





RAPID QUALITATIVE RESEARCH ON SPECIFIC HIV AND AIDS VULNERABILITY OF RAE COMMUNITIES IN KOSOVO

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Prishtina, April 2016

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Report preparation

This report is prepared by Prof.asoc.dr Merita Berisha, Chief of the Observatory, for Mother, Child and Youth Health, the Institute of Public Health of Kosovo and Prof.asoc.dr Naser Ramadani, Director of the Institute of Public Health of Kosovo.

Research Implementing Institution

The research has been conducted by the National Institute of Public Health. The technical assistance, development of protocol, training of focus groups, in-depth interviews and compilation of the final report was financed by the Global Fund through CDF, the Principal Recient of the R7 HIV grant in Kosovo.

Leaders of the Focus Groups and In-depth Interviews

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Acknowledgment

We would like to extend our thanks to all people involved in the research, specifically the participants in this reseach, and the leaders of the RAE communities that enabled the selection of the persons for focus groups and interviews.

Abbreviations/Acronims

NIPHK	National Institute of Public Health of Kosova
GF	The Global Fund
RAE	Roma Ashkali Egyptian
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome
MDG	Millenium Development Goals
Р	Participant/s
PFG	Participants in the Focus Groups
MSM	Men who have sex with men
NGO	Non-governmental Organisation
PWID	People Who Inject Drugs
STI	Sexually Transmisive Infections
SW	Sex workers
PEN	Peer Education Network
PLHIV	People Living with HIV
LGBT	Lesbian, Gay, Bisexual, Transgender
MICS	Multiple Indicator Cluster Survey

OVERVIEW

The report presents findings from the qualitative study conducted in four municipalities of Kosovo: Fushë Kosovë, Ferizaj, Gjakovë and Pejë among RAE communities aged 15-49 years during December 2015 and January 2016. Main objective of this research is to ensure in-depth information on knowledge, practises and attitudes for HIV and AIDS, risk factors and to provide data for programs and policies for the national response. The project has been financed by the Global Fund through CDF and has been implemented by National Institute of Public Health of Kosova. This was a qualitative research which has been realized through focus group discussions and in-depth interviews.

Main findings show that HIV and AIDS are perceived as problem by majority of participants in the research with RAE communities. They have basic knowledge about the HIV and AIDS, mostly as disease terminology and it varies based on the level of education. Participants have shown knowledge about risk groups i.e. key populations, but there are differences among the municipalities subject to the number and type of trainings attended. They declare stigma towards people living with HIV and AIDS, whereas they have supportive attitude towards affected children, regardless their gender.

The vast majority of respondents have no information about the HIV testing centers. Most of them would hesitate to do an HIV test due to prejudice. Their perception is that HIV is not a problem in their communities.

Participants are not aware whether there is difference between generations with regards to the age when first sexual experience occurs. Man believes that women start their sexual life earlier than man and this is what RAE belive in all municipalities. The main reasons for early start of sexual life is considered to be early marriage of girls, mostly influenced by the family; severe socio-economic conditions in the family; lack of trust in daughters and social pressure.

Participants have highlighted that there is commercial sex in their communities due to financial reasons. They identify women as subjects of commercial sex more often than men, whereas they also claim there are MSM in their communities. Majority of interviewees say that both are risk

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groups for transmission of HIV. In terms of drug use, respondents declared hashish as the most common drug used among youth in these communities, and there were no differences between municipalities. They also claim there are users who inject drugs, whereas they know small number of PWIDs and consider them to be most at risk for HIV due to needle and syringe sharing for drug injection.

Strengthening of RAE communities requires overall commitment of central and local government as well as of civil society. The research recommendations are: through multi-sectoral approach to develop policies, programs and action plans for social inclusion of RAE vulnerable groups; design specific programs focusing on identification of inequalities, and implementing activities specifically tailored to the RAE communities needs.

1. INTRODUCTION

1.1 Rationale of rapid qualitative research

Roma, Ashkali and Egyptian communities face highest poverty rates, high unemployment, poor socio-economic conditions, lower education, poor health and nutrition status and remain one of the most marginalised and vulnerable communities in the country. In addition to it, RAE work in severe and unhealthy conditions and have less paid jobs. Similar to many countries of the Central and Eastern Europe, Kosovo lacks statistics and analysis on Roma, Egyptian and Ashkali¹ health and access to healthcare. It is assumed that there are approximately 35.000 to 40.000 Roma, Ashkali and Egyptian, currently living in Kosovo, and that there are many more living abroad. Vast majority of RAE communities live in: Gjakova, Prizren, Ferizaj, Fushë Kosovë, Obiliq, Pejë, Graçanica, Gjilan, Mitrovica and Leposaviq². According to Kosovo Agency of Statistics, by the end of 2011 there were 1.739825 inhabitants living in the country, out of whom 92.9% were Albanian, 1.47% Serb, 1.08% Turkish, 1.58% Bosnian, 0.51% Roma, 0.89% Ashkali, 0.66% Egyptian or 2.06% of RAE communities and 0.88%³ other. First MICS research in the country was conducted during 2013 and 2014, and the study reveals there are differences between RAE communities and general population, regarding the knowledge about HIV and AIDS⁴, therefore the request for further qualitative analysis has been proved to be necessary in order to better address health needs of RAE communities and especially the issues regarding reproductive health, STIs, knowledge on HIV and AIDS. United Nations General Assembly Special Session on HIV and AIDS (UNGASS) has called on governments to improve knowledge and skills of young people to prevent HIV among themselves. Indicators to measure this

¹ Foldes M. E., Covaci A., 'Research on Roma health and access to healthcare: state of the art dhe future challenges', Int J Public Health, 2011

² Strategy for integration of Roma, Ashkali and Egyptian communities in Republic of Kosovo, 2009-2015, p 31-37

³ https://ask.rks-gov.net/ENG/pop/publications

⁴ Kosovo Agency of Statistics. 2014. Multiple Indicator Cluster Survey. Prishtina, Romë, Ashkali and Egyptian Communities in Kosovo 2013-2014

objective and MDG in reducing the HIV by half, include improvement of the knowledge on HIV and HIV prevention, as well as behaviour change for prevention of further spread of infection. There are more "specific" factors reported such as early initiation of first sexual intercourse and also early marriages, increase in number of sexual partners and high use of drugs including injecting drugs all this put RAE communities into risk group for HIV. Findings from "Multiple Indicator Cluster Survey 2013-2014" among Roma, Ashkali and Egyptian communities show that stigma and discrimination have been considered to be high above 90% regarding the attitudes related to HIV and AIDS. The most common misconception about HIV transmission for both sex are: sharing the food with person living with HIV, among women: greetings or handshake with HIV infected person; and among men transmission from mosquito bites:⁵ Based on the fact that 10% of Roma, Ashkali and Egyptian (RAE) aged 15-19 give birth to a child, 4% are pregnant for the first time, one in five (17%) of RAE women aged 20-24 years have had a live birth before the age of 18 years and the prove that adolescents have less chances (19%) to use contraceptive means is sufficient for the initiation of some measures of public health with regards to reproductive health and protection from HIV. Kosovo belongs to countries with lower HIV and AIDS prevalence with less than 1% on general population and under 5% among key populations. However given the fact that testing among population is not at satisfactory level and that there are numerous risk factors, and that Kosovo has a considerable potential for increase of HIV prevalence, especially between men having sex with men, people who inject drugs and vulnerable and marginalised groups. According to available data, from the onset of first case with AIDS in 1986, there are 100 reported cases, 46 are with HIV, 54 with AIDS, 41 deaths as a consequence of AIDS. Based on gender, 69% are men, based on the transmission methods: 82% heterosexual, 12% MSM, 4% vertical transmission, 2% intravenous drug users while based on group ages: 33% from 25-34 years, 30% from 35-44 years. Only during 2015, 2 cases have been reported, one with HIV and one with AIDS ⁶.

⁵ Kosovo Agency of Statistics. 2014. Multiple Indicator Cluster Survey. Prishtina, Romë, Ashkali and Egyptian Communities in Kosovo 2013-2014,

⁶ Report of NIPHK, Departament of Epidemiology, NIPHK , 2015

2. THE GOAL AND THE OBJECTIVES OF THE RESEARCH

Main objective of the research was to collect in depth data for development of evidence based interventions among RAE communities and improve HIV and AIDS national response.

Specific objectives of research among RAE communities were the assessment of:

- Knowledge, attitudes and resources for obtaining information on HIV and AIDS;
- Stigma and discrimination towards people living with HIV or AIDS;
- Knowledge about voluntary counselling and testing for HIV;
- Knowledge, attitudes and practices on sexual relationships
- Presence of risk behaviours key populations among RAE communities (e.g. sex workers, men who have sex with men, lesbians and people who inject drugs) and to assess knowledge about these groups as risky for transmission of HIV and STIs.

The significance of the research lies on provision of evidence based facts regarding HIV and AIDS, which could assisst on development of relevant policies as well as decision making in order to improve and promote health for RAE communities in Kosovo.

3. METODOLOGY OF THE RESEARCH

This qualitative research is counducted among RAE communities aged 15-49 years. Selection of municipalities was based on the high percentage of RAE communities living in these municipalities according to 2011 Kosovo census. In order to assess the HIV vulnerability among RAE communities' focus groups discussions and in-depth interviews were counducted. Distribution of respondents in focus groups was done by gender and age-group, as presented in the table 1a.

3.1. The sample size

The sample size planned was 128 participants, distributed in 4 municipalities, and in each municipality there were 4 focus groups selected with the following structure: Focus Group I - women aged 15-24, Focus Group II - men aged 15-24, Focus Group III - women aged 25-49, and Focus Group IV - men aged 25-49, in total 16 Focus groups. Each Focus Group had from 6 to 8 persons. There were 116 respondents out of 128 planned, with the ratio of involvement of 90.6% (table 1a).

Discussions in the focus groups have been registered with Dictaphone and transcript from was used to analyse the discussion among focus groups. Focus Group Discussions lasted approximately 90-120 minutes. As planned, 40 in-depth interviews were conducted with duration of 45-60 minutes each.

3.2 Criteria for selection of participants in Focus Groups

Criteria for selection of participants in focus groups were:

- a) The participant belongs to RAE communities
- b) Age group 15 49 years
- c) Equal gender representation

d) The participant lived and worked for more than one year in selected municipality (Fushe Kosova, Peja, Ferizaj, Gjakova).

	Women		Μ	len			
Municipality	15-24	25-49	15-24	25-49	Total		
	Ν	N	N	N	N	% of inclusion	
Gjakova	8	7	8	6	29	90.6	
Peja	6	8	7	6	27	84.4	
Ferizaj	7	7	8	8	30	93.8	
Fushë Kosova	8	6	8	8	30	93.8	
Total	29	28	31	28	116	90.6	

Table 1a. Distribution of participants in focus groups disaggregated by municipality, age group and sex

40 in depth interviews took place, 10 in each municipality: Gjakova, Peja, Ferizaj and Fushe Kosova. Sociodemographic characteristics and distribution of respondents in in-depth interviews are presented in table 2a.

