick” unless suffering from severe pain or other restrictive symptoms.⁵⁰ Similarly, Dr. Zylfije Bajrami of Gaqke, Ferizaj/Uroševac expresses strong concern about low health awareness and a consequent inability to connect symptoms with serious diseases.⁵¹ She is also worried about the widespread reluctance to seek treatment for hypertension, diabetes, high blood cholesterol and STDs.⁵²

4.3.4 Use of medication and treatment

Out of those affected by a disease during the past 12 months, 89.7% have taken or are currently taking full medication or treatment for their health problem. A further 6.7% are on partial medication or treatment. Thus, the survey findings suggest that lack of medical treatment is not a widespread problem among the Roma, Ashkali and Egyptian communities. The qualitative interviews help interpret the survey findings from another perspective. Several doctors expressed concern regarding patients following medication instructions. Drs. Radosavljevic and Bajrami note many cases of patients stopping taking medication as soon as the disease symptoms start to disappear. As a result, the disease may not be cured completely, and the symptoms may reappear in a worse form.

4.3.5 Use of and satisfaction with different types of health services

Health care services offered in Kosovo can be divided into four categories, which are:

- Kosovo public health care system;
- Parallel institutions (financed by Serbia);
- Alternative (including religious and folk healing);
- Private.

Survey respondents ranked services according to how much their household members use them. As expected, public health services provided by Kosovo institutions are the most utilized health services, 71.2% of respondents. Unexpectedly, 55.5% of the households regularly use private health services. This is a high figure considering the poverty of the majority of the households. Health services offered by parallel Serbian institutions are utilized by 13.1% of the sample. Most of these households are near Gračanica/Graçanicë, Obiliq/Obilić and Fushë Kosova/Kosovo Polje. Alternative health services such as religious and folk healing are regularly used by 7.5% of households, and mainly in Gjakova/Đakovica, Fushë Kosova/Kosovo Polje and Obiliq/Obilić municipalities.

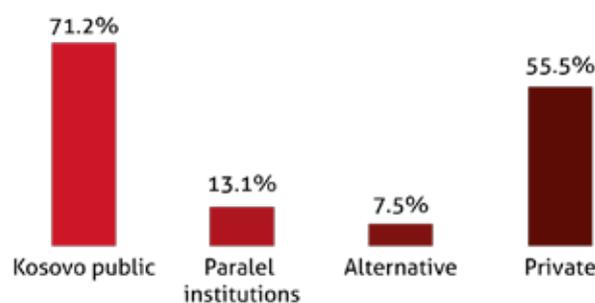


Figure 23. Comparative use of various health services providers

⁴⁹ Interview, November 2014.

⁵⁰ Ibid.

⁵¹ Interview, December 2015.

⁵² Ibid.

Four qualitative interviews provided conflicting information about the usage rates of alternative and private services: Dr. Bajrami (Gaqke, Ferizaj/Uroševac) said the majority of the minority households have no financial means to pay for private health services. Dr. Beqiri (Dubrova, Ferizaj/Uroševac) reports that people from these communities do use private health service providers. Dr. Radosavljevic (Plemetina, Obiliq/Obilić) knows several families who have spent large sums of money, even taking loans, for private health treatment. He says that alternative health care is also popular in the village. Dr. Bajrami also notes high utilization of folk healing among the Roma, Ashkali and Egyptian communities of Gaqke, while Health Mediator Avnore Morelli (Gjakova/Đakovica) says almost no one from her area uses alternative health services.

The survey measured respondents' satisfaction with different types of services. The majority of the Roma, Ashkali and Egyptian users are generally satisfied with all four types of services. However, we do find some issues. For example, more than one in four (27.0%) has experienced some degree of discrimination when using Kosovo public health care services, while the figure is 14.5% among those using health care services from parallel institutions. Of those using Kosovo public health care services, 38.3% have given money or a gift when using the services. The corresponding figure is 12.5% among the users of health services from parallel institutions. Serbian health insurance card holders (zdravstvena knjizica) are significantly less likely to give extra cash or a gift for health services. (OR=4.8, CI: 95%).

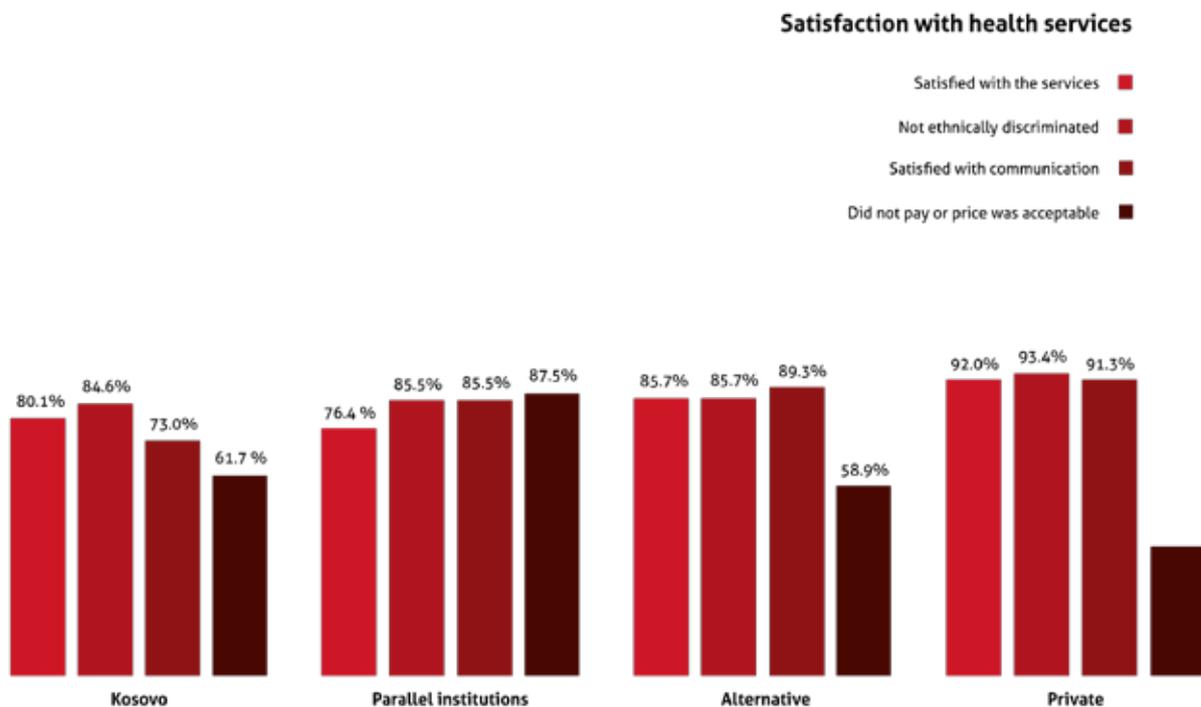


Figure 24. Comparative satisfaction with 4 different kinds of health service providers

4.3.6 Reasons for avoiding health services

In the survey design, we presumed that the main reasons for avoiding health services are:

- Inability to pay the services or treatment;
- Long distance to the health care premises and lack of transport;
- Inability to pay transport.

With these factors in mind, we asked each household how many times during the past 12 months any member of their household has avoided health services because of the abovementioned reasons. We asked separate questions about visits to family medicine center, hospital and pharmacy. A summary of the results is provided in Figure 18.

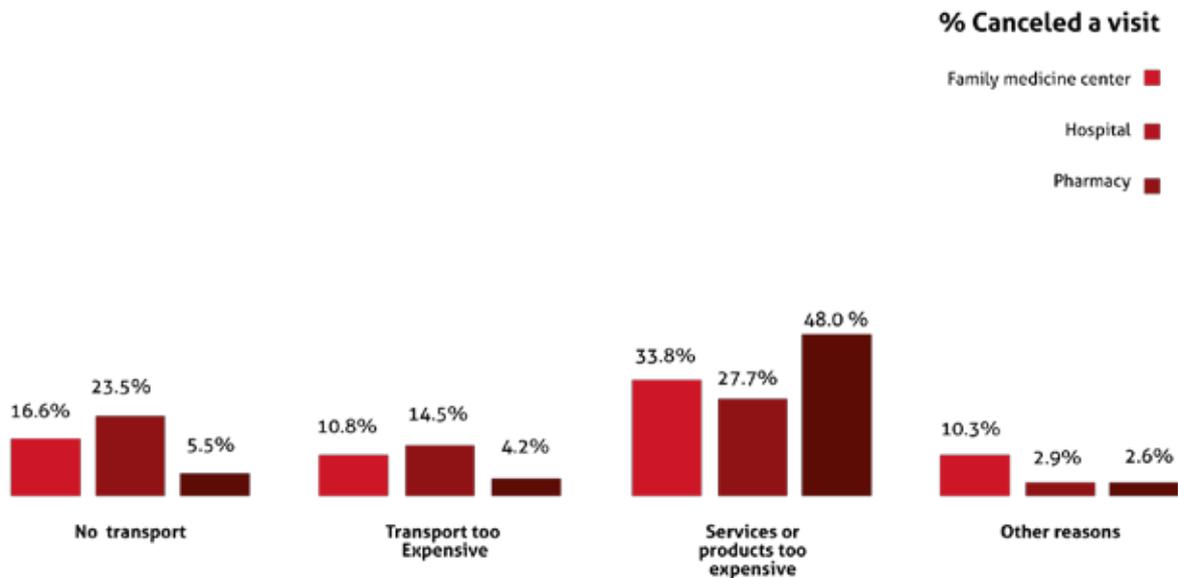


Figure 25. Health services or purchases canceled due to cost

The most common reason for canceling a visit to family medicine center, hospital or pharmacy is the unaffordable price of services (or products in case of pharmacies). In 33.8% of the households, at least one household member has canceled a visit to a family medicine center because of the perceived prohibitive cost of services. Similarly, in almost half of the households (48.0%) someone has canceled a visit to a pharmacy because of the cost of medicines and other medical products. To a lesser extent, our respondents have also canceled visits due to lack or transport or unaffordable prices of transport. These problems appear particularly prevalent in the municipalities of Obiliq/Obilić and Fushë Kosova/Kosovo Polje. Some households also reported other reasons for canceling visits to health care premises. These include lack of medical supplies at family medicine centers, poor quality of services, and bribery.

The survey further questioned if family members avoid doctor visits for other reasons. We can observe, for example, that 50.8% are not visiting a doctor more often because of "Being healthy". This is an interesting finding as it can partially explain the low utilization of preventive health care services and the common tendency of not visiting a doctor before the appearance of painful or otherwise restrictive disease symptoms. Another interesting and relevant finding is that 28.8% agree that they are not visiting a doctor more often because their health problem has cured itself. This discovery supports an observation that the communities are generally not using health services unless "feeling sick".

