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## POLICY BRIEF 2 PREVALENCE OF DISEASE IN THE ROMA, ASHKALI AND EGYPTIAN COMMUNITIES

# **K@sana**

## **INTRODUCTION**

Roma, Ashkali and Egyptian communities, of whom 70% live below the national poverty line, are particularly vulnerable to the cost of health care in Kosovo.

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The main aim of the KOSANA Project is improvement of the health and social security of the population of Kosovo through support of active participation by civil society in the development and implementation of a health insurance system in the country.

The KOSANA Project empowers the CSO-s representing citizens and patients to create advocacy positions based on facts, information, and the needs of the people. This process requires a long-term effort and commitment by organizations that represent citizens' interests. The study identified high prevalence of heart diseases (30% of respondents), asthma (20%) and diabetes (13.3%)<sup>3</sup>. Similarly, a 2010 study in Serbia found a considerably higher prevalence of diabetes among the Roma.

"Since 1999, the conditions of the Roma, Ashkali and Egyptian communities of Plemetina have worsened a lot. We have seen a high increase in hepatitis, cardiovascular diseases, anemia, tuberculosis and blood sugar. Many children here have anemia because of poor nourishment."

> **Ramiz Berisha** Laboratory Technician Plemetina Health House

Solidar Switzerland together with partner Bal-kan Sunflowers Kosova took action to address the knowledge gap by conducting a health sur-vey among the three communities in 2014. The full research findings and methodology will be available in separate publication<sup>1</sup>.

Chronic diseases were a particular focus as diagnosing and treating these diseases consumes a large proportion of health care funds. Preliminary findings indicated high levels of morbidity. For example, a non-randomized 2010 household survey by Health for All in Fushë Kosova/Kosovo Polje municipality found that 64% of the 100 respondents were suffering from a disease<sup>2</sup>.



1 New National Health Insurance Will Save Lives: Life Expectancy and Health in Kosovo's Roma, Ashkali and Egyptian Communities

2 http://www.unfpakos.org/wp-content/uploads/2012/04/HFAreporteng.pdf

### **KEY FINDINGS**

Out of the 1592 people covered in our survey, a total of 494 had been suffering from a disease during the past 12 months. Of respondents, 95.4% affected by any disease had their condition diagnosed by a doctor. Of those with a diagnosed disease, 89.7% are currently receiving medication or other treatment.

The most commonly occurring diseases, as summarized in Table 1, are: hypertension (26% of the respondents affected by a disease), cardiovascular diseases (17%), skeletal disorders (11%), diabetes (10%), and kidney diseases, mainly kidney stones (8%).

Table 1: The most prevalent diseases among the Roma, Ashkali and Egyptian communities

Disease	% of affected respondents
Hypertension	26
Cardiovascular	17
Skeletal	11
Diabetes	10
Kidney disease	8
Gastro-intestinal	7
Rheumatism	5
Respiratory	5

Qualitative interviews with the health care professionals support the survey findings: the majority of informants expressed their concern regarding hypertension, diabetes and cardiovascular diseases in the Roma, Ashkali and Egyptian communities. Qualitative interviews also provided complementary information about the prevalence of diseases that are stigmatized in Kosovo. For example, according to Dr. Skender Marolli of Fushë Kosova/Kosovo Polje, hepatitis is common in these communities in this municipality. Similarly, Doctor Slavisa Radosavljevic of Obiliq/Obilic is worried about the high occurrence of sexually transmitted diseases in the three communities.

When looking at the prevalence of different diseases, consider that the sample represents only cases diagnosed by a doctor. The real occurrence may be significantly higher than suggested

by the survey. For example, the 2010 study in the Roma communities of Serbia found the number of previously undiagnosed cases of diabetes almost as high as the number of diagnosed cases<sup>4</sup>. Another study, conducted among the general population of Serbia in 2012, reveals that over 40% of those with hypertension are completely unaware that they have the disease<sup>5</sup>. These figures from Serbia suggest that the prevalence of hypertension, heart diseases and diabetes among Kosovo Roma, Ashkali and Egyptians is significantly higher than reported by our survey findings.

### Duration of the diseases

Chronic disease (3 months or longer) affected 330 individuals 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 been suffering from a chronic disease for a period of one year or longer.

As demonstrated in Figure 3, chronic diseases commonly last from one to ten years. In our sample, the average duration of a chronic disease is 7.9 years.



Figure 1: Duration of diseases in years

4 Zivkovic et al, 2010.

<sup>5</sup> Grujić Vera, Dragnić Nataša, Kvrgić Svetlana, Šušnjević Sonja, Grujić Jasmina, Travar Sonja. (2012) "Epidemiology of Hypertension in Serbia: Results of a National Survey". Journal of Epidemiology. 22(3), 261-266.