Characteristics		Ferizaj		Fushë Kosovë		Gjakovë		Pejë		Total	
		Ν	%	Ν	%	Ν	%	Ν	%	Ν	%
To	Total		100.0	10	100.0	10	100.0	10	100.0	40	100.0
Residennce	Rural	10	100.0	-	0.0	6	60.0	2	20.0	18	45.0
Residennce	Urban	-	0.0	10	100.0	4	40.0	8	80.0	21	52.5
	Unmarried	8	80.0	-	0.0	3	30.0	3	30.0	14	35.0
Marital Status	Married	2	20.0	10	100.0	7	70.0	6	60.0	25	62.5
Status	Divorced	-	0.0	-	0.0	-	0.0	1	10.0	1	2.5
Employment	Yes	5	50.0	2	20.0	2	20.0	1	10.0	10	25.0
Employment	No	5	50.0	8	80.0	8	80.0	9	90.0	30	75.0
	No educatio	1	10.0	3	30.0	2	20.0	-	0.0	6	15.0
Education	Primary	4	40.0	6	60.0	6	60.0	4	40.0	20	50.0
Education	Secondary	5	50.0	-	0.0	1	10.0	4	40.0	10	25.0
	University	-	0.0	-	0.0	2	20.0	2	20.0	4	10.0

Table 2a. Sociodemographic characteristics of the participants in the interviews

Based on residence more than half (52.5%) come from urban areas; according to marital status 62.5% are married, with some distinctions in municipalities: in Ferizaj 80% unmarried, in Fushe Kosove all married, in Gjakove 70% married and Peje 60% are married. Half of the respondents have completed primary school (50%), 25% secondary school, 10% or 4 respondents have university degree and 6 or 15% no education at all.

3.3 Criteria for selection of participants for the in-depth interviews

Criteria for selection of individual participants in the research were:

- a) The participant belongs to RAE communities
- b) Age group 15 49 years
- c) Equal gender representation

d) The participant has lived and worked more than one year in selected municipality (Fushe Kosove, Peje, Ferizaj, Gjakova).

3.4 The place of discussions and interviews

Discussions in focus groups and in depth interviews have been conducted in the offices of RAE leaders in respective municipalities: Peja, Fushe Kosova, Ferizaj and Gjakova.

In coordination with the RAE community leaders, participants from each municipality were selected in accordance to criteria and planned sample, and have been invited to join the group discussion, with the previously given verbal consent.

3.5 Collection and management of data

Questionnaires for focus groups and in-depth interviews, which have been previously tested and piloted, have been finalised from the research group of the NIPH. The collected data from 16 focus groups have been presented in details, and are classified in certain fields based on issues that are related to HIV, AIDS and perceptions of the risk:

- 1. Knowledge and sources of information
- 2. Knowledge about risk groups and infection prevention
- 3. Stigma against people living with HIV and AIDS
- 4. HIV testing
- 5. Sexual intercourse
- 6. Commercial sex
- 7. Drug use.

Findings for each area has been presented according to the segments of research targeted population. Focus group discussion questionnaires and guidelines are presented in the Annexes and are available at the NIPHK.

Forms of data collection:

- Questionnaire for focus group discussion (Annex A)
- Semi structured questionnaire for in-depth interviews (Annex B)
- Form of participation in focus group discussion (Annex C)
- Informed Consent for participants in focus group discussion (Annex D1)
- Informed Consent for participants in-depth interviews (Annex D2)

- Refusal form (Annex E)

- Transcript

Staff

Staff to conduct the focus group discussion and in-depth interviews have been trained by the NIPHK on how to administer questionnaires and counduct the research.

3.6 Data analysis

Recorded data has been uploaded to computers and the transcript from focus group discussion has been analysed by coding information based on the individual and mutual characteristics. Collected data from 40 in-depth interviews are coded, analysed and presented in tables and charts in the Appendixes. Comparative methods and triangulation of data have been used to validate the findings presented in the discussion part.

3.7 Ethical issues

Research team has given special attention to ethical issues. After the introduction and explanations about the research, the consent form has been read to the participants before initiating the focus group discussion. Same approach was used with participant in the in-depth interviews. Participation in the research was on voluntary bases and respondents were informed on their right to interrupt and withdraw from the discussion/interview at any time during the research process. All respondents had to state verbally they understood and agreed with all points included in the consent form, before becoming research subject. Special attention was given to confidentiality and privacy issues. The focus groups discussion and in-depth interviews were conducted in the offices of community leaders, in order to minimise eventual dissatisfaction due to the sensitive nature of questions and to ensure privacy and confidentiality. Respondents were free to refuse to answer in any of the questions.

All data and research tape recorded conversations are confidential. Data from the Dictaphone and in-depth interviews questionnaires are secured in a safe place in the NIPHK.

4. THE RESULTS OF THE RESEARCH

Research results are divided in two chapters:

- 4.1 Results of the focus groups discussions and
- 4.2 Results of in-depth interviews.

4.1 RESULTS OF THE FOCUS GROUP DISCUSSIONS

4.1.1 Results of the focus group discussions of women age group 15-24

Knowledge and source of information

Young girls age 15-24, have knowledge about HIV and AIDS as disease terminology and this the level of knowledge varies depending on the level of education. The majority have highlighted that the only way of HIV transmission is sexual intercourse with the distinction based on the level of education being aware about other ways of HIV transmission. Women age 15-24 years consider that AIDS is a problem in their communities due to lack of sufficient knowledge. Frequent sources of information among those who have knowledge about HIV and AIDS are trainings, while the rest who have heard about it, they know through media such as TV and Internet.

Interviewer: "Do you think this disease is a problem and if yes what makes it as a problem for your communities"

FGP: "We consider the disease to be a problem due to the lack of information especially the youth"

FGP: "the disease is considered to be a problem for our communities due to lack of information and not knowing the transmission routs"

Knowledge about the risk groups and prevention of infection

According to participants, the youth are more at risk for HIV and AIDS, since they belong to sexually active group and they are not much informed. Lack of knowledge is more significant among those who are illiterate. Participants identify groups with risk behaviours as: persons who frequently visit brothels, change frequently their partners, minors getting married at early ages and victims of trafficking.

Participation of the focus group, Ferizaj: "young women and girls/ minors are more at risk since they often get married with elder men who might have had a women who could have been infected and consequently they can get infected too due to lack of knowledge "

Majority of participants mention condom as a prevention tool. Those who attended or completed primary education have heard of condoms, but have never seen any.

According to participant in the focus group discussions from Gjakova "most common group that gets infected by HIV is youth which have no education and are poor. As they do not have knowledge about the disease, they are easily fooled and are frequetly trafficked, persons that travel frequently and the ones that come from abroad and since abroad they go often to brothels and discotheques they are in contact with persons who might be infected"

In many cases, participants have counfusion about prevention methods and contraceptive tools while in all municipalies they are not aware of the existence of any other preventon methods.

Stigma towards people living with HIV and AIDS

In order to understand whether there is stigma among RAE and what attitude have RAE populations about HIV infected person and person with AIDS, discussions in focus groups have started with questions such as: "Are there cases in RAE communities where there are HIV infected people or people who died from AIDS" and "What is the reaction and the attitude towards them".

One of the participants in the Gjakova Focus Group: *"with one word: he was adventurous"*

Women of this age-group in two municipalities Fushe Kosova and Gjakova declared they have heard there are persons from their communities who belonged to the risk groups and died from AIDS. Women of Peja municipality had negative attitudes towards HIV infected persons or people with AIDS, while in other municipalities they would help and support these persons.

Participant of Focus Group, Fushe Kosovo says that: "he knows a woman from Ashkali community who has HIV and AIDS; this woman was previously married and she changed many partners and she is married to a drug user now; she is also a drug user herselfand she has a child who is HIV infected"

HIV Testing

Women age between 15-24 have little knowledge about HIV testing and do not know where to do an HIV test.

Gjakova women: "this test is done in the family medicine center, in the information office".

Young women from Peja municipality have shown prejudice against people who could get tested for HIV, while other focus groups support the ones that do an HIV test.

Sexual intercourse

The most frequent age when women have their first sexual intercourse is between 15 to16 years and this is mainly related to their early marriages, and discussions reveal there are cases of girls getting married younger than 14. According to women who participated in the discussion of this focus group (age 15-24) sexual intercourse among women is always linked to marriages. There are cases when they are preassured by their families and in the cases when they come from poor families they get married at very young age; it also happens that their male peers "kidnap girls". It is all very much associated with the low level of education and poor economic and financial situation in the family as well as with the tremendous gender discrimination, especially against young women and girls. Preservation of family pride and moral were stated in the discussions many times, there are families that don't trust their daughters' behaviours and they are often forced to get married in order to preserve family honour.



Nevertheless, respondents in this research do not support sex at younger ages. According to their statements men also start sexual intercourse at young age between 15 and 16. Regarding the cause of early sexual intercourse there are no differences among respondents in four municipalities, but men indicate that most frequent reason is sex desire, they consider themselves more mature, but this can also be associated with the low level of sexual education. Related to the question on whether this traditional practice has changed, they highlight that the situation has improved but it should change even more. Young women of this group do not support early marriages, exept in the cases when it happens on their own will.

PFG: "one of my clasroom mates (a girl) got married at 13"

PFG: "they give their daughter away from home"

Risk behaviour groups

When asked about the risk behaviour groups, women of age group 15-24 consider that key populations at risk are MSM and youth that visit places where commercial sex services are provided. According to them, sex work is present as phenomenon in their communities and severe financial situation is mentioned as one of the main factors favourizing it.

PFG: "had a friend who told me he had sex with a same gender partner (MSM)"

One of the participants' recommendations about the HIV prevention was to provide information to the population about HIV and AIDS and also to increase the level of awareness among youth about the use of condom when they have sexual intercourse with unknown persons, as well as female sex workers to use female condoms.

One of the focus group women, Fushe Kosova: "my aunt told me that in a village near Ferizaj, Dubrave, there is a women (single) who would have sex in exchange for money, for 3 euro"

There are prejudices within RAE communities towards different professions and gender, and this mind set is not very much different compared to conservative patriarchal mentality in the general population. The same stands for commercial sex. The anecdotal data speak about trafficking of women and also about their engagement in offering sexual services in exchange for money or goods. They deny the existence of LGBT communities among RAE.

Participants in focus group discussion, Gjakove: "Commercial Sex workers are doing harm to young men aged 15-16, since they have sex with them and men might not be aware about the infections they may transmit"

According to PFG, most at risk groups for HIV are female sex workers and MSM since they have multiple partners; neertheless during the discussions about MSM it was not mentioned what makes MSM communities risk group.

Drug use

The most frequent type of drug mentioned to be used among RAE youth, is weed-hashish. According to participants drugs are used more by men, with some differences in municipalities. According to few respondents, these are risk groups for HIV and AIDS due to exchange of syringes while injecting drugs. Participants consider that informing of young people is a key factor for prevent and reduce this problem.



Drug use was reported to be very high in Ferizaj among youth, especially at the age of 16 and 17. According to them, hashish is mostly used due to cheaper price and easier use (rolled cigarettes).

PFG Fushë Kosovë: "I had a friend in the secondary school who has inhaled drugs"

PFG, Gjakovë: **"weed" sells with bags"**, **"it costs 5 euro"**, **"police knows drug users, who are the drug users"**

In Gjakova, respondents reported they know drug users in their community and are quite familiar with their aggressive behaviour. They claim they have been provided with information, education and comunication materials on drug related issues.

4.1.2 Results of focus group discussion with men of age group 15-24 years

Knowledge and information sources

Men group aged 15-24 years have knowledge about HIV and AIDS, although this level of education varies and depends on the level of education, involvement in HIV and AIDS related trainings. The level of knowledge in the municipalities is approximately the same, with the exception of youth in Gjakova Municipality who didn't have much knowledge regarding the disease terminology and the routs of transmission of HIV. They highlighted that the only way of transmission of HIV is through sexual intercourse. The most frequent sources of information for HIV and AIDS were trainings in the schools, and few social networks, as well as lectures in the schools when marking the world AIDS day.