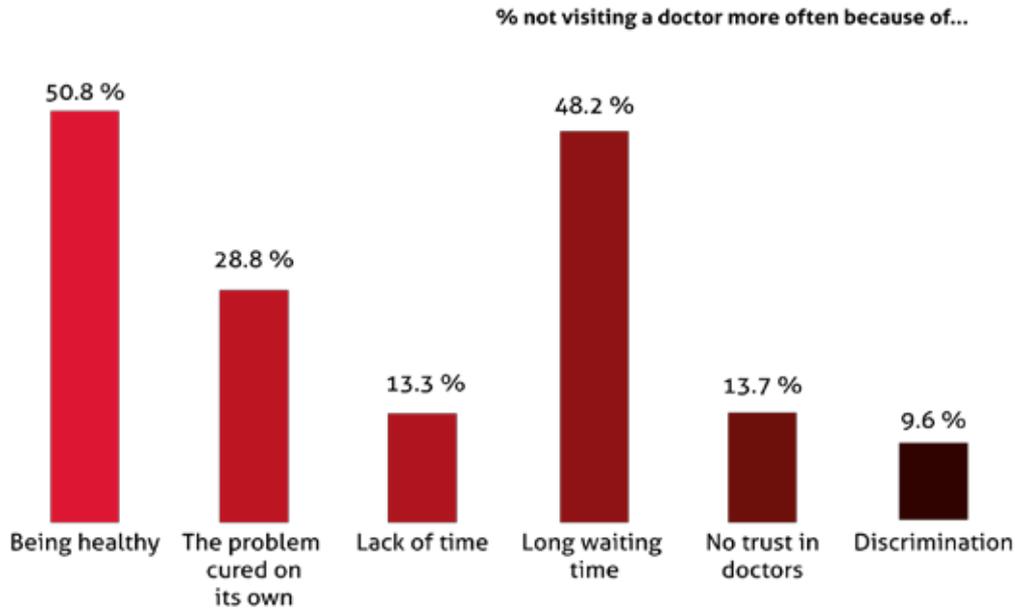


Figure 26. Non-financial reasons for avoiding or delaying visits to health care providers

Figures 18 and 19 indicate that only a minority of the Roma, Ashkali and Egyptian communities experience ethnically based discrimination when using health services. This is a positive finding of reduced rates of discrimination. The qualitative interviews⁵³ suggest that the situation though improved can be seen from other angles. Some of our consultants suggest that Roma, Ashkali and Egyptian are so used to discrimination that they do not recognize discriminative behaviour as such. According to the Strategy Advocate Fridon Lala, only extreme acts, such as physical violence because of ethnicity, are generally perceived as discriminatory acts among the Roma, Ashkali and Egyptian communities.⁵⁴ Individuals may not recognize, for example, poor delivery of health services as possible discrimination.



Figure 27. Shefki Berisha brought his son whose knee was injured during a soccer match to a health center. He said that without a Serbian health insurance card he would not be able to afford medical control and treatment.

⁵³ Interview, November 2014.

⁵⁴ Interview, January 2015.

4.4 Nutrition and life practices in Roma, Ashkali and Egyptian communities

4.4.1 Background

According to the literature review, undernutrition and malnutrition in the Roma, Ashkali and Egyptian communities is serious. A 2014 UNICEF study revealed alarming occurrence of micronutrient deficiencies among women and children.⁵⁵ Also, according to the recently published UNICEF Multiple Indicator Cluster Survey, the underweight, stunting and wasting rates are significantly higher among these children than among children from the other communities.⁵⁶ There is a high daily intake of sugar, salt, oil, doughbased food and low quality meat products among households belonging to the three communities. Excessive frying food rather than using the healthier options of boiling, steaming or baking is noted. Inadequate nutrient intake is a risk factor behind many non-communicable diseases including diabetes, anemia, cardiovascular diseases and skin diseases. It was to be a reasonable hypothesis that the incidence of these diseases is linked to improper nutrients intake.

In addition to nutrition, the survey investigated other life factors that are known to impact individual health. The literature review indicated that the majority of Roma, Ashkali and Egyptian adults are smokers. Studies in other Southeast Europe countries also report high rates of alcohol consumption and substance abuse. Therefore, the survey queried smoking and alcohol consumption. As good health is also associated with physical activity, we asked the respondents about the frequency of physical activity. Finally, as many diseases are linked to personal and living environment conditions, the survey noted the presence and use of bathing facilities and hot water.

4.4.2 Method of analysis

The survey explored the statistics on the frequency of consuming different food items. Similarly, with other life habits, we investigated the frequency of smoking, consumption of alcohol, physical exercise and bathing or showering. The findings were compared with the general recommendations of the World Health Organization (WHO) and UN Food and Agriculture Organization (FAO). The qualitative interviews with health professionals helped us to interpret the survey findings.

4.4.3 Nutrition findings

Out of all surveyed households, 18.7% are daily consuming meat or meat products and 10.7% at least four times per week. 46.3% report consuming meat two or three times per week. Meat is consumed by 23.6% as part of their meals once per week or less. Fish consumption is dramatically lower with 14.7% of the households consuming fish at least two times per week. At the same time, 39.4% are eating fish less than weekly, and 22.7% report never consuming fish as part of their meals.

Vegetables are consumed by 60.7% of the households daily; by 25.5% at least two times per week; and 15% are eating vegetables only once per week or less frequently. Out of fresh, canned and frozen vegetables, fresh vegetables are the most popular with 95.5% of the households reporting using primarily fresh vegetables. As for fruit, 49.8% of the households report consuming fruits daily, and 17.4% at least two times per week. 23.6% report consuming fruits once per week or less often.

Of surveyed households, 50% report consuming dairy products daily and 28.8% at least two times per week. Dairy products are consumed once per week or less frequently by 17.2%. Eggs are consumed daily in 36.6% of the households, at least twice per week in 42.3% of households, and in 25.1% eggs are being consumed once per week or less often.

⁵⁵ Maloku-Gjergji, Tahire, and Frits Van Der Haar. "Nutritional Survey Of Pregnant Women And School Children In Kosovo." UNICEF, March, 2010, [www.unicef.org/kosovoprogramme/Nutritional_Survey_Eng\(1\).pdf](http://www.unicef.org/kosovoprogramme/Nutritional_Survey_Eng(1).pdf).

⁵⁶ UNICEF, "Multiple Indicator Cluster Survey" 2014.

Sweet products, including cookies and sweet spreads, are being consumed daily in 41.6% of the households. A further 18.6% report consuming such products at least two times per week and 29.9% report eating sweet products once per week or less frequently.

Respondents, by 99.7%, report using sunflower or vegetable oil for cooking. The second most popular type of oil is margarine, used in 13.2% of the households. Olive oil is used in 5.3% of the households. Less than 3% of households use butter or lard for cooking.

Survey respondents reported the drinks they consume with meals: 96.4% still or carbonated water (from tap or bottled); 13.7% non-carbonated juice; and carbonated soda drinks, 14.0%; milk and other dairy-based drinks 18.6% of the households.

4.4.4 Life / hygiene practices

Of sampled household members, 38.1% shower or bathe daily; 17.0% are bathing four to six times per week; 39.9% are bathe or shower two or three times per week; and 5% only once per week. 82.9% of the sampled households have access to hot water and 85.2% have a shower or bath inside their homes. There was no statistical difference in bathing frequency between those with access to hot water in the home and those without. Likewise, the presence of an indoor shower or a bath did not significantly impact the bathing habits of household members.

	Number	% of the sample
0	1025	70.4
1-3	21	1.4
4-6	21	1.4
7-9	44	3.0
10-19	133	9.1
20 or more	212	14.6

Table 16. Average number of cigarettes/day

In contrast to smoking, alcohol consumption is very low. As many as 96.7% of the household members in the sample never consume alcoholic drinks. Less than 1% of the respondents consume 20 or more alcoholic drinks per week. Low alcohol consumption can be associated with adherence to Islam in the three communities. On the other hand, one doctor says that some of his patients try to relieve disease symptoms (pain, discomfort) with alcoholic drinks.⁵⁷

⁵⁷ Interview, November 2014.

Food Type	Daily Households Consumption %
Meat or meat products	18.7
Fish or fish products	0.8
Dairy products	54.0
Eggs	36.1
Vegetables	60.7
Fruits	39.3
Sweet products	41.6

Table 15. Family daily food consumption

Daily smoking is habitual among 29.6% of all respondents. Among adults, respondents aged 18 years or older, 34.6% smoke on a daily basis. Of all households, 70.1% have at least one smoking family member; in 34.3% of the households, smoking takes place in the presence of children, while 37.7% of the households report smoking takes place only outside of the home. Figures 16 and 17 provide an overview of the smoking habits in these communities.

In the presence of children	34.3 %
Always go outside	37.7 %
No family member smokes	29.9 %

Table 17. Smoking habits

Recreational or health-related exercise is low with 41.1% of the sample never exercising, while 26.8% are doing daily physical activity.⁵⁸ As expected, there is a strong negative correlation between age and frequency of physical exercise. Out of those aged 17 or less, 28.1% are engaged in physical activity every day, and 29.1% at least three times per week. In contrast, of those between 30 and 39 years or age, 55.4% are never doing physical exercise. If we take a look at the population aged 30 or over, 54.8% are never engaged in physical activity and a mere 19.3% are exercising daily.



Figure 28. Avnora, a health project mediator for the Roma, Ashkali and Egyptian communities, in an interview with Mimoza Telaku, representative of the health project funded by Solidar Suisse and implemented by Balkan Sunflowers.

4.4.5 Qualitative information on nutrition and life choice issues

In order to better understand the survey findings and their implications, we asked the interviewed health care professionals about their impressions on the nutritional situation among the Roma, Ashkali and Egyptian communities. All informants agree that there is a lot to improve both in terms of nutrition and in the quality of the daily diet. Informants report many Roma, Ashkali and Egyptian families are not eating enough vegetables. At the same time, they tend to be overconsuming potatoes, bread and other flourbased meals that are generally very low in nutrients.⁵⁹

Dr. Radosavljevic says that a typical meal among Roma, Ashkali and Egyptian families is beans, potatoes and low quality sausages with high fat and salt content.⁶⁰ He associates a high prevalence of anemia in the Obiliq/Obilić municipality with the poor nutrients intake. He argues that many common chronic diseases such as hypertension and diabetes could be avoided by better weight control.

Family medicine doctor Sylfije Bajrami is concerned that the typical daily meal of the Roma, Ashkali and Egyptian families is beans, potatoes, peppers and bread, and that most families in her community are not consuming fruits, vegetables or dairy products on a daily basis. The problem is compounded by overconsumption of salt, sugar and low quality oil products.