## Locality-specific occurrence of diseases

Environmental factors such as air and water pollution or lack of sewage connection impacts the occurrence of disease. The survey explored whether there are any locality-specific differences in disease prevalence.

No significant deviation from the normal distribution of hypertension, cardiovascular diseases or diabetes was found. In contrast, of 55 cases of respiratory diseases, 25.5% occur in Obiliq/Obilic municipality, though this municipality constitutes only 7.1% of the overall sample. The connection to air pollution caused by the power plant and mine is clear.

We identified 37 cases of genitourinary diseases, mainly kidney stones. Almost half of them (48.9%) are in Gjakova municipality, again, disproportionately high as 19.1% of respondents were from Gjakova. According to Gjakova Strategy<sup>6</sup> Advocate Fridon Lala, the prevalence of genitourinary diseases can be associated with the low quality drinking water in some of the Roma, Ashkali and Egyptian neighborhoods<sup>7</sup>. Moreover, 30.3% of the 33 cases of digestive system diseases are located in Gjakova.

## Impact of diseases on daily activities

"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."<sup>8</sup> We also explored the impact of diseases on human activity, the limitations these diseases cause in people's daily activities. The survey asked respondents how limited they feel in their daily activities because of a disease.

Such limitations mean affected people are not able to enjoy "complete physical, mental and social well being". Such limitations also imply reduced working capacity, which means higher dependence on social assistance and financial help from other family members. Therefore, we were particularly interested to explore the levels of limitations among the working age population (individuals between 18-65 years of age).



Out of the overall sample, including those respondents not affected by a disease during the past 12 months, 25% declare themselves as "limited" or "very limited" in their daily activities. The corresponding proportion is 27.9% among the working age population. The limitations in daily activities among different age groups are illustrated in Figure 2. We can observe that limitations are most prevalent among the age groups over 40 years.

For example, in the age group of 50-64 years, a total of 77 individuals (34.1% of the age group) are "limited" in their daily activities, whereas 50 individuals (33.6%) regard themselves as "very limited". For the age group of 40-49 years, the corresponding figures are 62 individuals (24.7%) for "limited" and 39 individuals who are (15.5%) "very limited".

#### Figure 2: Limitations in daily activities by age



6 The Advocate is part of a Balkan Sunflowers Kosova program promoting implmentation at the municipal level of the Strategy for the Integration of the Roma, Ashkali and Egyptian Communities in Kosovo.

#### 7 Interview, 2015.

8 Constitution of the World Health Organization, 45th Edition (2006); http://www.who.int/governance/eb/who\_constitution\_en.pdf

## **DISCUSSION AND RECOMMENDATIONS**

This presentation of the most commonly occurring diseases and the levels of limitation in daily activities among the Roma, Ashkali and Egyptian communities leads to concern regarding the high prevalence of diseases and limitations among the working age population. We are especially concerned about the presence of noncommunicable chronic diseases, particularly diabetes, hypertension, cardiovascular diseases and skeletal disorders.

These diseases and the consequent limitations are causing significant problems to personal and communal well-being. In addition to the loss of the enjoyment of a healthy life, and the potential burden on one's family, treatment of the diseases constitutes a heavy financial burden for society. The financial impact is especially severe if we consider that the majority of the Roma, Ashkali and Egyptian families live below the national poverty line.

The high number of working age people with limitations in daily activities means reduced working capacity and increased dependence on social assistance and informal income sources. Conversely, investing in maximal health among the working age population would help in improving working capacity and thus, decrease dependence on social assistance.

Reducing the prevalence of diseases among the Roma, Ashkali and Egyptian communities requires action of the national government, local governments, international organizations, local non-governmental organizations and within and by the communities themselves.

#### The Government of Kosovo should:

- Proceed towards implementing the public health insurance system;
- Fund preventive health care services, including screening for the most commonly occurring diseases.

#### Municipal governments should:

- Ensure the provision of preventive and early intervention health care services;
- Increase access to communal services such as water and sewage connections, and solid waste collection;
- Through health institutions provide facilities, materials and human resources for health education and awareness-raising.

#### International organizations should:

• Provide financial and expert resources supporting sustainable prevention and early intervention strategies.

#### Civil society organizations should:

- Advocate for implementation of health care reform;
- Deliver health education, health mediation and awareness raising in vulnerable communities;
- Facilitate communication between the beneficiary communities implementers.

#### Community actors should:

- Work in their respective communities for making health impact changes available even if living in poverty<sup>9</sup>;
- Participate in planning and preparation of the campaign materials, observing the response from the community and gathering and delivering the feedback to the other implementing actors.

9 See Policy Brief 3, Nutrition and Life Choices, for a more thorough treatment of this theme.





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