Focus Group discussions with men from Peja, reveal misconceptions about the route of transmission: besides sexual transmission they say they've heard of other routes of transmission of HIV such as use of others' personal hygienic kits ("razor", teeth brush) i.e. through infected blood.

Knowledge about risk groups and infection prevention measures

Respondents repeatedly stated that youth is the most at risk group for HIV due to the lack of information. According to them prevention measures for HIV infection are: use of condom, being faithful to a partner and not exchangin personal hygienic kits. There are differences at the level of knowledge regarding risk groups and infection prevention measures accross municipalities, due to respondents' education.

Focus group participants from Peja say that there are cases when community members practice sexual intercourses with multiple partners and drug users, sex workers, trafficked women, those who do tattoos, but from the discussions it was noted that they are not informed that HIV is more common among these groups, while in Gjakova there are misconceptions about injecting drug users, confusing them with youth who do weed. With regards to condom, they are aware that this

is a prevention measure but when asked whether they practice condom use, they declare the RAE communities don't use condom that much.

PFG, Fushe Kosove: **"immoral people (in the sence** of changing the partners), homosexuals, drug users, are at risk"

Stigma towards people living with HIV and AIDS

In general, among RAE communities there are prejudices regarding different diseases, mainly related to communicable diseases and especially those that are spread through sexual intercourse. In Peja this group has pointed out that there was an infected person coming from their respective community, who has lived abroad and who died of AIDS, whereas in Gjakova they only heard of the disease but they do not know anyone in particular. Stigma within these focus groups are subject to the level of knowledge about the disease and the way of transmission of the infection. In general it is a conclusion that stigma is present at all focus groups of all age groups included in the research, especially towards women suffering form the disease; the majority say thay would not support a women living with HIV. It is most likely that community will abandon her.

PFG, Ferizaj: "this person is condemned by God because of immoral behaviours" PFG, Fushë Kosovë: "These persons got what they deserved"

PFG, Fushë Kosovë: "I would not mind staying with the HIV infected person, I would greet him/her, drink from the same glass etc. but would pay special attention not to have sexual intercourse with him/her.

In Fushe Kosove, stigma is a subject to an infected persons' age, namely if they were children they are not to blame and abandon, compared to the adults and members of groups such as "drug users and prostitutes".

In general the level of stigma varies due to level of knowledge about the disease and the routes of transmission.

HIV testing

There are differences regarding knowledge on HIV testing. Participants with higher level education and participants that have attended trainings are aware of HIV testing. The level of knowledge was lowest in Gjakova where none of the participants knew about the HIV testing. Vast majority declare they would hesitate to get tested due to prejudice, since suspicions would arise in the society about them, as the disease is related mainly with "inappropriate" sexual behaviours. According to them, those communities do not aply HIV testing because they think that they might be prejudged and stigmatized by their small communities.

Sexual intercourse

The most common response on the question on when does the first sexual experience take place, was that this happens among girls age 14 to 15, while there are cases of Roma population that have sexual intercourse at the age of 13 and cases of early marriages imposed by families due to the severe economic status.



The most reported age of men having their first sexual expirience is between age 15 to 16. This is due to low level of education and awareness among youth and their families. Early sexual activity is also linked with their marriage at young age, especially among women, which is also proven by Kosovo MICS study. Another reason is poverty i.e. severe socio-economic situation that RAE communities face.

Risk behaviour groups

Commercial sex and MSM activities are reported to be present in all municipalities selected for the research. According to respondents, there are many women who provide sexual services in exchange for money. Also according to their opinions, MSM have sexually harassed other men (e.g. one PFG declared that he was sexually harassed by 3 such persons, meaning MSM). Financial aspect is mentioned as one the favourizing factors. They are aware that these groups are at high risk for HIV, while they are not aware of the factors causing the risk, therefore they propose to inform the population about the routes of transmission and infection prevention, as well as about use of condom as a prevention measure.

PFG Fushe Kosove: "we know a person named E. who used to be MSM and 4-5 ago he started bringing his friends from Peja, Gjakova", but the communities abandoned him to protect the moral of the society/community"

PFG, Peja: **"we know a case where mother and daughter sell sex "**

Drug use

The most frequent type of drug used among youth in RAE communities is reported to be weedhashish. According to them weed-hashish is cheap and it is bought mainly in the form of rolled cigarettes. They have identified injecting drug users, but they do claim a high rate of PWID within their communities, and this applies to all municipalities in the research. They consider these groups to be at high risk for HIV but don't know the reasons of risk. In addition they consider that informing the population and risk groups about the risk would result in lower spread of HIV.

The vast majority of participants in Peja declared they have seen injecting drug user. According to them he has returned from abroad and his repatriation may be linked to that kind of behavior. Among RAE youth in Peja the most common type of drug is hashish. One of FGP declared to have used hashish (weed).

4.1.3 Results of the focus group among men of age group 25-49 years

Knowledge and sources of information

The level of knowledge about HIV and AIDS varies across four municipalities. The majority stated that they heard it is a communicable disease that is transmitted through sexual intercourse, but have no knowledge about other ways of HIV transmission. Most frequent sources of information among men aged 25-49 years have been media (TV), schools and trainings that some of participants have attended. In the Municipality of Fushe Kosova, the majority have gained knowledge from trainings, whereas in other municipalities they have received the information through TV and some of them in schools. Respondens percieve the disease as a global problem due to the high rates of mortality, whereas they do not consider it as a problem for their communities, since there are no infected persons.

According to the respondents from Fushe Kosova, they consider the disease to be more serious for youth. According to them HIV is transmitted through sexual intercourse with women that are HIV infected. There is also a perception that homosexuals and prostitutes are sources of infection due to multiple partners. Participants indicated that sources of information are mainly trainings in the RAE centre in Fushë Kosova.

Knowledge about risk groups and infection prevention measures

Majority of respondents mention condom as prevention measure, whereas participants from municipalities of Ferizaj and Fushe Kosova are aware that even abandoning from risk groups and obtaining correct information regarding the disease reduces the possibility of spreading the infection. FGP from Peja mention MSM as risk group as well as persons that have multiple partners. They declare they know MSM among their communities.

PFG, Ferizaj: "most at risk groups for HIV and AIDS are persons who do not take care of themselves and due to bad personal hygiene and sex with unknown persons, those who drink alcohol, drug users, prostitutes and youth"

HIV infection is spread: "through the touch and through the air"

In most cases respondents declare that the disease is transmitted through unprotected sexual intercourse with infected women or sexual intercourse with men who are "homosexuals", drug users, but it is noticed from discussions there are misconceptions with regards to the transmission of HIV and prevention, which relates to poor social and economic status. This is same across all municipalities.

Stigma towards people living with HIV and AIDS

Participants in Peja and Ferizaj have said they knew persons who belonged to risk groups, who had AIDS and have died from the disease. During the discussions, some of FGP were very reserved towards the people living with HIV or AIDS, whereas they have different attitudes if the affected person would be a family member.

PFG: "Since it is a communicable disease I would abandon that person, if that person would be my wife I would leave her and I would not take care of her, but if he/she would be my child I would help him/her"

HIV testing

Knowledge about HIV testing as a diagnostic method is an issue of great concern, with many information gaps among respondents. In general this group of men does not have knowledge about HIV testing, they do not know where the HIV testing is carried out and whether this service is costed or free. They have no prejudice about persons who tests for HIV which is than associated with the low level of knowledge about the infection, as well as they have a low perception of this problem in the communities where they live.

Sexual intercourse

The most common age women start their sexual activities according to this focus group is between 14 to 15 years old, and early marriages are very frequent. According to them early marriages are related to preservation of family honor, the changes that occur during puberty and to prevent immorality as "there are more possibilities to have new contacts through social network". According to this focus group men also start sexual activities at young age between 15 to 16 years old, and that is in all municipalities covered by the research. With no differences among municipalities, almost all participants have mentioned same reasons for early start of sexual experience or early marriages.

It shall be highlighted that they never mentioned any advice /perception about risk related to early marriages. According to them "families do not prevent women from getting married".

Peja focus group claimed that the most common age women start their sexual activities is 13 to 14 years old.

Interviewer: *Does the tradition have an impact in this aspect?*

PFG: "When women become 14 till 18 years they are niether on earth nor in heaven, they care for nothing and that is why they abandon their family and get married"

PFG: "No in the contrary, currently relationships and marriages start earlier, as they find partners through social media, phones and internet"

Risk behaviour groups

Commercial sex is present as a phenomenon in RAE communities especially in Peja, Fushë Kosova and Gjakova. According to them financial reasons are favourizing factor for sex work. They consider this as a problem since the youth go to these places where commercial sex is provided and they get at risk for HIV, due to frequent change of partners.

They have identified MSM, especially in Peja and Fushë Kosovë. They mentioned a house in Fushë Kosovë that was frequented by many MSM during 2004-2005, but that house/spot is no longer in function. They consider that these groups are at higher risk for HIV and AIDS. One of their recommendations to reduce the risk from HIV, was to inform the population regarding HIV and AIDS. They also indicated that informing and raising the awareness among youth on condom use when frequenting sex work places and in cases when they have contact with unknown partners

FGP in Peja confirm that there are MSM in their communities: "now some of them are married but there are young men who have identified themselves publicly as homosexuals", whereas they consider that high risk of getting HIV is related to "personal hygiene".

In Gjakovë they have indicated that there are some women coming from Albania who are engaged into commercial sex in one pub. With regards to MSM, they declared they do not know anyone although they have heard of them.

FGP in Fushe Kosova was that there are persons that are engaged in commercial sex, female as well as MSM. They declared there are MSM in their communities. They pointed out there was a pub frequented by many homosexuals during 2004 - 2005: "there were people coming from all parts of Kosovo, but that pub does not exist any longer".

Drug use

Weed-hashish is the most frequent type of drug used among the youth and especially men. There is no difference in response to this question accross municipalities in the research. The problem is the same in all municipalities where the research was conducted; those that are considered as risk groups are the ones that inject due to syringe exchange.

4.1.4 Results of focus groups among women aged 25-49 years

Knowledge and sources of information

The level of knowledge about HIV and AIDS varies by municipalities. The majority stated that they heard it is a communicable disease that is transmitted through sexual intercourse, but have no knowledge about other ways of HIV transmission. They often confuse it with the hygiene of genital organs, or that it is transmitted through breath or touch. Some of PFG in Gjakova which were illiterate never heard of the disease. Most frequent sources of information for those who had some knowledge were media, TV and trainings. In Fushe Kosova, the majority have obtined knowledge from trainings whereas in Ferizaj, women of this group age have heard of the disease from TV, newspapers and also from trainings and schools. As the disease is incurable they perceive it as a problem and they lack knowledge regarding ways the disease is transmitted. Since there are no infected cases within the communities, they consider the disease is not to be a problem.

Knowledge about risk groups and infection prevention measures

According to them youth are more at risk since they belong to sexually active group and are not informed about the disease and they often act without thinking about the consequences. The respondents also indicated persons that have multiple partners, and men above 35 years that have multiple partners, drug users, sex workers and groups that have unprotected sex. All participants in Fushe Kosova think that all people are at risk without mentioning any particular group. Majority mention the condom as prevention measure, whereas participants from municipalities of Ferizaj and Fushe Kosova are aware that even distancing from risk groups reduces the possibility of getting and spreading the infection. According to municipalities there are differences at the level of knowledge in the municipalities where trainings were held.