⁵⁸ Due to inconsistencies in the data, we have excluded Lipjan/Lipljan and Shtime/Štimlje municipalities from these figures.

⁵⁹ Interview, November 2014.

⁶⁰ Interview, November 2014.

4.4.6 Comparison with the general nutrition recommendations

According to the World Health Organization, a healthy diet should include at least 400 grams of fruits and vegetables daily (excluding potatoes and other starchy products).⁶¹ According to our findings, almost 40% of the Roma, Ashkali and Egyptian families are not consuming vegetables as part of their daily meals. Moreover, about half of the households are not consuming fruits on a daily basis. In fact, far short of the recommended 400 grams of fruits and vegetables each day as recommended by the WHO, it is strongly indicative that the majority of the individuals belonging to the three communities frequently consume no fruits or vegetables during the course of a day.

Furthermore, the WHO recommends an average daily protein intake of 0.8 grams per kilogram for adults.⁶² To achieve the recommended levels, one should consume protein-rich food ingredients as part of every meal (breakfast, lunch and dinner). This recommendation is not reached in a large number of the Roma, Ashkali and Egyptian families. One in four of the households are not consuming any protein rich foods (meat, fish, dairy products or eggs) on a daily basis. Furthermore, one fifth of the households are eating these ingredients as part of their meals less than four times per week.

4.4.7 Discussion and recommendations

An unbalanced diet, with insufficient variety, and inadequate nutritional value poses serious health risks for the Roma, Ashkali and Egyptian communities. We propose action to raise community awareness regarding diet and life choices that will promote good health and longer life expectancy, well aware of families' economic reality. Five aims are proposed:

- 1) Increase the daily intake of fruits and vegetables;
- 2) Increase variety in the diet;
- 3) Reduce consumption of processed food, fat, salt and sugar, and particularly tobacco;
- 4) Increase the frequency of physical exercise;
- 5) Increase knowledge of ways to shift limited financial resources to healthier practices.

Progress on the five aims would require community buyin. If that is present, then there could be collaboration among the relevant national and local governmental institutions, donors, and civil society organizations. Both literature review and field research suggest that the design and implementation of activities to achieve these recommendations should consider the following points:

- "Long life" as well as "good health" may act as incentive when promoting better nutrition and life choices in the Roma, Ashkali and Egyptian communities.⁶³
- Health promotion activities must take into account the socio-economic reality of the majority of households. Examples for offering realistic choices might be:
 - Steaming vegetables is healthier and less expensive than frying them;
 - Fruit is always a better choice for the available money than sweets, or sweet drinks;
 - Smoking a pack per day is equal to burning five €100 notes per year while making everyone in your family less healthy;

⁶¹ World Health Organization (2005) Healthy Diet: Fact Sheet N 394, www.who.int/mediacentre/factsheets/fs394/en/

⁶² WHO Technical Report Series: Protein and Amino Acid Requirements in Human Nutrition (2007) - http://whqlibdoc.who.int/trs/who_trs_935_eng.pdf

⁶³ Interview Ardita Tahirukaj, WHO Public Health Officer, December 2014; also Dr. Radosavljevic, Plemetina Health House.

- Dependent on season, cabbage, squash, and root vegetables will offer more nutritional value than breads and pastas;
- Reduce sugar use in coffee and tea and the amount of salt in everyday food preparation.
- Health intervention activities should reach entire communities, including all ages and both genders. WHO National Public Health Expert Arditë Tahirukaj recommends targeting all segments of the community, using short films and multimedia, as the way to reach “common understanding” on issues such as community hygiene and healthy life practices.

4.4.8 Stakeholder-specific recommendations

The Government of Kosovo should:

- Finalize all actions required for implementation of the national health insurance program, particularly insuring the costs of primary health care services;
- Allocate health insurance funds for community health education programs.

Local governments should:

- Be actively engaged in the design and implementation of community education programs including contributing to the programs with human resources, materials and facilities;
- Task health care and social workers with planning and delivery of the health education programs, including health education as an aspect of everyday activities.

International organizations should:

- Support the Government of Kosovo to implement the national health insurance policy.

Civil society organizations should:

- Develop and provide training for the health care workers;⁶⁴
- Plan and deliver community education sessions;
- Facilitate communication and dialogue between the communities and the policy makers.

Community actors⁶⁵ should:

- Consult with their respective communities about needs and expectations regarding community education programs;
- Ensure first-level monitoring and evaluation according to the standards set by the civil society organizations and the donor bodies;
- Take into account the socio-economic reality of the majority of the Roma, Ashkali and Egyptian households in developing health promotion activities.

⁶⁴ The health care workers are the health professionals. Civil society organizations may support and train professionals on effective delivery of their message to communities.

⁶⁵ Community actors are those who represent the interests of the Roma, Ashkali and Egyptian communities.

4.5 Financial Implications of the Health Care Costs

4.5.1 Total population aggregated annual income versus annual health care costs

The household survey of 393 households included 1,592 individuals excluding children under 12, or 2,194 individuals including children under 12. This sample size enables calculating financial aspects as it is a starting point for estimating healthcare needs for the whole population of 35,784 Roma, Ashkali, and Egyptians in Kosovo.⁶⁶

The total monthly income of the surveyed sample of households was found to be €79,400. That works out to an estimated €952,800 annually. From this we project that the annual income of the total population of Kosovo Roma, Ashkali, and Egyptians to be €15,540,107 (see Table 18 for details). If we compare this to annual healthcare costs, this infers that 38% of the total income of Roma, Ashkali, and Egyptians is spent on healthcare. This is a strikingly high ratio of healthcare costs to income.

Sample size including children under 12	2,194
Sample size excluding children under 12	1,592
Total population	35,784
Estimated Roma, Ashkali and Egyptian population excluding children under 12	25,965
Total monthly income of the surveyed sample	€ 79,400
Estimated monthly income of the total Roma, Ashkali and Egyptian population	€ 1,295,009
Estimated annual income of the total Roma, Ashkali and Egyptian population	€ 15,540,107
Average monthly household income of Roma, Ashkali and Egyptian population	€ 201.47
Average annual healthcare cost per diseased person	€ 557
Total annual healthcare costs of the interviewed sample	€ 262,964
Estimated annual healthcare costs of total population of Roma, Ashkali, and Egyptians excluding children under 12	€ 4,288,926

Table 18. Sample Healthcare Costs and Population Estimated of Healthcare Costs, and Household Incomes of Roma, Ashkali and Egyptians in Kosovo

The average annual healthcare costs per ill person were found to be €557. The total annual healthcare costs of the interviewed sample were €262,964 which means that the estimated annual healthcare costs for the total population of Roma, Ashkali and Egyptians excluding children under 12 is €4,288,926, and it is €5,910,744 when children under 12 are also included.⁶⁷

Designing public policies only according to the total annual costs of a given group is not sufficient, which is why it is important to report the distribution of those costs: 19.5% of ill Roma, Ashkali, and Egyptians had annual health care costs of less than €100. 17.4% of them had annual healthcare costs of €100 to 199, 14.2% of them had costs of €200 to 299, 15.5 % of them had costs of €300 to 499, 12.1% of them had costs of €500-599, and the rest of them (21.4%) had costs of €600 and above.

⁶⁶ Kosovo Agency of Statistics – Kosovo Population and Housing Census (2011), Main Data. Pg. 143.

⁶⁷ The cost estimation which includes children under 12 is a rough approximation since the interview does not contain data about children under 12, and therefore this estimation assumes that the annual costs of healthcare in children are similar to annual healthcare costs of adults. This assumption was not made in other cases of the Policy Brief.

4.5.2 Estimating effect of health care unrealized because of cost

One aspect of estimating health care costs of any proposed health insurance law is finding out how many people cannot afford medical treatment. Of Roma, Ashkali and Egyptians, 55.1% reported not visiting a doctor more often because of the inability to afford medical treatment. This projects that an estimated 19,700 community members could not afford medical treatment. This percentage has implications in that costs of treatment could increase more than payments into the system. Only 13.5% (or an estimated 4833 people) reported that this is definitely not the case. See Table 20 for details.

Possible correlations of health care costs and other variables collected in the survey were analyzed. Three variables significantly correlated with the costs of health care: Age, Total Monthly Household Income from All Sources, and Doctor Visits during the Past 12 Months.⁶⁸ In other words, older people are correlated with higher health care costs, as it can be expected. More frequent doctor visits are correlated with higher healthcare costs, of course.

One correlation, though, which needs particular attention is the significant correlation (even at the 0.01% level) between total monthly household income and healthcare costs. This suggests that the household income is a very important factor to consider, when trying to predict or influence the healthcare costs under national health insurance.

To have a clearer view of how health care costs of Roma, Ashkali and Egyptian Families can be influenced through changes in household income, a simple linear regression model was created between these two variables. The following result was found: A total monthly household income increase of €1, increases the monthly household healthcare costs by €0.15. This indicates that the low levels of health service utilization of Roma, Ashkali, and Egyptians community members are forced down by their low household incomes. Therefore, social policies designed to increase the general welfare of Roma, Ashkali and Egyptian communities would also increase accessibility of these communities to healthcare services, and improve their health outcomes.

⁶⁸ The widely practiced cut-point of 0.05 significance level was used to determine significance of the correlations between variables.

Euro Healthcare Costs	Frequency	Percentage
€ 0-99	92	19.5
€ 100-199	82	17.4
€ 200-299	67	14.2
€ 300-399	49	10.4
€ 400-499	24	5.1
€ 500-599	57	12.1
€ 600-699	18	3.8
€ 700-799	10	2.1
€ 800-899	9	1.9
€ 900-999	2	0.4
€ 1000-1999	30	6.4
€ 2000 and above	32	6.8
Total €	472	100

Table 19. Sample Healthcare Costs and Population Estimated of Healthcare Costs, and Household Incomes of Roma, Ashkali and Egyptians in Kosovo

	Percentage	Frequency Estimate for total RAE Population
True	55.1	19704
Somewhat true	24.4	8737
Partially false	6.8	2417
False	13.5	4833
Don't know	0.3	93
Total	100.0	35784

Table 20. Reason for not visiting a doctor more often: Unable to afford medical treatment

Age	N	Significance	Pearson Correlation
Total Monthly Household Income from all sources	464	0.01*	0.13
Diseases with ICD 10 Chapters	268	0.00	0.27
Doctor visits during the past 12 months	471	0.62	-0.02
Times cancelled a visit because health services too expensive	471	0.00	0.13
Reason for not visiting a doctor more often: Unable to afford medical treatment	164	0.20	0.10
	163	0.47	-0.06

Table 21. Correlation between Health care costs in euros and other variables

4.5.3 Financing health care

The financing side of the health insurance system is also in need of support, considering that 58.6% of Roma, Ashkali, and Egyptians interviewed were unemployed. For the whole population, then, we estimate 15,206 unemployed people for whom the state will have to cover the insurance premium (See Table 22). Furthermore, the total income earned by people who work is smaller than by those who do not work among Roma, Ashkali, and Egyptians, which is a serious problem regarding the sustainability of premium contributions from these communities.

	Sample Frequency	Percent	Estimated Population Frequency of Employment	No. of Payers of Private Insurance	No. of People by State Covered Insurance	Annual Income of Category	Annual Income of Category (Population Estimate)	Estimated Total Premium Contributions (7% Premium-Employer+ Population)	Estimated Total Premium Contributions (7% Premium)-Population
Private Sector	104	6.7	1,732	1,732	€ 9,780	€ 1,954,620	€ 136,823		
Public Sector	61	3.9	1,016	1,016	€ 11,675	€ 2,333,352	€ 163,335		
NGO	42	2.7	700	700	€ 5,269	€ 1,053,056	€ 73,714		
Self employed	74	4.7	1,232	1,232	€ 9,400	€ 1,878,674	€ 131,507		
Student or at school	211	13.5	3,514	3,514	€ 2,135	€ 426,699	€ 29,869		
Unemployed	913	58.6	15,206		€ 32,156	€ 6,426,662		€ 449,866	
Pensioner	63	4.0	1,049		€ 6,475	€ 1,294,086		€ 90,586	
Disability pension	19	1.2	316		€ 1,550	€ 309,781		€ 21,685	
under 18 year old and not at school	72	4.6	1,199		€ 390	€ 77,945			
Total	1,559	100.0	25,965	8,194	€ 16,572	€ 78,830	€ 15,754,876	€ 535,248	€ 562,137
Children under 12 not covered by the survey	665		9,819						

Table 22. Estimating Premium Contributions and State Covered Premium Contributions for the Roma, Ashkali, and Egyptian Population



Figure 29. Halil Berisha.

The unemployed population and pensioners receive around €7.7 million annually, which is more than the €7.1 million annually which the employed earn in the private sector, public sector, NGO's and self-employment. This means that the insurance premiums that can be collected from the paying population (including the 3.5% paid by the employee, and the 3.5% paid by the employer) is only €535,248 annually.

This is smaller than the annual insurance premium that the state will have to cover for the unemployed, pensioners, and disability pension, which would amount to €562,137. To clarify the point, the total annual premium contributions collected from Roma, Ashkali, and Egyptians and their employers would be around €1.1 million while the health insurance costs for the same population are around €4.3 million.⁶⁹

4.5.4 Recommendations

- A government social policy together with a special healthcare policy is needed to make sure that the healthcare costs of Roma, Ashkali, and Egyptian are properly covered. The 38% healthcare cost to household income ratio is a good indicator that this issue needs serious attention.
- Further study is needed to project savings and potential new financial contributions to the system resulting from improved health of the beneficiaries of national health insurance. Potential savings and new revenue to the system can results from, for example:
 - Early diagnosis and treatment of diseases or response to early warning factors substantially reducing long term treatment costs;
 - Productive work life (and therefore tax payments) be increased;
 - Reduced hazard of untreated or preventable conditions affecting others who in turn have treatment costs.

⁶⁹ Children under 12 are excluded from this calculation to make the amounts comparable to each other

5 LITERATURE REVIEW: LIFE EXPECTANCY AND HEALTH OF KOSOVO ROMA, ASHKALI AND EGYPTIANS AND REGIONAL COMPARISONS

5.1 Introduction

This research identifies areas of interest for further assessment regarding the health needs of Roma, Ashkali, and Egyptians⁷⁰ vis-a-vis Kosovo's anticipated national health insurance system. To accomplish this we performed a literature review of factors contributing to poor health among Roma, Ashkali, and Egyptians and conducted minimal but useful qualitative research. We propose further studies to:

- 1) highlight the gap between these communities and the majority, as seen through the lens of life expectancy;
- 2) identify illnesses that are more endemic in these communities;
- 3) identify mental health conditions exacerbated by repatriation to Kosovo; and
- 4) project increased access to services, resulting costs to proposed national health insurance, and potential savings resulting from prevention or early intervention amelioration of potential health problems.

5.2 Overview of the situation of Roma, Ashkali, and Egyptians in Kosovo

In order to explore the health needs of the Roma, Ashkali, and Egyptians in Kosovo, we first looked at the health issues of Roma in other countries. We found significant health disparities between Roma and non-Roma, highlighted by the difference in life expectancy for these two groups. A Roma Early Childhood Inclusion report from 2012 shows that Roma live an average of ten years less than non-Roma in the 27 European Union states (before the addition of Croatia).⁷¹ In Slovakia, Roma are estimated to have a 7.5 year lower life expectancy than non-Roma,⁷² and in Serbia, Roma die on average 10-12 years younger than non-Roma.⁷³ Regarding specific health problems, some studies have found that Roma suffer from increased rates of type two diabetes, coronary artery disease, malnutrition, anemia, measles and hypertension.^{74, 75, 76}

⁷⁰ In Kosovo, three communities – Roma, Ashkali and Egyptians – are addressed often together as they have similar social and economic conditions. When looking at reports from other countries, studies are generally referring only to Roma.

⁷¹ Bennett, John. "Roma Early Childhood Inclusion: The RECI Overview Report." Open Society Foundations, Roma Education Fund, and UNICEF, 2011, www.unicef.org/romania/RECI-Overview.pdf.

⁷² Ginter, Emil, and Vlado Simko. "Short Life Expectancy And Metabolic Syndrome In Romanies (Gypsies) In Slovakia." *Central European Journal of Public Health* 18, no. 1 (2010): 16-18, <http://apps.szu.cz/svi/cejph/archiv/2010-1-03-full.pdf>.

⁷³ Dragan Bogdanović, Dragana Nikić, Branislav Petrović, Biljana Kocić, Jovica Jovanović, Maja Nikolić, and Zoran Milošević. "Mortality of Roma Population in Serbia, 2002-2005." *Croatia Medical Journal* 48 (2007): 720-726, www.ncbi.nlm.nih.gov/pubmed/17948958.

⁷⁴ Vozarova de Courten, B, M de Courten, RL Hanson, A Zahorakova, HP Egyenes, PA Tataranni, PH Bennett, and J Vozar. "Higher prevalence of type 2 diabetes, metabolic syndrome and cardiovascular diseases in Gypsies than in non-Gypsies in Slovakia." *Diabetes Research and Clinical Practice* 62, no. 2 (2003): 95-103, www.ncbi.nlm.nih.gov/pubmed/14581146 as found in Schaaf, Marta. "Confronting a Hidden Disease: TB in Roma Communities." Open Society Institute, 2007, www.romadecade.org/cms/upload/file/8567_file1_confronting-a-hidden-disease.pdf.

⁷⁵ Council of Europe. "Breaking the barriers: Romany women and access to public health care." Luxembourg: Office for Official Publications of the European Communities, 2003, http://fra.europa.eu/sites/default/files/fra_uploads/180-ROMA-HC-EN.pdf as found in Schaaf, Marta. "Confronting a Hidden Disease: TB in Roma Communities." Open Society Institute, 2007, www.romadecade.org/cms/upload/file/8567_file1_confronting-a-hidden-disease.pdf.

⁷⁶ Masseria, C, P Mladovsky, and C Hernández-Quevedo. "The socio-economic determinants of the health status of Roma in comparison with non-Roma in Bulgaria, Hungary and Romania." *European Journal of Public Health* 20, no. 5 (2010): 549-554, Doi: 10.1093/eurpub/ckq102.

Roma are also generally more economically disadvantaged than other population groups,⁷⁷ and the trend shows that an individual's health is worse the lower socioeconomic position s/he occupies,⁷⁸ which is consistent with longitudinal studies in various countries.⁷⁹ Thus, when looking at the health needs of a population, social inequalities are an indicative factor for explaining health disparities. In this way, the similarly impoverished conditions of Roma, Ashkali, and Egyptians in Kosovo and Roma elsewhere suggest that these groups may face similar health problems as well.

A major obstacle to thoroughly assessing the health of Roma, Ashkali, and Egyptians in Kosovo is the paucity of health data on these groups. The literature focusing on these minorities in Kosovo tends to be based on observation rather than statistical analysis and highlights broad challenges and general characteristics rather than providing measurable data. Without ample, accurate, reliable data it is difficult to make effective policy decisions or design appropriate advocacy strategies. However, it is possible to get a basic view of the social, economic, and health disparities facing Roma, Ashkali, and Egyptians in Kosovo based on the existing literature.

According to the OSCE Community Profiles Report for 2010, Roma, Ashkali, and Egyptians are among the most vulnerable groups in Kosovo and suffer disproportionately from low levels of education and low economic status.⁸⁰ This report states that these communities face social exclusion, precarious living conditions, and difficulties accessing social services including health care. The unemployment rates for these communities vary across studies, but the UNDP 2012 Kosovo Human Development report found these rates to be 80% for the Egyptian community and 60% for the Roma and Ashkali.⁸¹ A KFOS study from 2009 reported that 60% of Roma, Ashkali, and Egyptian families make less than €180 per month, yet only 42% of these communities receive social assistance.⁸² The same report found that most families from these communities lack the basic elements to provide their homes with safe and hygienic conditions. According to the UNDP 2004 Human Development Report for Kosovo 25% of Roma, Ashkali and Egyptians do not have a safe source of drinking water, 39% do not have sewage, and 25% do not have access to piped water.⁸³ Furthermore, a UNDP study from 2004 found that 72% of people from the Roma, Ashkali, and Egyptians communities did not have a toilet or bathroom in their house.⁸⁴

⁷⁷ Ringold, Dena. European Roma Rights Centre. Accessed November, 2013, www.errc.org/popup-article-view.php?article_id=710.

⁷⁸ Marmot, Michael. "Achieving health equity: from root causes to fair outcomes." *The Lancet* 370, no. 9593 (2007): 1153-1163, Doi: 10.1016/S0140-6736(07)61385-3.