Interviewer:

Do you know how can we protect ourselves from the disease?

PFG:

"If the women is smart, educated and uses condoms, only condom protects her from the disease"

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Stigma towards people living with HIV and AIDS

Women between 25-49 years have stated they would never abandon their husband if he is HIV infected or has AIDS, with the exception of Fushe Kosova PFG, who have declared they would have abandoned them. They would have taken care of their family members and would support them, but they would have isolated PLHIV, since it is a communicable disease. Out of the discussions it is clearly noted that there is stigma and fear to have contacts with these persons. This women focus groups in Peja know the person that has died from AIDS, 15 years ago "he was homosexual although he was married". The vast majority have prejudice attitudes and would distance themselves from them, "*unless the infected person is the "husband" or "family member*"; women of this age group would not abandon them but take care instead. In Ferizaj, majority of participants had prejudice, and they would leave the affected person. If the husband is affected, they all declared they would not abandon him because of the children, but they would have isolated him.

The opinion of participants from Fushe Kosove about HIV and AIDS persons, are they would have been labeled by their neighbors and if the affected person would be their husband they would have abended him.

HIV testing

This women group have little knowledge about HIV testing. They have no knowledge where HIV testing is carryout out, with the exception of women from focus group of Ferizaj and Fushe Kosova that have attended some trainings about HIV and AIDS. They do not have prejudice about the persons getting HIV tested with the opinion that it is for their own good to be tested, except the participants from Fushe Kosovo FG, that have prejudices about the those who do the HIV test.

Sexual intercourse

According to the women of focus group age 25-49, the most frequent age when women start their first sexual activities is between 14 to 15 without distinction based on the municipalities, and these relationships are always linked to early marriages. The most frequent reason for this is

voluntary sex, the influence of their families or poor financial conditions in the family and often the influence of their peers. According to this focus group, men also start their first sexual activities at young age such as 15 to 16 years old. There were no differences accross municipalities, almost in all municipalities PFG highlighted the same reasons with regards to early onset of sexual intercourse, but most frequently they mentioned to be sex desire and the impact of peers which is related to low level of education.

PFG, Pejë: "we do not support early marriages"

In Peja PFG think that most frequent age when women have sexual intercourse is between 14 to 15 and some think it is age of 13.

Risk behaviour groups

According to participants women aged 25-49 years in focus group discussion, the presence of commercial sex varies according to municipalities. In Ferizaj and Gjakove this phenomenon is not present, while it is very frequent in Fushë Kosovë and Pejë and this is due to financial reasons. In Pejë and Fushë Kosovë they declared that there are those who have sex with the same gender, MSM. According to them these groups, commercial sex workers and MSM, are most at risk groups for HIV due to frequent change of partners.

Drug use

According to this focus group, the most frequent type of drug used among the youth in this communities is reported to be hashish which is used by almost all youth, especially men. They declared there are drug users in three municipalities mainly hashish users, with the expection of Gjakova PFG, where according to them there are no drug users. (?!) They consider these groups at high risk for HIV due to the injecting drugs with syringes.

4.2 Results of in-depth interviews

Knowledge and sources of information

40 in depth interviews were conducted in 4 selected municipalities. In the question "What is HIV and AIDS" 87.5% of respondents define it as a communicable and incurable disease, 2 of the respondents know that HIV is an infection and AIDS is a disease and only 3 of them (7.5%) have no knowledge what do these two terms mean. That the disease is incurable and communicable, the level of knowledge among RAE communities was very high. In Ferizaj 80% know that it is an incurable and communicable disease whereas in other municipalities 90% of interviewers know that. (Table 1, chart 1).

More than 67% of interviewers percept the disease as a problem among RAE communities, according to municipalities: Gjakova 80%, Fushë Kosova 70% while Peja and Ferizaj with the percentage of 60%. (table 2, chart 2) (which differes from the focus group since they do not consider it as a problem). Although the majority of respondents consider the disease a problem in the question "What makes the disease a problem", 37.5% do not know the reason, 25% think "it is incurable and communicable disease ", 22.5% declare "lack of information and low level of knowledge among the RAE communities and with regards to transmission of the disease". Accross the municipalities, in Gjakove 50%, Peje 30% and Ferizaj 10% of respondents have declared due to the *lack of information*. Fushe Kosova with 40%, Ferizaj 20%, Peja 20% and Gjakova 10% respond based on the "fact" that it is *incurable and communicable disease* (table 3, chart 3).

Out of 40 interviewers, 92.5% have declared that the disease is spread through sexual intercourse, 27.5% through blood, brush, shaving razor and syringes, during birth from mother to child. 10% use misconceptions regarding transmission routs: by air, cough, hands and alimentary transmission through food have declared 12.5%, while 7.5% have no knowledge how the disease is transmitted. According to municipalities, Fushe Kosova respondents know that the disease is transmitted through sexual intercourse. For the second modality that the disease is

spread through blood, teeth brush, shaving razors and syringes the best responses are from Peja and Fushe Kosovo municipalities with 40 % and 30%.

With regards to the third modality: during child birth and through breastfeeding the best responses came from Peje municipality with 40% (table 4, chart 4).

Knowledge for risk groups and infection prevention measures

As risk groups have been identified *uninformed youth* with 42.5%, *persons changing many the partners* 30.0%, "*prostitutes*" 25%, "*drug users*" 17.5%, "*homosexuals*" (MSM) 7.5%, *alcoholics* 5.0%, *pregnant women and children* 2.5% and 7.5% have declared they have no knowledge that the risk groups are. Also a quarter of respondents have declared that we are all at risk for HIV and AIDS subject to our risk behaviors. across four municipalities, the majority in three municipalities think that youth are most at risk group for HIV and AIDS disease, whereas in Peja have declared that persons that frequently change their partners (table 5, chart 5).

With regards to HIV prevention methods, more than half of respondents 60% mention the condom use. Based on municipalities in Gjakova 90%, in Peja 70%, Fushë Kosova 50% and Ferizaj 30%, know about the condom use, as a prevention method.

Lower percentage of 17.5% does not know any method, while equally indicate abstaining from sexual intercourse with many partners and with unknown persons.

Another method mentioned by 15 % of respondents is informing youth about HIV and AIDS, other methods are mentioned with the same percentage of 5%, abandoning drug use and 5% non-exchange of personal belongings and abandoning the affected people by HIV and AIDS (table 6, chart 6).

Stigma towards people living with HIV and AIDS

Among RAE communities, 95% deny there is an HIV infected or person with AIDS, 2 or (5.0%) out of 40 respondents have heard that someone has died from this disease (table 7, chart 7).

Prejudice towards HIV infected or persons with AIDS have a quarter of the respondents whereas 62.5% did not want to prejudge whether they would leave and HIV infected person or persons

with AIDS indicating "I do now know", whereas only 12.5% have declared whether they would behave normally, but would have abstained from sexual intercourse with them. In Gjakova respondents have more stigmatizing attitudes toward PLHIV, 60% (table 8, chart 8).

HIV testing

Majority of respondents, 72.5% have no knowledge where the place for carrying out HIV testing and counselling is, while only 12.5% have heard of Centers for Voluntary Testing. Based on municipalities, Fushe Kosovo and Peja 20%, Gjakovë 10 % and in Ferizaj no one had precise information (table 9, chart 9). Interviewers did not show any stigmatization about persons that carry out HIV testing, since they do not know any of them.

Sexual intercourse

In the research is demonstrated the phenomenon of early sexual experience which is related to early marriages among this communities. The average age of women' first sexual intercourse is 15.1 ± 1.6 year olds.

Based on the collected data from 40 interviewers, regarding the most common age of first sexual intercourse, 35% think between 14-15 years, 35% between 16-17 years, 20% between 12-13 year olds and 10% above 18+years old. Divided in two age groups, under the age of 18 and above 18, 90% of respondents of RAE communities in this research share the opinion that first experience of sexual intercourse is under the age of 18, whereas 20% of respondents share the opinion that the first experience of sexual intercourse is between the age of 12-13. (Table 10, chart 10, 11).

The range of most frequent reasons of sexual intercourse among RAE communities women, linked with early marriages is: 50% financial conditions, 32% influence of peers and "kidnapping young women", 30% voluntary, 17.5% influence of family (having no trust in their daughters) as well as 15% the influence of social network (table 11, chart 12).

The most common age for early experience of sexual intercourse among RAE communities men is the age between 15.3 ± 1.9 . The average age of men first sexual intercourse does not vary much from the average age of women. About 70% of respondents from Fushe Kosovo, 50% from Peja
and 40% from Ferizajit and Gjakova have declared for the age between 14-15 (table 12, chart 13).

The most common reason about men first sexual experience is sexual desire 57.5%, influence of peers and society 17.5% and 15% of them think social network (table 13, chart 14). Respondents were asked about the most frequent ways of sexual intercourse among the communities, 97.5% claim they had vaginal sex but they do not exclude oral and anal sex. It is worth highlighting that despite the small sample, the respondents emphasized that young women often practice anal sex. In Fushe Kosovo 50% and Gjakove 60% of respondents mention anal sex as one of the most practiced sexual intercourse (table 14, grafikoni 15).

Risk behavior groups

When asked "does commercial sex exist in your communities and who are more engaged women or men" the respondents indicated that women are more engaged in commercial sex. According to the respondents, 40% think there is commercial sex in their communities, 12.5% are not aware concerning the existence of commercial sex and 47.5% think it is not present among their communities. According to municipalities 50% of respondents from Ferizaj, 40% from Peja, 40% from Fushe Kosova and 30% from Gjakova indicated there are women sex workers among their communities (table 15, chart 16).

Out of all interviewers, 16 have declared that women are engaged in commercial sex. The most common reasons of the engagement in commercial sex are economic conditions (56.3%), (12,5%), are used to having such life, (12.5%) consider it a consequence of trafficking and a low percentage 6.3% or 1 case thinks they are forced by their parents (table 16, chart 17).

According to them there are fewer cases of men that are engaged in commercial sex. Only 8 persons or 20% of respondents declared there are cases of men engaged in the commercial sex. Based on municipalities, 50% of respondents of Fushë Kosovo and 30% of Peja think there are cases of commercial sex among men in their communities (tablea 17, chart 18).

Respondents were asked if there are risk groups such as MSM among their communities: 30% of respondents claimed there are MSM. According to respondents in municipalities of Fushe Kosova and Peja 60% indicated there are MSM which they know (table 18, chart 19). In the

question whether they consider them a risk group, almost all respondents have declared that this group poses risk for HIV and AIDS, whereas there were few cases that had no knowledge about this.

Based on the respondents, more than half (57.5%) *do not refuse* the use of condom, only 25% have declared they refuse it, and this varies among municipalities in Fushë Kosovë 60% e of interviewers and 30% in Peja declared they do not refuse the use of condom. (tabe 19, chart 20).

Drug use

Participants were asked about drug use in their communities and 72% have declared that the drug that is most used among their communities is hashish, and out of this percentage 2 persons have claimed to know injecting drug users in their communities. Based on municipalities, in Gjakova 90% of youth consumes "weed", Ferizaj 80%, Peja 70% and Fushe Kosove 50% (table 20, chart 22).

5. DISCUSSION

Knowledge and sources of information

The knowledge rate on HIV and AIDS is high. Regarding the routes of transmission the majority of respondents in the discussions groups but also in individual interviews higlited sexual intercourse as the only route of transmission.