⁷⁹ The following references contribute to this citation:

- Adler, NE, WT Boyce, MA Chesney, S Folkman, and LS Syme. "Socioeconomic inequalities in health: no easy solution." *JAMA* 269, no. 24 (1993): 3140-3145. www.ncbi.nlm.nih.gov/pubmed/8505817
- Marmot, MG, M Kogevinas, and MA Elston. "Social/economic status and disease." *Annual Review of Public Health* 8, (1987): 111-135. Doi: 10.1146/annurev.pu.08.050187.000551
- Pappas, Gregory, Susan Queen, Wilbur Hadden, and Gail Fisher. "The increasing disparity in mortality between socioeconomic groups in the United States, 1960 and 1986." *New England Journal of Medicine* 329, (1993): 103-109. Doi: 10.1056/NEJM199307083290207
- Marmot, MG, MJ Shipley, and G Rose. "Inequalities in death-specific explanations of a general patterns?" *Lancet* 1, no. 8384 (1984): 1003-1006. www.ncbi.nlm.nih.gov/pubmed/6143919
- Sorlie, PD, E Backlund, and JB Keller. "US mortality by economic, demographic and social characteristics: the National Longitudinal Mortality Study." *American Journal of Public Health* 85, no. 7 (1995): 949-956. www.ncbi.nlm.nih.gov/pubmed/7604919
- Salonen, JT. "Socioeconomic status and risk of cancer, cerebral stroke and death due to coronary heart disease and any disease: a longitudinal study in eastern Finland." *Journal of Epidemiology and Community Health* 36, no. 4 (1982): 294-297. www.ncbi.nlm.nih.gov/pmc/articles/PMC1052236/

⁸⁰ Organization for Security and Cooperation in Europe Mission in Kosovo, "Kosovo Community Profiles." Organization for Security and Cooperation in Europe, 2010, www.osce.org/kosovo/75450.

⁸¹ UNDP. "Kosovo Human Development Report 2012." UNDP, 2012, www.undp.org/content/dam/kosovo/docs/KHDR/KHDR2012_eng.pdf.

⁸² Vrenezi, Nait, and Jusuf Thaci. "The Position of Roma, Ashkali and Egyptian Communities Kosovo." Edited by Blerinda Idrizi. Kosovo Foundation for Open Society, 2009, http://kfos.org/pdf/The%20Position%20of%20RAE%20Communities%20in%20Kosovo%20Baseline%20Survey_ENG.pdf.

⁸³ UNDP. "Human Development Report Kosovo 2004." UNDP, 2004, http://hdr.undp.org/sites/default/files/kosovo_2004_en.pdf.

⁸⁴ UNDP. "Faces of Poverty, Faces of Hope: Vulnerable Profiles for Decade of Roma Inclusion countries." UNDP, 2004, http://issuu.com/undp_in_europe_cis/docs/faces_of_poverty_faces_of_hope.

The substandard housing and unhygienic conditions in which many members of these communities live increase exposure to communicable disease.⁸⁵ This risk is increased by the fact that vaccination rates among the Roma, Ashkali, and Egyptians appear to be lower than what municipalities are reporting. KFOS mediators working in the Roma, Ashkali, and Egyptians communities in five municipalities in Kosovo found that vaccination rates among children were much lower than what the municipalities and OSCE report.⁸⁶ According to a report by WHO, the World Bank, and UNICEF, vaccination is considered to be one of the most cost-effective health interventions, especially in reducing infectious diseases.⁸⁷ Low vaccination rates among Roma, Ashkali, and Egyptians may be indicative of low access to health services, lack of civil registration, and frequency of home births, but it may also be a symptom of low health education among these communities.

5.2.1 Health education

According to the World Health Organization, health education is an effective tool for improving the general health of a population. However, it receives little attention because its tangible benefits, which are often in the form of prevention rather than treatment, are sometimes difficult to measure.⁸⁸ Furthermore, weak health education “drains human and financial resources in the health system” because it has been shown to result in “less healthy choices, riskier behavior, poorer health, less selfmanagement and more hospitalization.”⁸⁹

Since health literacy is linked to general literacy,⁹⁰ the level of literacy of a population is suggestive of its level of health education as well. In this regard, the Roma, Ashkali, and Egyptian communities in Kosovo are at risk of low health education because of their disproportionately low levels of literacy. KFOS found in 2009 that 96% of people in these communities hadn’t finished the obligatory level of education and 20% hadn’t finished a single year, with major differences between the genders.⁹¹ To further highlight the disparity between the sexes in these communities, a randomized survey study in 2008 by Kosovo Center for Gender Studies found that 38% of women in these communities were illiterate⁹² while the overall illiteracy rate for these communities was found to be 16%.⁹³ Therefore, these data suggest that Roma, Ashkali, and Egyptians in Kosovo are vulnerable to low health education, with women being at a greater risk.

Though no comprehensive national study has been done on the health education of Roma, Ashkali, and Egyptians in Kosovo, a study using participatory observation methods in Mitrovica found low levels of health education in the areas of skin diseases, hygiene, chronic respiratory diseases, and negligence in prevention of child diseases.⁹⁴ A non-randomized, quantitative survey carried out in Fushë Kosova from 2008-2010 found hygiene and family planning to be the most requested topics for training as a result of low health education.⁹⁵

⁸⁵ Haliti, Mensur. “Blindspot: Kosovo Roma and the Decade.” Open Society Foundations, January, 2011, www.opensocietyfoundations.org/sites/default/files/blindspot-kosovo-roma-20110530.pdf.

⁸⁶ KFOS, personal communication, 1 November 2013.

⁸⁷ WHO, UNICEF, World Bank. “State of the world’s vaccines and immunization, 3rd edition.” World Health Organization, 2009, http://whqlibdoc.who.int/publications/2009/9789241563864_eng.pdf.

⁸⁸ WHO, UNICEF, World Bank. “State of the world’s vaccines and immunization, 3rd edition.” World Health Organization, 2009, http://whqlibdoc.who.int/publications/2009/9789241563864_eng.pdf.

⁸⁹ Kickbusch, Ilona, Jürgen M. Pelikan, Franklin Apfel, and Agis D. Tsouros. “Health Literacy: The solid facts.” WHO, 2013, www.euro.who.int/__data/assets/pdf_file/0008/190655/e96854.pdf.

⁹⁰ Baker, D.W., R.M. Parker, M.V. Williams, and W.S. Clark. “Health literacy and the risk of hospital admission.” *Journal of General Internal Medicine* 13, no. 12 (1998): 791–798, www.ncbi.nlm.nih.gov/pubmed/9844076.

⁹¹ Vrenezi, Nait, and Jusuf Thaci. “The Position of Roma, Ashkali and Egyptian Communities Kosovo.”

⁹² Kosovo Center for Gender Studies. “Position of Roma, Ashkali and Egyptian Women in Kosovo.” Kosovo Center For Gender Studies, 2008, www.womensnetwork.org/documents/20130529134917547.pdf.

⁹³ UNDP. “Human Development Report Kosovo 2004.”

⁹⁴ Ibernì, Elisabetta. “Report On Assessing, Monitoring And Evaluating Of Psychosocial Needs And Activities In Roma Mahalla (Mitrovica).” University of Essex, June, 2010, [www.internal-displacement.org/8025708F004CE90B/\(httpDocuments\)/BF6661536CB170C4C1257968004CA19E/\\$file/Report+on+psychosocial+activities+by+Elisabetta+Ibernì.pdf](http://www.internal-displacement.org/8025708F004CE90B/(httpDocuments)/BF6661536CB170C4C1257968004CA19E/$file/Report+on+psychosocial+activities+by+Elisabetta+Ibernì.pdf).

⁹⁵ Health For All. “Improving Health of Roma, Ashkali, and Egyptian Communities in Fushë Kosova.” Health For All, March, 2011, www.unfpakos.org/wp-content/uploads/2012/04/HFAreporteng.pdf.

5.2.2 Hygiene

Hygiene is a very important component of health education, but it extends beyond the teaching of sanitary behavior. Hygiene is also important as it relates to environmental conditions such as access to clean water, housing, sewage and other basic infrastructure. The lack of these services for Roma, Ashkali, and Egyptians is in some cases due to these communities' being relocated to environmentally noxious locations: IDP camps and later permanent housing were built on lead-contaminated land in Mitrovica and next to power plants in Obiliq.⁹⁶

5.2.3 Family planning

Another vital component of health education is family planning because it contributes to reducing poverty and mortality, empowering women, and improving environmental sustainability.⁹⁷ These are issues that the Roma, Ashkali, and Egyptian communities of Kosovo face, and thus family planning should be a key consideration in any strategy to empower these communities and reduce health and economic disparities from which these communities disproportionately suffer.



Figure 30. Halil Berisha, house.

Knowledge and use of contraception form an integral part of family planning. Knowledge about the use of modern forms of contraception helps in successful family planning and in the prevention of sexually transmitted diseases. Though there have been no national studies done on contraception knowledge and use in the Roma, Ashkali, and Egyptian communities in Kosovo, Health For All's study in Fushë Kosova revealed low rates of contraception use (40%), high rates of induced abortions and home births (34%), and low rates of planned pregnancies (56%) among Roma, Ashkali, and Egyptian women.⁹⁸

The cost of modern contraceptives and lack of awareness and knowledge are some of the reasons for not using them, but a lack of knowledge about and use of contraceptives reflects gender discrimination, stereotyping, and limited bargaining power on the part of women.⁹⁹ The lack of education among women in the Roma, Ashkali, and Egyptian communities leads to disempowerment in decision-making regarding family planning. In Montenegro, a UNICEF research project revealed that nearly 70% of Roma, Ashkali, and Egyptian women did not take part in deciding the size of their family, with this decision being made by the husband and his family.¹⁰⁰

⁹⁶ Prathumratana, Lunchakorn, Rokho Kim, and Kyoung Woong Kim. "Heavy Metal Contamination of the Mining and Smelting District in Mitrovica, Kosovo." Proceedings of the International Symposia on Geoscience Resources and Environments of Asian Terranes. Bangkok, Thailand, November, 2008,

⁹⁷ Cleland, John, Stan Bernstein, Alex Ezeh, Anibal Faundes, Anna Glasier, and Jolene Innis. "Family planning: the unfinished agenda." The Lancet, October, 2006, http://cdrwww.who.int/reproductivehealth/publications/general/lancet_3.pdf.

⁹⁸ Health For All. "Improving Health of Roma..."

⁹⁹ Hagman, Malin. "Maternal Mortality: Gender and Access to Health Services – The Case of Ghana." Journal of Politics & International Studies 9, (2013): 173-211, www.polis.leeds.ac.uk/assets/files/students/student-journal/sum-13/130930-sum13-hagman.pdf.

¹⁰⁰ UNICEF. "Breaking the Cycle of Exclusion: Roma Children in South East Europe." UNICEF Serbia, February, 2007, www.unicef.org/ceecis/070305-Subregional_Study_Roma_Children.pdf.

Women from these communities may face similar disempowerment in Kosovo regarding family planning, and this can have deleterious effects on the health of both mother and child.

5.2.4 Antenatal care

A child's health is first affected by the mother's ability to access quality antenatal care, which is a key entry point for a pregnant woman to receive a broad range of health promotion and preventive health services.¹⁰¹ However, the quality, access, and awareness of antenatal care in Kosovo are not satisfactory.

In 2009 it was reported that over 60% of women in Kosovo did not start using antenatal services until the fourth month of pregnancy, and 66% did not have any physical examination during the antenatal care.¹⁰² Furthermore, the same study reported that 16.5% of women were not offered any health advice during pregnancy.¹⁰³ These data suggest a low quality of antenatal services and low health education regarding antenatal care in Kosovo. These prospects are probably grimmer for Roma, Ashkali, and Egyptians as they face greater barriers to accessing services generally and are at a greater risk for low health education as compared to the majority population.

In addition to women in Kosovo lacking access to quality antenatal services, there is still a high percentage of cases in which the decision for an antenatal visit is made by somebody other than the pregnant woman.¹⁰⁴ This is most likely more prevalent among Roma, Ashkali, and Egyptians because of the aforementioned limited role of women in these communities taking part in family planning. This may be a contributing factor to the high rate of women from the Roma, Ashkali, and Egyptian communities who never visited a gynecologist during pregnancy, which is reported to be over 60%,¹⁰⁵ compared to the national average of 98.5%.¹⁰⁶ This is consistent with data from other countries that show reduced access to and use of antenatal services during pregnancy among Roma, Ashkali, and Egyptian women. In FYR Macedonia 38% of Roma women did not receive a single examination by a medical practitioner during their pregnancy.¹⁰⁷ A study of Roma, Ashkali, and Egyptian women in Montenegro found that only 10% had ever seen a gynecologist.¹⁰⁸

Low reproductive health education and access to antenatal care may contribute to home births in unhygienic conditions still being a common practice among Roma, Ashkali, and Egyptians in Kosovo.¹⁰⁹ This practice is not only dangerous to the child but risky for the mother's health as well. According to KFOS, further dangers to the health of Roma women include frequent births (specific to young mothers), poor nutrition, and lack of effective services about family planning.¹¹⁰ Furthermore, Roma, Ashkali, and Egyptian women are "most susceptible to health risks arising from substandard living conditions" because they spend more time in the house than their male counterparts.¹¹¹ Roma, Ashkali, and Egyptian women find themselves in this position of vulnerability from a young age in part because of the cultural tradition of early marriage.

¹⁰¹ Lincetto, Ornella, Seipati Mothebesoane-Anoh, Patricia Gomez, and Stephen Munjanja. "Antenatal Care." Opportunities for Africa's Newborns, WHO, 2006, www.who.int/pmnch/media/publications/aonsectionIII_2.pdf. UNICEF. "Antenatal Care in Kosovo: Quality and Access." UNICEF, April, 2009, [www.unicef.org/kosovoprogramme/Kujdesi_Antenatal_-_Anglisht\(per_Web\)02.pdf](http://www.unicef.org/kosovoprogramme/Kujdesi_Antenatal_-_Anglisht(per_Web)02.pdf).

¹⁰² UNICEF. "Antenatal Care in Kosovo: Quality and Access." UNICEF, April, 2009, [www.unicef.org/kosovoprogramme/Kujdesi_Antenatal_-_Anglisht\(per_Web\)02.pdf](http://www.unicef.org/kosovoprogramme/Kujdesi_Antenatal_-_Anglisht(per_Web)02.pdf).

¹⁰³ Ibid.

¹⁰⁴ Ibid.

¹⁰⁵ Kosovo Center for Gender Studies. "Position of Roma, Ashkali and Egyptian Women in Kosovo."

¹⁰⁶ UNICEF. "Antenatal Care in Kosovo: Quality and Access." UNICEF, April, 2009, [www.unicef.org/kosovoprogramme/Kujdesi_Antenatal_-_Anglisht\(per_Web\)02.pdf](http://www.unicef.org/kosovoprogramme/Kujdesi_Antenatal_-_Anglisht(per_Web)02.pdf).

¹⁰⁷ UNICEF. "Breaking The Cycle Of Exclusion: Roma Children In South East Europe." UNICEF Serbia, February, 2007, www.unicef.org/ceecis/070305-Subregional_Study_Roma_Children.pdf.

¹⁰⁸ Ibid.

¹⁰⁹ OSCE Mission in Kosovo. "Kosovo Community Profiles."

¹¹⁰ Kosovo Center for Gender Studies. "Position of Roma, Ashkali and Egyptian Women in Kosovo."

¹¹¹ Ibid., 8.

5.2.5 Early marriage

According to UNICEF, girls who married early often abandoned formal education and became pregnant.¹¹² As mentioned previously, this is visible in Kosovo as girls from the Roma, Ashkali, and Egyptian communities have a higher dropout rate than their male counterparts. Further consequences of early marriage include unemployment as a result of insufficient education, endangerment of health with frequent birth deliveries, domestic violence, and isolation from friends and family.^{113,114} The Kosovo Center for Gender Studies found that 33% of Roma, Ashkali, and Egyptian women thought a girl should marry early in order to give birth to a healthy baby.¹¹⁵ The average age of marriage for girls from these communities is 15-16, whereas for boys it is eighteen.¹¹⁶ Furthermore, fourteen municipal courts reported 116 requests for early marriage in 2010 and 107 in 2011, and these were mostly among Roma, Ashkali, and Egyptians.¹¹⁷

Early marriage, low health education regarding family planning, and reduced access to antenatal services leave Roma, Ashkali, and Egyptian women and children vulnerable to many health complications. Poor nutrition is another risk factor that disproportionately affects children from these communities.

5.2.6 Nutrition and non-communicable diseases

It is generally cited that widespread poor health among the Roma, Ashkali, and Egyptians is exacerbated by poor nutrition.¹¹⁸ In a report by the Kosovo Center for Gender Studies, women from Roma, Ashkali, and Egyptian communities mentioned nutrition as one of the biggest aspects of vulnerability in their communities.¹¹⁹ Yet, most members of these communities have no access to nutrition or correct information on nutrition.^{120,121} A cluster randomized nutritional survey UNICEF carried out Kosovo-wide in 2010 found micronutrient deficiencies among women and children, two of the most at-risk groups among Roma, Ashkali, and Egyptians.¹²² Therefore, a combination of low economic status, degraded environmental and living conditions, and poor knowledge about and access to nutrition leave the Roma, Ashkali, and Egyptians in Kosovo vulnerable to poor health.

This vulnerability puts these communities at increased risk of developing non-communicable diseases such as cardiovascular diseases, respiratory diseases, cancer, and diabetes among others. In fact, in a nonrandomized, quantitative survey Health for All found that 62% of participants said they suffered from a disease.¹²³ The four risk factors for the development of non-communicable diseases as cited by WHO are tobacco use, physical inactivity, excessive use of alcohol, and unhealthy diets.¹²⁴

¹¹² "Child Marriage." UNICEF. Accessed 12 November, 2013, www.unicef.org/protection/57929_58008.html.

¹¹³ Kosovo Center for Gender Studies. "Position of Roma, Ashkali and Egyptian Women in Kosovo."

¹¹⁴ UNFPA. "Kosovo Child Marriage." UNFPA, November, 2012, www.unfpakos.org/wp-content/uploads/2012/10/KOSOVO-English-final.pdf.

¹¹⁵ Kosovo Center for Gender Studies. "Position of Roma, Ashkali and Egyptian Women in Kosovo."

¹¹⁶ *Ibid.*

¹¹⁷ UNFPA. "Kosovo Child Marriage."

¹¹⁸ European Roma Rights Centre. "Abandoned Minority." European Roma Rights Centre, December, 2011, www.errc.org/cms/upload/file/abandoned-minority-roma-rights-history-in-kosovo-dec-2011.pdf.

¹¹⁹ Kosovo Center for Gender Studies. "Position of Roma, Ashkali and Egyptian Women in Kosovo."

¹²⁰ *Ibid.*

¹²¹ Visoka, Gezim, and Adem Beha. "Repatriation without Responsibility: The nature and implications of Roma, Ashkalia and Egyptian forced repatriation to Kosovo." FORUM 2015, October, 2010, www.aktion302.de/fileadmin/aktion302/10RADrepatriation.pdf.

¹²² Maloku-gjergji, Tahire, and Frits Van Der Haar. "Nutritional Survey Of Pregnant Women And School Children In Kosovo." UNICEF, March, 2010, [www.unicef.org/kosovoprogramme/Nutritional_Survey_Eng\(1\).pdf](http://www.unicef.org/kosovoprogramme/Nutritional_Survey_Eng(1).pdf).

¹²³ Health For All. "Improving Health of Roma..."

¹²⁴ "Noncommunicable Diseases." UNICEF, March, 2013, www.who.int/mediacentre/factsheets/fs355/en/.

Though research is scarce on the prevalence of these factors among Roma, Ashkali, and Egyptians, in Kosovo, these communities appear to be at a high risk for these factors – a 2004 UNICEF report stated that Roma children sometimes start to smoke and drink at the age of 15 or 16.¹²⁵ Tobacco and alcohol use have debilitating effects on health and will be important considerations when providing health insurance to the Roma, Ashkali, and Egyptians.

Type-two diabetes is another high risk for these communities because of their exposure to the above risk factors. Diabetes requires frequent treatment and can be very costly, particularly and prohibitively for low-income socioeconomic groups. Though research is scant on diabetes' prevalence among Roma, one study done in Slovakia found a higher rate of type 2 diabetes among Roma than among non-Roma.¹²⁶ Similarly, a study done on Roma in Serbia suggests a higher prevalence of diabetes among Roma than non-Roma.¹²⁷ The same study found that almost all cases of diabetes among Roma were type 2 and were twice as prevalent among participants with abdominal obesity, which represented 41% of the Roma participants in the study.¹²⁸ Contributing factors to the occurrence of type two diabetes include inactivity, poor nutrition, obesity, and hypertension,¹²⁹ all of which the Roma, Ashkali, and Egyptians of Kosovo may be susceptible to due to the general poverty affecting these communities. The prevalence of type-two diabetes will be a significant factor to consider when providing health insurance to these groups because of the disease's need for frequent care such as insulin injections and blood sugar tests.

5.3 Strategy for the integration of Roma, Ashkali, and Egyptian communities in the Republic of Kosovo

There has been national recognition of the need to improve economic, educational, social, and health disparities in the Roma, Ashkali, and Egyptians communities. In 2008 the government of Kosovo created the Strategy for the Integration of Roma, Ashkali, and Egyptian Communities in the Republic of Kosovo 2009-2015 and a year later approved an accompanying action plan to address the inequalities experienced by these communities. Though the action plan included specific activities to address many of the problems discussed above, specifically regarding discrimination, education, economic empowerment, health, housing, registration, returns, gender issues, and political representation, a review of the implementation of the strategy plan in 2012 found that generally Kosovo institutions had not made much progress in fulfilling their obligations to improve the conditions of Roma, Ashkali, and Egyptians in Kosovo.¹³⁰ The action plan also calls for research to fill the quantitative and qualitative data gaps regarding various aspects of life in Roma, Ashkali, and Egyptian communities,¹³¹ which is a necessary precursor to making informed policy decisions, implementing advocacy campaigns, and designing intervention strategies.