There are many misinterpretations and misunderstandings concerning the transmission of the virus, so that the disease is often linked with the hygiene of genitals.

The level of knowledge varies among municipalities. There is higher rate of knowledge in the municipalities where trainings related HIV and AIDS have been organized. Those informed about HIV and AIDS, have received the information in trainings, schools, and lectures during marking of World AIDS day. While the ones that heard about the HIV and AIDS as terms, have gained the information from media and internet.

More than half (58 %) of women aged 15-49 years and three-quarters (78 %) of men aged 15-49 years have heard of AIDS⁷. The research conducted in 2003 in Albania reported about low level of knowledge about HIV and AIDS. It was reported recently that there is knowledge about the health and protective behaviors from HIV⁸. Similar results with ours have shown similar rate of knowledge about HIV and AIDS in Bulgaria, Serbia, Spain, Lahore ⁹, ¹⁰, ¹¹, ¹².

⁷ Kosovo Agency of Statistics. 2014. Multiple Indicator Cluster Survey. Prishtina, Romë, Ashkali and Egyptian Communities in Kosovo 2013-2014

⁸ Nevila Koçollari (Furxhiu). A Scientific review of Roma communities culture, health and living conditions presented by means of Albanian studies during the last two decades. Romanian Economic and Business Review - Vol. 8, No. 2

⁹ Djonic,D.; Djuric,M.; Bassioni-Stamenic,F.; McFarland,W.; Knezevic,T.; Nikolic,S.; Zivkovic,V.; Vallabhaneni,S, HIV-related risk behaviors among Roma youth in Serbia: results of two communities-based surveys. J Adolesc Health. 2013 Feb; 52 (2):234-40.

¹⁰ Amirkhanian, Y.A.; Kelly, J.A.; Kabakchieva, E.; Antonova, R.; Vassileva, S.; Difranceisco, W.J.; McAuliffe, T.L.; Vassilev, B.; Petrova, E.; Khoursine, R.A. High-risk sexual behavior, HIV/STD prevalence, and risk predictors in the social networks of young Roma (Gypsy) men in Bulgaria.

¹¹ Khan,L.K.; Sethi,S.M.; Kokab,F.; Qureshi,A. HIV/AIDS knowledge amongst gypsies in Lahore and their preventive practices J Coll Physicians Surg Pak. 2011 Sep;21(9):553-5.

¹² Teira,R.; Suarez-Lozano,I.; Lozano,F.; Viciana,P.; Domingo,P.; Galindo,P.; Geijo,P.; Terron,A.; Gonzalez,J.; Cosin,J.; Ribera,E.; Roca,B.; Garcia-Alcalde, M.L.; Sanchez, T.; Munoz-Sanchez, A.; Vergara, A.; Lopez-Aldeguer, J.; Pedrol, E.; Vidal, F.; Garrido, M.; Santamaria, J.M.

The rate of knowledge level of Roma population in many European countries and the perception of the risk for HIV is low, which is a result of high percentage of school dropout of Roma children and youth. Main sources of information about HIV, AIDS and Sexually Transmitted Diseases (STD), are media and peers, whereas school and family are regarded as lees imported sources¹³.

Author's research¹⁴ has shown that rate of knowledge level on HIV and AIDS was inadequate, low percentage of people have heard the word "AIDS", whereas none of them have heard the term "HIV". More than two thirds of Roma population had no clue how the disease is transmitted.

Knowledge about risk groups and infection prevention measures

Uninformed youth, individuals with multiple partners, drug users, persons engaged in sex work, minors getting married, victims of trafficking and those married to persons that might be infected with HIV are the risk groups identified from the focus group discussions and in-depth interviews. It is worth mentioning that both in focus group discussion and in individual in-depth interviews "Uninformed youth" are the first ones to be considered as risk groups for HIV and AIDS, whereas in Peja persons with multiple sex partners are considered to be the most at risk groups. Majority of respondents, have mentioned the use of condom as prevention method, with the slight difference depending on the level of knowledge i.e. education.

There are misconceptions in terms of preventive measures for HIV. Respondents, especially women of both age groups, often confuse contraceptive measures, while men mention other ways such as not exchanging personal belongings, not changing often their partners, staying away from risk groups.

Characteristics and outcome of HIV infection in gypsies in the Spanish VACH Cohort. Enferm Infecc Microbiol Clin. 2010 May;28 (5):266-72. doi: 10.1016/j.eimc.2009.04.018. Epub 2010 Feb 2.

¹³ Rapid assessment and response for HIV/AIDS in Albania, 2005

http://www.unicef.org/albania/sq/LIBRI_VLERESIM_MBI_HIV_AIDS.pdf

¹⁴ Lubna Khurram Khan, Shahid Mahmood Sethi, Farkhanda Kokab and Aaeisha Qureshi, HIV/AIDS Knowledge Amongst Gypsies in Lahore and their Preventive Practices, J Coll Physicians Surg Pak 2011 Sep;21(9):553-5

Stigma towards people living with HIV and AIDS

There are prejudices about communicable diseases among RAE, especially concerning the sexually transmitted diseases. In general, among RAE communities there are negative attitudes, fear, stigma and discrimination towards people living with HIV and AIDS. This may be explaind by a very low level of education, as evidenced also in MICS. Most of women that have negative attitude toward HIV infected people or people living with AIDS, declared they would abandon and isolate them; in case a person infected would be their husband they would abandon him. Women, would take care of any other member of the family, especially child and would support, but not a husband, as this is a communicable disease; they would prefere to isolate them. Stigma is even higher among RAE men. In all focus groups men age 25-49 involved in the research claimed that if the HIV infected person would be their wife they would leave them, while they would take care and support the infected children.

A quarter of respondents reveal stigma, while 12.5% report they would behave normally but would abstain from sexual intercourse with infected persons. In Gjakove according to interviews there is even more (60%) stigma towards PLHIV, In Kosovo prejudices concerning the HIV transmission, AIDS disease and STDs is widely present, similar to the situation in Bulgaria and Hungary¹⁵. Prejudice and stigma often prevent the spread of information among RAE communities¹⁶. Stigma and often the discrimination pose a barrier among these communities to use the current available services. Silence, stigma, denial and taboos are key concepts to understand why there are so many ambiguities and why the current interventions are insufficient, as well as the necessity of interventions in the future. HIV infected women are often discriminated more than men, especially in some developing countries. Moreover, it is known less about the unique features that affect the HIV infected women, some cultural factors put

¹⁵ Kelly JA, Amirkhanian YA, Kabakchieva E, Vassileva S, Vassilev B, McAuliffe TL, Di Franceisco WJ, Antonova R, Petrova E, Khoursine RA, Dimitrov B. Prevention of HIV and sexually transmitted diseases in high risk social networks of young Roma (Gypsy) men in Bulgaria: randomised controlled trial BMJ. 2006 Nov 25;333 (7578):1098. Epub 2006 Oct 13

¹⁶ Nevila Koçollari (Furxhiu). A Scientific review of Roma communities culture, health and living conditions presented by means of Albanian studies during the last two decades . Romanian Economic and Business Review – Vol. 8, No. 2

particularly women in risk. Usually men have many partners and without even knowing they transmit the HIV to their wives¹⁷.

HIV testing

Generally, the respondents in the research don't have needed knowledge about HIV testing, they don't know where the testing centres are, nor places where HIV testing could be carried out. The vast majority of respondents, 72.5% don't know the HIV testing place; only 12.5% have heard of Voluntary HIV testing Centres. As with other set of questions, there are differences regarding the level of knowledge on HIV testing depending on level of education. Majority of respondents declared they would hesitate to do the HIV test due to prejudices, as their communities will find out and judge them considering how small are the places where they live. According to most of respondents who know something about HIV testing the main reason for not doing the HIV test is they do not percive the HIV to be a problem in their communities.

Sexual intercourse

Most common age in women when first sexual experience occures is reported at age of 14-15, whereas in men at age 15 to 16. Early sexual experience among young women is mainly linked to early marriage, which is also proven by evidence in the country and regionaly. According to respondents the average age of women' sexual intercourse is between 15.1 ± 1.6 years. In general 90% of respondents shared the opinion that first experience of sexual intercourse is under the age of 18, in their communities.

The most common reasons of having first sexual experience at early age is marriage at early age due to economic-financial situation, than influence of peers and "kidnapping young women", whereas 30% report this is on voluntary basis. According to respondents families play a crucial role in influencing the early marriages of their due to poverty, illiteracy or very low level of education, moral, lack of trust in their daughters, as well as RAE cultural traditions.

Based on discussions, men's first sexual experience takes place when they are 15 to 16, and this mostly on their own will, and not linked to RAE cultural norms of early marriage. Average age

¹⁷ Rapid assessment and response for HIV/AIDS in Albania, 2005

of first sexual intercourse at men is 15.3±1.9 years, which does not vary much from women, while 50% of respondents think that 14-15 years is the most common age. The rationale behind was as follows: 17.5% of respondents think it is socialy influenced, peer- preassure and 3 or 15% think this is related to influence of social networks such as Facebook and internet. Cultural norms and tradition was not indicated at this case by any respondent. RAE men in Kosovo similar to Bulgaria and Hungary have more sexual freedom on sex before marriage, while women are more prone to sexual intercourse after marriage, which explains the reasons of early marriages¹⁸. Average age of marriage for Roma women in Albania is 15.5 years, for Egyptian women is a bit higher 17.2 years¹⁹. Even research in Bulgaria has shown that half of pregnant women aged between 13-16 years have Roma origin²⁰. First experience of sexual intercourse among Roma occurs at relatively young age. High rate of sexual risk behaviour is in contrast with the level of knowledge and perception of risk²¹.

Risk behaviour groups

Commercial sex work is reported to be present as phenomenon in the communities. It is highlighted to be a problem due to young people who often visit these venues where sex services are provided, but also due to low level of knowledge about HIV. According to respondents women are more engaged in sex work, but reports also claim there are MSM who provide sex services. In general there is low level of knowledge on key populations at risk for HIV, but perceptions on HIV risk for these groups is quite high, although there are misconceptions on the risk related issues. Based on other surveys²² the use of condom by Roma communities in general is very low, the majority think that community people refuse the use of condom especially in marriage. Interviewers in this research highlight that young women often practice anal sex in order not to lose their virginity and they indicate the crucial need for information and education on HIV and AIDS.

¹⁸ Kelly JA, Amirkhanian YA, Kabakchieva E, Vassileva S, Vassilev B, McAuliffe TL, Di Franceisco WJ, Antonova R, Petrova E, Khoursine RA, Dimitrov B. Prevention of HIV and sexually transmitted diseases in high risk social networks of young Roma (Gypsy) men in Bulgaria: randomised controlled trial BMJ. 2006 Nov 25;333 (7578):1098. Epub 2006 Oct 13

¹⁹ A needs assessment study on Roma and Egyptian communities in Albania. Tirana, Albania: (UNDP 2012)

²⁰ Steve Hajioff, Martin McKee. The health of the Roma people: a review of the published literature, J Epidemiol Communities Health 2000;54:864-869 doi:10.1136/jech.54.11.864

²¹ Rapid assessment and response of HIV/AIDS in Albania, 2005

²² Assissment of HIV/AIDS among Roma young people, www.unicef.org/albania/hivaidsroma.pdf

Drug use

Similar to the survey in Albania²³ drug use especially hashish, "weed" in the form of cigarette is the most common drug used among RAE communities especially young men, whereas women do not use drugs. According to discussions in the focus group and in-depth interviews, in RAE communities the number of persons injecting drug is small, due to financial realted matters (price of opiates).

 $^{^{\}rm 23}$ Rapid assessment and response of HIV/AIDS in Albania, 2005

6. CONCLUSIONS

Knowledge and sourse of information

HIV and AIDS are considered to be a problem by the majority of respondents. RAE have basic knowledge, they have heard of HIV and AIDS as a disease term and this level of knowledge varies and is a subject to the level of literacy. The level of education is such that during the research the interviewers faced difficulties to explain the matter of discussion. For vast majority of participants the only route of HIV transmission is sexual intercourse. More than half of respondents have indicted condom use as prevention method, whereas nearly one fifth of respondents have no knowledge about prevention measures. Main source of information are trainings, schools, media and internet.

Knowledge about risk groups and infection prevention measures

Participants have some knowledge on key populations at risk for HIV, subject to the number and type of trainings attended. Men are more informed then women on other preventive measures Majority of participants have identified the condom use as prevention method, but there are misconceptions among men and women mainly based on perceptions that this is a sexually transmitted infection.

Stigma towards people living with HIV and AIDS

There is stigma towards people living with HIV and AIDS. Majority of women declare they would support and help HIV infected persons or persons with AIDS, but they are also reserved and have a dose of stigma when it comes to having direct contacts with these persons. Stigma is

more expressed among men, especially if the infected person would be their wives, men aged 25-49 years would abandon them, whereas they would support infected children.

HIV testing

Knowledge on HIV testing varies among respondents and is a subject to the level of literacy and information on HIV and AIDS. Majority, have no information about HIV testing centres or places where testing is carryout out. Also, the vast majority of those who have some information declare they would hesitate to do the HIV test due to prejudices and missinterpretations in their communities. The other reason for not testing on HIV is they do not percive the disease to be a problem for their communities.

Sexual intercourse

Respondents think there are no changes over time in the RAE traditions with regard to the first sexual experience, while the reason for early initiation of sexual life they consider is the marriage at young age among women, mostly imposed by their families, poverty, severe socio-economic conditions in the family, peer preasure of the opposite sex, "kidnaping young women", low level of education, fear from breaching "family honour", lack of trust in their daughters, and least the influence of social networks. Women have their first sexual experience earlier than men, regardless RAE municipalities where the research was conducted..

Risk behaviour groupss

Participants have revealed that commercial sex work is present in their municipalities. According to responses received, it is the economic-financial situation that attracts young women into sex work. Respondents claim they know that HIV is more common among sex workers. They report that women are more engaged in sex work than men, whereas they also identify MSM among their communities, who provide sexual services in exchange for money. Although majority of interviewees perceive these groups as at higher risk for transmission of HIV, they don't know how to explain the reason why. Vaginal sex is reported as most common sexual intercourse

97.5%, but they do nott exclude oral or anal sex, which is practiced among young women due to cultural norms (mainly loss of virginity).

Drug use

The most common drug used among young men of RAE communities is hashish, used mainly in the form of rolled cigarette, due to lower cost. Respondents identify also injecting drug users, but they know less such persons, and this stands for almost all municipalities. It is important to note that PWIDs are considered a risk group among RAE due to the injecting drugs with syringes, but this risk is not perceived in terms of HIV transmission, it is rather of other consequences and criminal records.

7. RECOMMENDATIONS

- Development of policies for social inclusion of RAE vulnerable groups through development of programs and action plans, programs focused on identification of inequalities and implementation of activities in communities.
- 2. Strengthening information provision among RAE communities through formal education, enriching the school curriculas with more accurate information regarding HIV and AIDS, especially about routes of HIV transmission, prevention measures and the harm reduction, also focusing on harm that early marriages might have, risk behaviours, especially those related to sex workers, MSM and injecting drug use.
- Increase the number of extracurricular trainings in the communities designed based on specific needs and requirements of RAE communities, especially women, focusing in places where trainings were not held before
- 4. Intensification of work with CSs and volunteers on providing information to RAE communities on HIV prevention and correct use of means for prevention of HIV, in a way that supports families and community leaders to extend their influence raise awareness on the importance of school attendance, in obtaining the accurate information timely, so that there are informed decision especially among youn women and girls.
- Include testinonials of affected people from the communities in all activities related to HIV and its prevention and treatment, which would result in reducing stigma and discrimination towards HIV infected people.
- Increase advocacy on health promotion and improve content of information related to voluntary HIV counselling and testing by using all possible channels and by tailoring information to the RAE communities needs.

- 7. Engagement of media in attempt to jointly design the programs related to information about prevention, treatment and fighting stigma and discrimination.
- 8. Continue the work on behavior related surveys and surveys related to stigma and discrimination towards HIV and AIDS.

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ANNEXES

Annex A

Questionnaires for Focus Groups:

Estimated time for discussion: 1.5 - 2 hours

Perceptions of high risk related to HIV and AIDS

1. What do you know about HIV and AIDS? How big is the problem of HIV and AIDS for the people of your communities and what makes the problem of great importance or little importance?

a. QUESTION: Discuss where you got this information and where RAE communities does get this information?

b. QUESTION: Did the importance of HIV and AIDS change in your communities during the last years and if yes why? Is it an important issue for some groups then others, and if yes, which groups are they and why is more important? Do they accept or deny AIDS as a problem / issue?

2. Do you think some groups are at higher risk of HIV acquisition then others in your communities?

a. QUESTION: Except your ideas with regards to the behaviours that put people in danger for getting HIV, do you have other ideas regarding the HIV risk factors in your communities?

b. QUESTION: If there are other ideas regarding the risks HIV risks in your communities, which of the certain groups do have these ideas? Do you think there are distinctions at the level of knowledge?

3. What do you use as prevention for HIV at your communities?

a.QUESTION: Expect discussed views among the participants; are they aware of any other ideas in the communities regarding the means of HIV and AIDS prevention?

4. Do you know anyone in your communities who is infected with HIV or has AIDS or do you know anyone that has died from AIDS?

a. QUESTION: Do these people belong to certain social group? For example, intravenous drug users, truck drivers with long distance, commercial sex workers, or men that have sex with men, etc.?

b. QUESTION: Based on your opinion, which are the responsible factors for their infection?

5. What do people in your communities think of persons infected with HIV or persons that have AIDS or that have died from AIDS?

a. QUESTIONS: Is there any stigma (are the HIV infected persons seen differently: negative attitude, distancing, difference, defilement)? If yes, describe. What do you think, are persons with HIV and AIDS influenced by these attitudes?

b. ASK: Would you leave your wife/husband + if she /he is infected with HIV? Why?

c. ASK: Do different groups think differently and if yes, describe these differences? Do you think these attitudes change based on the person who is infected and if yes describe these changes (e.g. children in comparison with women or in comparison with injecting drug users, etc.). Did these ideas change over time?

HIV Testing

6. Do you think HIV testing is important, and is HIV testing available in your communities? Do you know anyone that has been tested for HIV in your communities?

a. ASK: Where do people get tested?

b. ASK: How can they be informed about HIV testing? Do you think there are enough people that know where the places for HIV testing are?

c. ASK: Is the testing adequate when it comes to conditions of the place, or transport to the place etc.?

d. ASK: Is the testing accessible in terms of the cost, sufficient places, ease of setting the appointments etc.?

7. What do people think of testing, do they get tested or not, is there a stigma (are they seen differently: negative attitude, distancation, differentiation) regarding HIV testing in your communities?

a. ASK: Is there a stigma (are they seen differently: negative attitude, distancing, differentiation) regarding the HIV testing? If yes, describe it.

b. ASK: Do they think HIV is a low priority / or they think they are not in danger?

c. ASK: Are the attitudes and beliefs of people regarding HIV obstacles?

8. Do you think there are mayor obstacles regarding HIV and AIDS in your communities and what do you think can be done about it?

a. ASK: Can you identify the groups or individuals that are making these obstacles?

b. ASK: Is there adequate response of the communities for HIV testing? Why, or why not?

Questions on sexual intercourse and perception for HIV and AIDS

9. First of all let us talk about the girls and the age of their first sexual intercourse in this communities. What is the common age of first sexual intercourse among the girls in this communities?

a. ASK: Which are the favorable factors (financial difficulties, peer pressure, alcohol abuse etc.)?b. ASK: What are the possible reasons that the girls have had sex at that age?

c. ASK: What is the attitude in your communities in this regard? (Would they encourage or discourage this issue? What are the results?)

d. ASK: Do recent trends regarding this issue differ from previous tradition and customs? If yes, who is responsible for these changes or differences?

10. Now, let us talk about the boys and the age they start their sexual intercourse in this communities. What is the most common age of first sexual intercourse among boys in this communities?

a. ASK: What are the favorable factors (financial difficulties, peers pressure, alcohol use, etc.)?

b. ASK: What are the most possible reasons that boys had sex in that age?

c. ASK: Which is the attitude of your communities in this regard? (will they courage or discourage this issue? What are the results?)

d. ASK: Do the current trends in this regard differ from the previous tradition and customs? If yes, who are the responsible persons for these changes or distinctions?

We would like to discuss about a range of practices that may or may not be common in this communities, but have been observed in other countries. These will include commercial sex, men having sex with men (MSM), and others that are not included in this list but you would like to talk about. Let us start with the commercial sex (CS).

[Moderator: Define CS as sex exchange for money, gifts and favors].

11. In your communities, how often are girls and women engaged with commercial sex and what about boys and men?

a. ASK: What do you think women or men are more engaged with commercial sex?

b. ASK: What do you think is the reason?

c. ASK: Under what conditions may the situation change? Without mentioning names in particular, can you give us concrete examples why you do think this is the manner?

12. Discuss the risk of commercial sex workers for HIV and transmission of sexually transmitted diseases.

b. ASK: Discuss what can be done to reduce these risks.

13. How frequent is phenomenon of same sex relations, between men and women in your communities?

[Moderator: Verify the comfort of participants with the topic.]

a. ASK: on what basis you can say this?

14. Discuss the risk of men having sex with men (MSM) for STI and HIV. What can be done to reduce their risk and spread of HIV in your communities?

Questions regarding drugs

15. Based on your opinion, any person that is close to you that uses any illegal drugs (marihuana or hashish (cannabis), ecstasy etc.), how did he/she start using it?

16. Did you ever inject drug (for non-medical purposes), even though only once?

inject drugs, even though only o	lid you ever exchange syringes or other means the state once?	
1. Year of birth:	(years)	
2. Sex: a) Men b) Women		
3. Your education : a) Primary) H	igh c) University d) Post-university	
4. Are you employed: Yes No		
 5. If yes, which section do you we a) Education b) c Administration) f) Private G Business) pupil / stude 		
6. Your residence: Urban Rural		
7. Region: a) Fushë Kosovë b) Pejë c) Gjakov	vë d) Ferizaj	
8. Marital Status:a. Unmarried b. Marriedc. Divorced d. Widow		
9. Do you have children? a. Yes the If yes, how many children do you be a set of the s	o. No have?	
10. Number of family members t	hat live in the same house	
11. Economical condition of your	r family? a)very bad b) Poor c) Middle) d) Good	e) Very good
12. Your family incomes for a m	onth (EUR)	

THANK YOU FOR YOUR PARTICIPANCE

Annex B

Semi structured questionnaire for in depth interview:

Dear Miss/Mister

National Institute of Public Health, supported by the Global Fund for HIV and AIDS and TB will conduct a research on knowledges, practices and attitudes regarding HIV and AIDS and factors that have an impact in these issues among RAE communities in Kosovo. This research aims to reflect the knowledges, attitudes and practices of reproducing ages (15 to 49) for HIV and AIDS, focusing on factors that have an impact in the knowledges and attitudes.