¹²⁵ Kasai, Kayo. "Education of Minority Children in Kosovo." UNICEF, January, 2004, www.unicef.org/kosovoprogramme/kosovo_media_pub_educ.007.04.pdf.

¹²⁶ Vozarova de Courten, B, et al. "Higher prevalence of type 2 diabetes..." As found in Schaaf, Marta. "Confronting a Hidden Disease..."

¹²⁷ Živković, Teodora Beljić, Milica Marjanović, Stela Prgomelja, Ivan Soldatović, Branka Koprivica, Dragoljub Acković, and Rodoljub Živković. "Screening for Diabetes among Roma People Living in Serbia." *Croatia Medical Journal* 51, no.2 (2010): 144-150, Doi: 10.3325/cmj.2010.51.144.

¹²⁸ Ibid.

¹²⁹ "Diabetes, type-2 causes." NHS. www.nhs.uk/Conditions/Diabetes-type2/Pages/Causes.aspx. <Accessed 19 October, 2013>.

¹³⁰ Organization for Security and Co-operation in Europe: Mission In Kosovo. "Contribution to the Progress Review of the Action Plan of the Strategy for the Integration of Roma, Ashkali and Egyptian Communities in Kosovo, 2009–2015." September, 2012, www.osce.org/kosovo/94856.

¹³¹ Organization for Security and Co-operation in Europe: Mission In Kosovo. "Implementation of the Action Plan on the Strategy for the Integration of the Roma, Ashkali and Egyptian Communities in Kosovo." Organization for Security and Co-operation in Europe. May, 2011, www.osce.org/kosovo/77413.

With regards to health and social improvements, the action plan calls for the Ministry of Health to lead collaborative efforts with the Ministry of Labor and Social Welfare and the Ministry of Environmental and Spatial Planning.¹³² However, the OSCE found in its 2011 review of this action plan that “the only activity specifically carried out to improve access by Roma, Ashkali and Egyptians to social welfare and health services is the establishment of a technical working group within the MoH” whose task is to gather information on the health of these communities.¹³³ Furthermore, a 2012 OSCE report reviewing implementation of the action plan states that this working group failed to fulfill basic requirements set out in the action plan,

including the collection of data and production of monitoring reports.¹³⁴ In addition to the lack of data on the health needs of Roma, Ashkali, and Egyptians, the Ministry of Health’s Health Sector Strategy for 2011 does not reference these three communities or their unique health challenges in its plan for improving the health of Kosovo’s population.¹³⁵ The specific needs of the Roma, Ashkali, and Egyptian communities and especially vulnerable groups within these communities must be recognized in order to provide effective intervention and improve the health of this marginalized population.

5.4 Return, repatriation, and civil registration

Return and reintegration for repatriated Roma, Ashkali, and Egyptian are issues that need particularly urgent attention. To address these issues the action plan calls for involvement from the Ministry of Internal Affairs, Ministry for Communities and Return, Ministry of Local Government Administration, Ministry of Environment and Spatial Planning, and the office of the Prime Minister.¹³⁶ According to the OSCE report the Ministry of Communities and Returns has been very active in implementing activities and coordinating programs laid out in the Action Plan, but significant challenges remain especially regarding repatriated Roma, Ashkali, and Egyptians.¹³⁷ Not only was the database on returnees at the Department for Citizenship, Asylum and Migration not up to date as of 2010,¹³⁸ but the Ministry of Internal Affairs had not even established a database for forcibly returned persons, who represent the majority of Roma, Ashkali, and Egyptian returnees.¹³⁹

Fortunately, as of 2013 a database has been created and the Ministry reports meeting all returnees at the airport and creating a record. Furthermore, the Ministry of Health hasn’t fulfilled its obligations to provide health services to returnees upon arrival, adding to the many obstacles repatriated persons face upon return.¹⁴⁰

However, the issue of returnees cannot be ignored, as evidence suggests a significant number of Roma, Ashkali, and Egyptians have already returned to Kosovo and many more are scheduled to do so in the coming years. The UNHCR estimates that 29,000 Roma, Ashkali, and Egyptians returned to Kosovo from 2000-2010, many of these involuntarily.¹⁴¹ Furthermore, it is estimated that another 50,000 Roma, Ashkali, and Egyptians will be repatriated to Kosovo and will need social assistance. This represents a potential burden to the Kosovo economy and health care system because of the unique social and health needs of returnees, and this burden will increase as more returnees gain civil registration.

¹³² Ibid.

¹³³ Ibid. 5

¹³⁴ OSCE Mission In Kosovo. “Contribution to the Progress Review...”

¹³⁵ Ibid.

¹³⁶ OSCE Mission In Kosovo. “Implementation of the Action Plan...”

¹³⁷ Ibid.

¹³⁸ Knaus, Verena, and Peter Widmann. “Integration Subject to Conditions - A report on the situation of Kosovan Roma, Ashkali and Egyptian children in Germany and after their repatriation to Kosovo.” UNICEF Kosovo and the German Committee for UNICEF, 2010, www.unicef.org/kosovoprogramme/RAEstudy_eng_web.pdf.

¹³⁹ OSCE Mission In Kosovo. “Implementation of the Action Plan...”

¹⁴⁰ Knaus, Verena, and Peter Widmann. “Integration Subject to Conditions...”

¹⁴¹ Visoka, Gezim, and Adem Beha. “Repatriation without Responsibility...”

Without civil registration individuals in Kosovo are not able to get official ID documents that are necessary for accessing social services.¹⁴² In order to apply for civil registration an individual must present a birth certificate, marriage certificate (if married), certificate of residence, and certificate of citizenship.¹⁴³ This is a major obstacle for repatriated persons because they often do not have an official residence in Kosovo and were unable to get official ID documents in their host countries before repatriation.¹⁴⁴ The inability of repatriated individuals to get civilly registered will also pose obstacles to accessing health insurance. The future Kosovo's health insurance system, while still far from legal basis or implementation, may provide complete coverage for individuals on social assistance. Returnees without the proper documents for civil registration will have to pay for health care expenses out of pocket, which may be unaffordable for these individuals.

This may also be problematic for children returnees who are in need of vaccines and other health checks that are standard for young age.

A 2011 UNICEF study reported that nearly 50% of children repatriated to Kosovo did not have ID cards and three out of four did not attend school.¹⁴⁵ These children are thus unable to access social services and are vulnerable to social exclusion and other psychological and social problems. According to UNICEF, many repatriated Roma, Ashkali, and Egyptians live in degraded conditions, have poor psychological and physical health, and are left without resources for their needs upon arrival.¹⁴⁶ Another study by UNICEF found that among children and their parents repatriated to Kosovo, suicidal thoughts, depressed mood, social withdrawal, loss of development skills, aggression, separation anxiety, recurring fears, and post-traumatic stress disorder were widespread.¹⁴⁷ Furthermore, repatriation most severely affects young people because of their vulnerability and females because of the stricter gender roles found in Kosovo than the host countries.¹⁴⁸ As many returnees do not have civil registration and are thus denied social assistance and access to other services, there is a lack of detailed information on the psychological and health needs of these individuals.



Figure 31. Roma, Ashkali and Egyptian children, who attend the community centre in Brekoc village, Gjakova, pose for the Solidar Suisse photographer. During this day Balkan Sunflowers paid a visit to the center to research the health of the community, a project supported by the Solidary Suisse.

¹⁴² Organization for Security and Co-operation in Europe: Mission In Kosovo. "Access to Civil Registration in Kosovo." Organization for Security and Co-operation in Europe, July, 2012, www.osce.org/kosovo/92331.

¹⁴³ "Procedura e pajisjes me letërnjoftim të Republikës së Kosovës." Ministria e Punëve të Brendshme, accessed November, 2013, www.mpb-ks.org/repository/docs/leternjoftimi.pdf.

¹⁴⁴ Visoka, Gezim, and Adem Beha. "Repatriation without Responsibility..."

¹⁴⁵ Knaus, Verena. "No Place to Call Home - Repatriation from Germany to Kosovo as seen and experienced by Roma, Ashkali and Egyptian children." UNICEF Kosovo and the German Committee for UNICEF, 2011, www.unicef.org/kosovoprogramme/No_Place_to_Call_Home_English_2011.pdf.

¹⁴⁶ Ibid.

¹⁴⁷ Knaus, Verena, et al. "Silent Harm - A report assessing the situation of repatriated children's psychosocial health." UNICEF Kosovo in cooperation with Kosovo Health Foundation, 2012, www.unicef.org/kosovoprogramme/SILENT_HARM_Eng_Web.pdf.

¹⁴⁸ Visoka, Gezim, and Adem Beha. "Repatriation without Responsibility..."

5.5 Life expectancy in Kosovo

As noted above, in all other countries where life expectancy of Roma communities has been compared to that of the general population, Roma life expectancy is 7.5 to 15 years less than that of the majority. We worked with a statistician to look at life expectancy, based on Statistical Agency of Kosovo data. However, this was unsuccessful. Standard calculation requires factoring population numbers in multiple year ranges with registration of births and deaths. In Kosovo, we found, birth and death registrations in these communities are too low to achieve meaningful results this way.

5.6 Summary of findings from literature review

The following outline is a summary, for rapid access, of the findings of the literature review not the field research findings and remembering, as noted above, that the literature review includes information from years earlier.

I. Economic conditions:

1) Employment

5.1% are employed to public sector, 3.5% to private sector, 1% are involved in agriculture, totaling 9.6% official employment;¹⁴⁹

- 43% unemployment among Roma, 38% for Ashkali, 30% for Egyptians;¹⁵⁰
- 30.9% unemployment rate in all Kosovo,¹⁵¹ in 2011 unemployment for Egyptians was 80%, and 60% for Ashkali and Roma.¹⁵²

2) Income

• 20% of Roma, Ashkali, Egyptian families have an average income €50 per month; 20.06% €50 - €80; 3.76 % more than €300 per month; 42% have social assistance.¹⁵³

3) Living conditions

- 72% do not have a toilet or bathroom in house;¹⁵⁴
- Electricity and water are biggest problems cited by interviewees;¹⁵⁵
- Evidence of lack of infrastructure and waste collection in informal settlements;¹⁵⁶
- Evidence that homes lack basic services and amenities such as heating and insulation, sewage system, running water.¹⁵⁷

4) Municipal Services

- Many Roma, Ashkali, and Egyptians still have difficulty accessing municipal services. Affordability of utilities and administrative fees, lack of necessary personal documents, and limited awareness on relevant institutions and offices where these communities can address their concerns are still challenges.¹⁵⁸

¹⁴⁹ Vrenezi, Nait, and Jusuf Thaci. "The Position of Roma, Ashkali and Egyptian Communities Kosovo."