We would like to take 30 min. of your time to answer our questions. We guarantee that all your personal data will remain confidential. You do not need to give us your name and surname. Please note that your answers shall be sincere in this half structured interview.

Thank you

Risk perceptions regarding HIV and AIDS

1. What do you know about HIV / AIDS, how big is the problem of HIV and AIDS for the people in your communities and what makes the problem of great or small importance?

2. Do you know how do people get infected with the virus? If yes, show certain ways how people get infected?

3. Do you think some groups are more vulnerable to HIV infection than others in your communities? Why?

4. What can be done to get protected from HIV and AIDS, any other ideas in the communities on how one shall be protected by HIV infection?

5. Do you know people in this communities that might be infected with HIV or that might have died from AIDS and what does your communities think about people with HIV and AIDS or that have died from AIDS?

How would you behave with HIV positive persons, (socializing, hugs, food ...)

6. Do you think that people are open to go to the centers for HIV testing? Does the distance or cost have an impact in this issue? What are the attitudes of the health care providers? Socio-cultural factors (beliefs, taboos, norms etc.), is there any stigma regarding the testing?

7. Do you think there are major barriers (obstacles) that have to do with HIV and AIDS in your communities and what do you think can be done for them?

Questions on sexual intercourse and perception for HIV and AIDS

8. Let us firs talk about the girls and the age they start their sexual intercourse in this communities. What is the most common age the first sexual intercourse among the girls in this communities?

9. What are the favorable factors (financial difficulties, peers pressure, alcohol use, etc.)? What are the most common reasons that girls had sex at that age?

10. Now, let us discuss about the boys and the age they start first sexual intercourse in this communities. Which is the most common age they start sex in this communities?

55•

11. What are the favorable factors (financial difficulties, peers pressure, alcohol use, etc.)? What are the most common reasons that boys had sex at that age?

12. What is the most common type of sexual intercourse in your communities (vaginal, anal, oral)?

We would like to talk about series of practices that might or might not be common in this communities, but have been observed in other countries. These will include commercial sex, men having sex with men (MSM), and others that have not been included in this list and you might want to talk about them. Let us start with the commercial sex (CS).

[Moderator: Define CS as exchange of sex with money, gifts and favors].

13. In your communities, how often girls and women are engaged in commercial sex? What do you think is the reason behind this motive?

14. In your communities, how often boys and men are engaged in commercial sex? What do you think is the reason behind this motive?

15. How frequent is the phenomenon of homosexuality between men and women in your communities? Can you talk about the risk of men having sex with men (MSM) for sexually transmitted diseases and HIV.

What can be done to reduce their risk for spreading HIV?

16. How frequent in this communities is the rejection of condoms?

Questions regarding drugs

17. According to your opinion, does any person close to you use any illegal drug (marihuana or hashish (cannabis), ecstasy etc.), how did they start using it?

18. Did you ever inject any drugs (for non-medical purposes), even only once? (if the answer is no disregards question 19) ?

19. If you have injected drugs, did you exchange syringes or other means that are used to inject drugs, even though only once?
Socio-demographic questionnaire
1. Year of birth: (years)
2. Sex: a) Men b) Women
3. Your education : a) Primary) High c) University d) Post-university
4. Are you employed: Yes No
 5. If yes, which section do you work? a) Education b) c Administration) Health d) Trade) Hotels f) Private G Business) pupil / student h) Housewife i) Other
6. Your residence: Urban Rural
7. Region: a) Fushë Kosovë b) Pejë c) Gjakovë d) Ferizaj
8. Marital Status:a. Unmarried b. Marriedc. Divorced d. Widow
9. Do you have children? a. Yes b. No If yes, how many children do you have?
10. Number of family members that live in the same house
11. Economical condition of your family? a)very bad b) Poor c) Middle) d) Good e) Very good
12. Your family incomes for a month (EUR)

THANK YOU FOR YOUR PARTICIPANCE

Annex C

FORM AND THE LIST OF PARTICIPANTS IN Focus Group

Date of the interview with focus groups _____

The place of the interview (Municipality):	Age group:			
Initials of name and	Fulfill the	Consent is	Participant	Sex:
surname of	criteria for	given by the	refused	
participants:	participation Mark $$	participant Mark √	Mark $$	Mark √
1.	$\frac{\text{Mark v}}{\text{Yes } \square \text{ No } \square}$	$\frac{\text{Mark } \vee}{\text{Yes } \square \text{ No } \square}$		$F \square M \square$
1.				$\Gamma \sqcup VI \sqcup$
2.	Yes 🗆 No 🗆	Yes □ No □		$F \square M \square$
3.	Yes □ No □	Yes □ No □		$F \square M \square$
4.	Yes □ No □	Yes □ No □		$F \square M \square$
5.	Yes □ No □	$Yes \square No \square$		$F \square M \square$
6.	Yes \square No \square	Yes \square No \square		$F \square M \square$
7.	$Yes \square No \square$	$Yes \square No \square$		$F \square M \square$
8.	$Yes \square No \square$	$Yes \square No \square$		$F \square M \square$
9.	$Yes \square No \square$	$Yes \square No \square$		$F \square M \square$
10.	Yes □ No □	Yes □ No □		$F \square M \square$
The discussion in	Yes □ No □			
the Focus Group				
has been conducted.				
	Comments:			

Supervisor of the research Signature: ______ Date:

Annex D1

Informed consent of participants in Focus Group discussion

Title of the research: Rapid qualitative research for specific vulnerability of RAE communities regarding HIV and AIDS in Kosovo

Main researcher: _____

Institute: National Institute of Public Health of Kosovo

Introduction:

I am ______ from the National Institute of Public Health of Kosovo and we are conducting a rapid qualitative research among Roma, Ashkali and Egyptian communities regarding HIV/AIDS. I would like to invite you to participate in this research survey.

Informed Consent for participation in the Focus Group Discussion

You have been invited to participate in the focus group discussion conducted by the National Institute of Public Health of Kosovo. The aim of the interview is to try to understand the level of knowledge, attitudes and practices regarding HIV mong your communities. The information that is taken from the focus group discussion will be used to develop public health programs and health educational programs for your communities.

You may choose if you want to participate in focus group discussion or not and you have the right to stop group discussions at any time. Since the conversation and your answers will be recorded by Dictaphone, they will remain anonymous and no names will be mentioned in the report.

There is no right or wrong answer to the questions of focus group discussions. We would like to listen to your point of views. We hope that you will be giving sincere answers even when your

answers will not be in compliance with the rest of the group. In order to respect each other, only one person speaks at a time and the responses from all participants will be confidential.

I fully understand this information and agree to participate based on the abovementioned conditions:

Signed by: _____ Date: _____

Annex D2

Informed Consent for participation in the Deepth- Interview

The title of the research: Rapid Qualitative Research on the specific vulnerability of RAE communities regarding HIV and AIDS in Kosovo.

Main researcher:

Institute: National Institute of Public Health of Kosovo

Introduction:

I am from the National Institute of Public Health of Kosovo and we are conducting a rapid research among Roma, Ashkali and Egyptian communities regarding the HIV and AIDS. I would like to invite you to participate in this research survey.

You have been invited to participate in the interview conducted by the National Institute of Public Health of Kosovo. The aim of the interview is to try to understand the level of knowledge, attitudes and practices regarding HIV your communities. The information that is taken from your interview will be used to develop public health programs and health educational programs for your communities.

You may choose if you want to participate in the interview or not and you have the right to stop the interview at any time. Since the conversation and your answers will be recorded by Dictaphone, they will remain anonymous and no names will be mentioned in the report.

There is no right or wrong answer to the questions of the interview. We hope that you will be sincere in giving your answers.

I fully understand this information and agree to participate based on the abovementioned conditions:

Signed by:	Date:

Annex E

FORM OF REFUSAL

Instructions: This form shall be filled for each person that refuses to participate in the research, as the person who made the choice has confirmed that he/she meets the criteria for participation. The participant may refuse to participate at any phase of the research and the reasons for refusal shall be written below.

Date: _____

Reasons of refusal: (Only one response)

1. I do not give my consent to be part of this research.

2. I do not have any desire to be interviewed.

3. Others (specify):

ANNEX – Tables and charts of Interviews

		Region												
Do you know what are HIV and AIDS disease?	F	Ferizaj		ushe osovo	G	jakove		Peje	-	Гotal				
	Ν	%	Ν	N %		N %		%	Ν	%				
HIV-infection, AIDS-disease	-	0.0	-	0.0	1	10.0	1	10.0	2	5.0				
Communicable and uncured disease	8	80.0	9	90.0	9	90.0	9	90.0	35	87.5				
l do not know	2	20.0	1	10.0	-	0.0	-	0.0	3	7.5				
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0				

Table 1:Knowledge on HIV and AIDS among interviewers according to municipalities



Chart 1.

Table 2: Perceptions of respondents in the question "How much is HIV and AIDS aproblem among your communities" according to municipalities

Is HIV and AIDS a problem in your	Ferizaj		Ferizaj			Fushë Iosovë	G	Gjakovë		Pejë	Total	
communities?	N	%	N	%	N	%	N %		N	%		
It is a big problem	6	60.0	7	70.0	8	80.0	6	60.0	27	67.5		
It is not a problem	1	10.0	1	10.0	1	10.0	3	30.0	6	15.0		
l do not know	3	30.0	2	20.0	1	10.0	1	10.0	7	17.5		
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0		



Chart 2.

Tablea 3: Structure of reponses to the question: What makes AIDS a problem in your communities?

		•	•	Regi	ion				Tet	-1
What makes the disease	Ferizaj		Fushe	Kosove	Gjal	kove	Pe	eje	Total	
a big problem?	Ν	%	N	%	Ν	%	Ν	%	N	%
It is an incurable disease	3	30.0	4	40.0	1	10.0	2	20.0	10	25.0
Lack of knowledge among the communities	1	10.0	-	0.0	5	50.0	3	30.0	9	22.5
They do not know	5	50.0	5	50.0	3	30.0	2	20.0	15	37.5
It is not a problem	1	10.0	1	10.0	1	10.0	3	30.0	6	15.0
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



Chart 3.

Table 4: Structure of responses in the question "Do you know how the HIV and AIDS disease is spread"?

Do you know how HIV and AIDS	Ferizaj		Fushe Kosove		Gjakove		P	eje	То	ral
disease is spread?	Ν	%	Ν	%	Ν	%	Ν	%	Ν	%
Sexual Intercourse	9	90.0	10	100.0	9	90.0	9	90.0	37	92.5
Blood&Brush&Razor&syringes	2	20.0	3	30.0	2	20.0	4	40.0	11	27.5
During childbirth to the baby and through breastfeeding	-	0.0	-	0.0	-	0.0	4	40.0	4	10.0
Through the air, cough, sneeze, breath, with hands, with food	1	10.0	2	20.0	-	0.0	2	20.0	5	12.5
l do not know	1	10.0	-	0.0	1	10.0	1	10.0	3	7.5
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



Table 5. Range of most at risk groups for HIV and AIDS disease

Do you think that some groups are more at risk for HIV and	Ferizaj			Fushe Kosovo		Gjakove		Peje	TOTAL	
AIDS among your communities?	N	%	N	%	N	%	N	%	N	%
Uninformed youth	6	60.0	4	40.0	4	40.0	3	30.0	17	42.5
Persons with multiple partners	2	20.0	3	30.0	1	10.0	6	60.0	12	30.0
We are all at risk	2	20.0	2	20.0	5	50.0	1	10.0	10	25.0
Prostitutes	2	20.0	2	20.0	1	10.0	2	20.0	7	17.5
Drug users	2	20.0	2	20.0	1	10.0	2	20.0	7	17.5
Homosexuals (MSM)	-	0.0	1	10.0	-	0.0	2	20.0	3	7.5
Alcoholics	-	0.0	1	10.0	1	10.0	-	0.0	2	5.0
Pregnant women and children	-	0.0	-	0.0	1	10.0	-	0.0	1	2.5
They do not know	2	20.0	1	10.0	-	0.0	-	0.0	3	7.5
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



Table 6. Structure of responses for the question: What kind of method do you know for protection from HIV and AIDS disease?

What kind of method do you	Fe	Ferizaj		Fushe Kosove		Gjakove		Peje	Total	
know for protection from HIV and AIDS disease?	N	%	N	%	N	%	N	%	N	%
Condom use	3	30.0	5	50.0	9	90.0	7	70.0	24	60.0
Reducing the number of multiple sex partners	3	30.0	2	20.0	1	10.0	1	10.0	7	17.5
Informing the youth and population through trainings	1	10.0	2	20.0	1	10.0	2	20.0	6	15.0
Distancing from the drug users	-	0.0	-	0.0	-	0.0	2	20.0	2	5.0
Non-exchange of personal belongings	-	0.0	1	10.0	-	0.0	1	10.0	2	5.0
Distancing from HIV infected persons	-	0.0	1	10.0	-	0.0	1	10.0	2	5.0
Visit the doctor	-	0.0	-	0.0	-	0.0	1	10.0	1	2.5

T he second second									_	47.5
They do not know	3	30.0	2	20.0	-	0.0	2	20.0	1	17.5
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



Table 7. Structure of responses in the question: "Do you know anyone in your communitiesthat is HIV infected or suffering from AIDS?"

Do you know anyone in your communities that is HIV infected	Ferizaj		Fushe Kosove		Gjakove			Peje	Total	
or suffering from AIDS or that has died from AIDS?	Ν	%	Ν	%	Ν	%	N	%	Ν	%
Νο	10	100.0	9	90.0	10	100.0	9	90.0	38	95.0
I have heard that someone has died two years ago	-	0.0	_	0.0	-	0.0	1	10.0	1	2.5
One case that is suspected to have died from HIV and AIDS	-	0.0	1	10.0	-	0.0	-	0.0	1	2.5
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



Chart 7

 Table 8. Structure of responses in the question: "How would you behave with HIV infected persons or persons with AIDS"?

How would you behave with HIV infected persons or persons with AIDS?		Ferizaj		Fushe Kosove		akove		Peje	Total	
(STIGMA)	Ν	%	Ν	%	Ν	%	Ν	%	Ν	%
l do not know	7	70.0	8	80.0	3	30.0	7	70.0	25	62.5
I would abandon him	1	10.0	2	20.0	6	60.0	1	10.0	10	25.0
Normal behaviour, I would stay close to him/her, but no sexual intercourse	2	20.0	-	0.0	1	10.0	2	20.0	5	12.5
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



Chart 8

Table 9. Structure of responses in the question: Do you know where one can carry out theHIV test in order to know whether he/she is infected with HIV?

Do you know where one can carry out the HIV test in		Ferizaj		Fushe Kosove		akove		Peje	Total	
order to know whether he/she is infected with HIV?	N	%	N	%	N	%	N	%	N	%
l do now know	7	70.0	8	80.0	7	70.0	7	70.0	29	72.5
Doctor guides you where to go for HIV testing	3	30.0	-	0.0	2	20.0	1	10.0	6	15.0
Yes, in the Voluntary Testing Centers	-	0.0	2	20.0	1	10.0	2	20.0	5	12.5
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



Chart 9

Table 10. Structure of most common age RAE communities women have their first
experience of sexual intercourse

Age group	F	erizaj	Fus	he Kosove	Gjako		Peje	TOTAL		
	Ν	%	Ν	%	N	%	Ν	%	Ν	%
12-13	2	20.0	1	10.0	4	40.0	1	10.0	8	20.0
14-15	1	10.0	6	60.0	2	20.0	5	50.0	14	35.0
16-17	5	50.0	3	30.0	3	30.0	3	30.0	14	35.0
18+	2	20.0	0	0.0	1	10.0	1	10.0	4	10.0
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0
Average age ± SD	15	.6±1.9	1	4.9±1.0	14.7±1.9		15.2±1.4		15.1±1.6	





Chart 11

The most common reasons females have sexual intercourse at this age among RAE community		izaj	Fushë k	(osovë	Gjal	kovë	Pejë		То	otal
		%	N	%	N	%	N	%	N	%
Financial conditions	6	60.0	6	60.0	2	20.0	6	60.0	20	50.0
Influence of peers & pressure and robbery by males	1	10.0	1	10.0	4	40.0	7	70.0	13	32.5
Voluntary sex	5	50.0	2	20.0	2	20.0	3	30.0	12	30.0
Influence of family & "Family forces her to get married to preserve the honour of the family"	4	40.0	-	0.0	1	10.0	2	20.0	7	17.5
Influence of the social network & internet and fb	1	10.0	-	0.0	5	50.0	-	0.0	6	15.0
They are easily deceived	1	10.0	1	10.0	-	0.0	1	10.0	3	7.5
No education	1	10.0	1	10.0	1	10.0	-	0.0	3	7.5
Tradition	-	0.0	3	30.0	0	0.0	3	30.0	3	7.5
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0

Table 11. Range of most frequent reasons women have sexual intercourse at this age among
RAE communities



 Table 12. Structure of group age when RAE communities men have their first experience

 of sexual intercourse

Age group	Ferizaj		Fushë K	losovë	Gjal	kovë	Pe	ejë	Total		
	N	%	N	%	N	%	N	%	N	%	
12-13	-	0.0	1	10.0	4	40.0	1	10.0	6	15.0	
14-15	4	40.0	7	70.0	4	40.0	5	50.0	20	50.0	
16-17	4	40.0	1	10.0	1	10.0	1	10.0	7	17.5	
18+	2	20.0	1	10.0	1	10.0	3	30.0	7	17.5	
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0	
Average age ± SD	16.1	± 1.5	14.8 ±	2.1	14.4	± 1.8	15.7 ± 1.9		15.3 ± 1.9		



Table 13. Range of most frequent reasons of sexual intercourse among RAE communities

men

The most common reasons of sexual	Ferizaj		Fushë Kosovë		Gjakovë		Pejë		Totali	
intercourse among RAE community males ?	N	%	N	%	N	%	N	%	N	%
Voluntary sex	5	50.0	5	50.0	7	70.0	6	60.0	23	57.5
Influence of peers	2	20.0	1	10.0	1	10.0	3	30.0	7	17.5
Influence of social network & internet	2	20.0	2	20.0	2	20.0	•	0.0	6	15.0
The most appropriate time	2	20.0	1	10.0	1	10.0	1	10.0	5	12.5
Curiosity	1	10.0	-	0.0	2	20.0	1	10.0	4	10.0
Alcohol & narcotics use	2	20.0	1	10.0	-	0.0	-	0.0	3	7.5
Influence of the family & financial conditions	-	0.0	1	10.0	1	10.0	1	10.0	3	7.5
l do not know	1	10.0	1	10.0	-	0.0	·	0.0	2	5.0
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



Most frequent ways of	Ferizaj		Fushe Kosove		Gj	akove		Peje	Total	
sexual intercourse among RAE communities?	N	%	N	%	N	%	N	%	N	%
Vaginal	10	100.0	9	90.0	10	100.0	10	100.0	39	97.5
Oral	6	60.0	3	30.0	7	70.0	4	40.0	20	50.0
Anal	4	40.0	5	50.0	6	60.0	4	40.0	19	47.5
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



Table 15. Structure of presence of commercial sex among women

How often females or women are engaged in commercial sex?		Ferizaj		Fushë Kosovë		Gjakovë		Pejë		hsej
		%	Ν	%	Ν	%	Ν	%	Ν	%
There is no commercial sex	5	50.0	4	40.0	6	60.0	4	40.0	19	47.5
No cases	5	50.0	4	40.0	3	30.0	4	40.0	16	40.0
We have not heard	-	0.0	2	20.0	1	10.0	2	20.0	5	12.5
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



Table 16. Most frequent reasons of commercial sex among women

Which is the most common reason for comercial sex		Ferizaj		Fushë Kosovë		Gjakovë		Pejë	Gjithsej	
among women?	Ν	%	Ν	%	Ν	%	Ν	%	Ν	%
Financial conditions	3	60.0	3	75.0	2	66.7	1	25.0	9	56.3
They are used to such work	-	0.0	1	25.0	-	0.0	1	25.0	2	12.5
Trafficking	1	20.0	-	0.0	1	33.3	-	0.0	2	12.5
For a favour	-	0.0	-	0.0	-	0.0	1	25.0	1	6.3
Parents force them and severe financial conditions	-	0.0	-	0.0	-	0.0	1	25.0	1	6.3
I do not know the reason	1	20.0	-	0.0	-	0.0	-	0.0	1	6.3
Total	5	100.0	4	100.0	3	100.0	4	100.0	16	100.0





Table 17. How much is present the phenomenon of commercial sex among men?

How much are males/men	Ferizaj		Fushë	Kosovë	Gjal	kovë	Pejë		Gjithsej	
engaged in commercial sex in your community?	N	%	N	%	Ν	%	Ν	%	Ν	%
They are not engaged	10	100.0	5	50.0	10	100.0	7	70.0	32	80.0
Yes there are some cases	_	0.0	5	50.0	_	0.0	3	30.0	8	20.0
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



It is the phenomenon of	nenon of Ferizaj			ıshë sovë	Gja	kovë	Р	ejë	Gjithsej		
sex with same gender MSM, common among RAE communities?	Z	%	Z	%	Z	%	Z	%	Ζ	%	
There are not											
any & We do not											
know	10	100.0	4	40.0	10	100.0	4	40.0	28	70.0	
Yes there is	-	0.0	6	60.0	I	0.0	6	60.0	12	30.0	
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0	

Table 18. The phenomenon of sex with same gender MSM among RAE communities





Table 19. How often RAE communities members refuse the use of condom

How is often in your community	Ferizaj		Fushë Kosovë		Gjakovë		Pejë		Gjithsej	
refusal condoms by partners?	Ν	%	N	%	Ν	%	Ν	%	Ν	%
They do not refuse it	7	70.0	4	40.0	7	70.0	5	50.0	23	57.5
They refuse it	0	0.0	6	60.0	1	10.0	3	30.0	10	25.0
l do not know	3	30.0	0	0.0	2	20.0	1	10.0	6	15.0
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0





Table 20. Structure of responses in the question "Does anyone use drugs in your communities?

Does anyone use drugs in your community (marihuana, hashish,	Ferizaj		Fushë Kosovë		Gjakovë		Pejë		Total	
ecstasy etc)	N	%	Ν	%	Ν	%	Ν	%	Ν	%
Yes	8	80.0	5	50.0	9	90.0	7	70.0	29	72.5
No	2	20.0	5	50.0	1	10.0	3	30.0	11	27.5
Total	10	100.0	10	100.0	10	100.0	10	100.0	40	100.0



Chart 22