¹⁵⁰ Ibid.

¹⁵¹ Kosovo Agency of Statistics. "Results of the Kosovo 2012 Labour Force Survey." Kosovo Agency of Statistics, September, 2012, www.esk.rks-gov.net.

¹⁵² UNDP. "Kosovo Human Development Report 2012."

¹⁵³ Vrenezi, Nait, and Jusuf Thaci. "The Position of Roma, Ashkali and Egyptian Communities Kosovo."

¹⁵⁴ UNDP. "Faces of Poverty, Faces of Hope..."

¹⁵⁵ "Monitoring Report for the Implementation of the Gender Perspective Within the Strategy and Action Plan for the Integration of Roma, Ashkali and Egyptian Communities in the Republic of Kosovo 2009 – 2015." The Network of Roma, Ashkali and Egyptian Organizations of Kosovo, 2012, www.rrograek.org/rrograek/pdf/Monitoring_report_-_English.pdf.

¹⁵⁶ OSCE Mission in Kosovo. "Kosovo Community Profiles."

¹⁵⁷ Kosovo Center for Gender Studies. "Position of Roma, Ashkali and Egyptian Women in Kosovo."

¹⁵⁸ OSCE Mission in Kosovo. "Kosovo Community Profiles."

5) Registration

- 14.7 % of children age 0-6 do not have civil registration;¹⁵⁹
- Estimated in 2006 that 20-40% of Roma, Ashkali, and Egyptians are not civilly registered;¹⁶⁰
- Many Roma, Ashkali, and Egyptians don't have official ID documents, without which they cannot get social assistance or other public services;¹⁶¹
- Almost 10% unregistered from 2008-2010.¹⁶²

II. Education:

1) General Education ¹⁶³

- 20% have not finished one year of school;
- 96% have not finished the obligatory level of education;
- 12% have finished 9-12 years of education;
- 2% have more than 13 years of education.

2) Literacy

- 18% illiteracy rate for Ashkali and Egyptians, 24% for Roma (illiteracy is much higher for women from these communities);¹⁶⁴
- On average women finish two fewer years of education than males.¹⁶⁵



Figure 32. Roma, Ashkali and Egyptian children, who attend the community centre in Brekoc village, Gjakova, pose for the Solidar Suisse photographer Vedat Xhymshiti.

¹⁵⁹ UNFPA and the Women, Peace and Security Initiative. "Gender-based Violence in Kosovo: A Case Study." UNFPA, 2005, www.unfpa.org/women/docs/gbv_kosovo.pdf.

¹⁶⁰ UNHCR Kosovo Office of the Chief of Mission (OCM), Protection Unit, Civil Registration Campaign Targeting RAE Community in Kosovo. "Action Plan." July, 2006.

¹⁶¹ OSCE Mission in Kosovo. "Kosovo Community Profiles."

¹⁶² Health For All. "Improving Health of Roma..."

¹⁶³ Vrenezi, Nait, and Jusuf Thaci. "The Position of Roma, Ashkali and Egyptian Communities Kosovo."

¹⁶⁴ Ibid.

¹⁶⁵ Ibid.

3) Health Education

- Usually have no access to correct information on nutrition, and malnutrition puts in danger the health of women in these communities;¹⁶⁶
- 40% of Roma and Ashkali women hadn't heard of HIV/AIDS;¹⁶⁷
- 29% of Roma women and over 50% of Ashkali men and women thought the risk of HIV/AIDS could be reduced by abstinence;¹⁶⁸
- 19% of Roma women and 25% of Ashkali men and women justified some form of domestic violence;¹⁶⁹
- 37% of Ashkali women aged 15-49 had used any form of contraception;¹⁷⁰
- 83% of Ashkali men and 65% of Ashkali women had heard of HIV/AIDS;¹⁷¹
- National Institute of Public Health reports 95% immunization coverage, except among Roma, Ashkali and Egyptian communities;¹⁷²
- In Mitrovica low levels of health education in the areas of skin diseases, hygiene, chronic respiratory diseases, and negligence in prevention of child diseases;¹⁷³
- In Fushë Kosova hygiene and family planning were most requested topics for training;¹⁷⁴
- 60% of women did not visit gynecologist during pregnancy;¹⁷⁵
- Home births in poor hygienic conditions without midwives' assistance remains a common practice among Egyptians;¹⁷⁶
- 33% thought girls should marry early to give healthy birth.¹⁷⁷

¹⁶⁶ Kosovo Center for Gender Studies. "Position of Roma, Ashkali and Egyptian Women in Kosovo."

¹⁶⁷ Statistical Office of Kosova. "Demographic, Social and Reproductive Health Survey in Kosovo, November, 2009." Statistical Office of Kosova, February, 2011.

¹⁶⁸ Ibid.

¹⁶⁹ Ibid.

¹⁷⁰ Ibid.

¹⁷¹ Ibid.

¹⁷² European Commission. "Kosovo 2013 Progress Report." European Commission, October, 2013, http://ec.europa.eu/enlargement/pdf/key_documents/2013/package/ks_rapport_2013.pdf.

¹⁷³ Ibern, Elisabetta. "Report On Assessing..."

¹⁷⁴ Health For All. "Improving Health of Roma..."

¹⁷⁵ Rossi, L., T. D'Arca, M. Ferrari, and F. Branca. "Micro-nutrient Status Survey in Kosovo." UNICEF, June, 2002, www.unicef.org/kosovoprogramme/kosovo_media_pub_survival.004.04.pdf as found in Kosovo Center for Gender Studies. "Position of Roma, Ashkali and Egyptian Women in Kosovo."

¹⁷⁶ OSCE Mission in Kosovo. "Kosovo Community Profiles."

¹⁷⁷ Kosovo Center for Gender Studies. "Position of Roma, Ashkali and Egyptian Women in Kosovo."

III. Health and Healthcare:

- 64% admitted having a disease in 2010;¹⁷⁸
- 30% said they had heart diseases, 20% said they had asthma, and 13% said they had diabetes;¹⁷⁹
- Costs of medication and treatment are not affordable in many cases;¹⁸⁰
- Discrimination at Albanian health places reported by Roma, Ashkali, Egyptian inhabitants all over Kosovo;¹⁸¹
- 86% didn't have access to WHO free "essential drugs" at some point during previous 12 months in 2004.¹⁸²

IV. Women/Maternal Welfare:

- 43% of women had abortions;¹⁸³
- 58% of surveyed women said domestic violence is both physical and psychological and only 36% knew of services for women and girl victims of domestic violence;¹⁸⁴
- Women's access to services, especially women in rural areas, remains a challenge because of lack of adequate infrastructure, curtailment of freedom of movement imposed by families and security concerns;¹⁸⁵
- Average age of marriage for girls is 15-16 and 18 for boys;¹⁸⁶
- Girls receive little information about sex education from family and community.¹⁸⁷

¹⁷⁸ Health For All. "Improving Health of Roma..."

¹⁷⁹ Ibid.

¹⁸⁰ OSCE Mission in Kosovo. "Kosovo Community Profiles."

¹⁸¹ Bloom, J.D., I. Hoxha, D. Sambunjak and E. Sondorp. "Ethnic segregation in Kosovo's post-war health care system." *European Journal of Public Health* 17, no.5 (2007): 430-436, Doi: 10.1093/eurpub/ckl270.

¹⁸² UNDP. "Human Development Report Kosovo 2004."

¹⁸³ Health For All. "Improving Health of Roma..."

¹⁸⁴ Kosovo Center for Gender Studies. "Position of Roma, Ashkali and Egyptian Women in Kosovo."

¹⁸⁵ UNFPA and the Women, Peace and Security Initiative. "Gender-based Violence in Kosovo..."

¹⁸⁶ Kosovo Center for Gender Studies. "Position of Roma, Ashkali and Egyptian Women in Kosovo."

¹⁸⁷ CARE International. "Sexual and Reproductive "Knowledge, Attitudes, Behaviour and Practices" research report for youth target groups – FGDs i IDIs Report." Prism Research, June, 2005, www.unfpakos.org/wp-content/uploads/2005/06/CAREKABPPFINALREPORT.pdf.

V. Returnees

- 75% of surveyed repatriated Roma and Ashkali children did not return to school in Kosovo. Main reasons were language barriers, missing school certificates, family's poverty;¹⁸⁸
- 40% of repatriated Roma, Ashkali, and Egyptian children surveyed did not have civil documents;¹⁸⁹
- Marked progress from 2010 to 2011 in civilly registering surveyed repatriated children;¹⁹⁰
- No improvement in school reintegration for surveyed repatriated children;¹⁹¹
- From 2010 to 2011 living conditions for surveyed repatriated families worsened;¹⁹²
- 8,012 Roma, Ashkali, Egyptians returned voluntarily between January 2000 and November 2008;¹⁹³
- Forced returnees experience human rights abuses during process of repatriation;¹⁹⁴
- Forced returnees are at risk of becoming homeless due to various complications with property rights and lost property from 1999 conflict;¹⁹⁵
- Forced returnees have difficulties accessing and affording health care services;¹⁹⁶
- Negative psychological effects, especially on children, suffered by forced returnees;¹⁹⁷
- In 70% of interviews, housing, food, and education were most urgent needs for Roma and Ashkali returnees.¹⁹⁸



Figure 33. Roma, Ashkali and Egyptian children, who attend the community centre in Brekoc village, Gjakova, pose for the Solidar Suisse photographer. During this day Balkan Sunflowers paid a visit to the center to research the health of the community, a project supported by the Solidary Suisse.

¹⁸⁸ Knaus, Verena. "No Place to Call Home..."

¹⁸⁹ Ibid.

¹⁹⁰ Ibid.

¹⁹¹ Ibid.

¹⁹² Ibid.

¹⁹³ "Strategy for the Integration of Roma, Ashkali and Egyptian Communities in the Republic of Kosovo: 2009-2015." Republic of Kosovo, Office of the Prime Minister, December, 2008, www.kryeministri-ks.net/zck/repository/docs/Strategy_for_the_Integration_of_Roma,_Ashkali_and_Egyptian_communities_2009-2015.pdf.

¹⁹⁴ Visoka, Gezim, and Adem Beha. "Repatriation without Responsibility..."

¹⁹⁵ Ibid.

¹⁹⁶ Ibid.

¹⁹⁷ Ibid.

¹⁹⁸ Tmava, Milena, and Adem Beha. "Helplessness: Roma, Ashkali, and Egyptian Forces Returnees In Kosovo." RAD Centre, August, 2009, <http://roma-center.de/wp-content/uploads/2013/05/Helplessness-RAE-Forced-Returnees-RADC.pdf>.

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Life Expectancy and Health
in Kosovo's Roma, Ashkali and
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