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## ACCESS TO HEALTHCARE IN KOSOVO

Results of a Nationwide Survey on Healthcare Issues in Kosovo

Presented to the Kosovo Women's Network and the Kosovo Ministry of Health

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### TABLE OF CONTENTS

EXECUTIVE SUMMARY	1
1. INTRODUCTION	1
2. RESEARCH METHODS	2
2.1 SURVEY DATA COLLECTION METHODS	2
2.2 STRATIFICATIONS OF ANALYSES	2
2.3 CREATION OF INDICES	3
2.3.1 Index Scores	4
2.4 SURVEY ANALYSIS METHODS	4
2.5 INTERVIEW METHODS	4
2.6 LIMITATIONS AND FURTHER ANALYSIS	4
3. KOSOVO HEALTHCARE SYSTEM	5
4. DEMOGRAPHICS	7
4.1 COUNTRY DEMOGRAPHICS	7
4.2 SAMPLE DEMOGRAPHICS	8
5. UTILIZATION OF HEALTHCARE SERVICES	8
5.1 Service Utilization Index Findings	9
5.1.1 Residency	10
5.1.2 Ethnicity	10
5.1.3 Age	10
5.2 FINDINGS IN DEPTH: CHECKUPS AND SCREENING	11
5.3 PHARMACEUTICAL USE	12
5.4 HEALTH INSURANCE AND PAYMENT	13
5.5 SERVICE UTILIZATION DISCUSSION	13
5.6 PUBLIC VERSUS PRIVATE HEALTHCARE SYSTEM	14
5.6.1 Divide between Public and Private Sector Discussion 5.7 Conclusion	<i>15</i> 16
	-
6. GENDER	16
6.1 DECISION MAKING	16
6.2 PRIORITIZATION	17
6.3 CULTURAL BARRIERS DISCUSSION	17
9. RESIDENCY	18
9.1 FINANCIAL BARRIERS	18
9.2 GEOGRAPHIC BARRIERS	18
9.3 Cultural Barriers	19
9.4 PATIENT-PROVIDER RELATIONSHIP (PPR)	19
9.5 PERCEIVED PERSONNEL QUALITY	19
9.6 AWARENESS OF RIGHTS	19
9.7 Conclusion	19



The Center for Public Policy and the Social Sciences

10. ETHNICITY	20
10.1 FINANCIAL BARRIERS	20
10.2 GEOGRAPHIC BARRIERS	21
10.3 Cultural Barriers	22
10.4 PATIENT-PROVIDER RELATIONSHIP (PPR)	23
10.5 PERCEIVED PERSONNEL QUALITY	24
10.6 Availability	25
10.7 AWARENESS OF PATIENT RIGHTS	25
10.8 CONCLUSION	26
11. KNOWLEDGE AND RIGHTS	26
11.1 KNOWLEDGE BARRIERS	26
11.2 PATIENT RIGHTS ABUSES	27
11.3 Confidentiality	28
12. CONCLUSIONS OF QUANTITATIVE ANALYSIS	29
12.1 Areas of Further Inquiry	29
12.2 POLICY STEPS	30
APPENDICES	31
APPENDIX 1. SURVEY METHODOLOGY	31
APPENDIX 2. INDEX QUESTION METHODOLOGY	33
REFERENCES	38



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### **EXECUTIVE SUMMARY**

During the summer of 2016, a nationwide household survey of 1,309 Kosovars was conducted for the Kosovo Women's Network and the Kosovo Ministry of Health on the state of the healthcare system and on the abilities of Kosovar citizens to access the healthcare system. This report analyzes the survey data in order to assess the degrees to which Kosovar citizens 1) face barriers to accessing the healthcare system, 2) utilize the services offered by the public and private healthcare systems, 3) are aware of their rights as patients, and 4) view the healthcare delivery system as efficient and effective. Each of these dimensions is operationalized through indices constructed through related survey interview questions. The barriers to access index is further delineated with additional indices focusing on financial, geographic, and cultural barriers. In a similar fashion, the quality of care index is sub-divided into indices focusing specifically on patient-provider relationships, perception of personnel quality, and availability of medical services. The findings of this report provide quantitative support for much of the anecdotal perceptions that have, to date, driven the policy debate on healthcare delivery in Kosovo. Progress is being made, yet much remains to be done. Ethnic minorities and rural residents of the Republic have consistently less access to quality healthcare. The current structures and administration of the public and private healthcare systems create mixed motives for doctors that often lead to less than optimal and efficient quality of care and access to the Kosovar healthcare system.

#### **1. INTRODUCTION**

In June 2016, the Kosovo Women's Network (KWN) conducted the country's first genderdisaggregated, national household survey to better understand Kosovars' access to health care. Supplemented by qualitative interviews with key informants, this report analyzes patient perceptions of access to healthcare. Key questions guiding the survey are as follows:

- 1. How do citizens utilize healthcare services?
- 2. What financial, geographical, and cultural barriers exist to citizens accessing healthcare in Kosovo?
- 3. How do citizens evaluate the quality of healthcare in Kosovo?
- 4. How aware are citizens of their healthcare needs and rights to healthcare?
- 5. Do disparities exist between women and men?

Written with support from and in collaboration between the Kosovo Ministry of Health, the University of Pristina, the United Nations Population Fund (UNFPA), the World Health Organization (WHO), the United Nations Development Program (UNDP), and Dartmouth College, the report focuses on how gender, residency, and ethnicity affect barriers to accessing healthcare, quality of healthcare, utilization of healthcare services, and knowledge of healthcare rights in Kosovo.

This report contains the quantitative data analysis of the national health survey, supplemented by key informant interviews. It will become part of a larger report on Kosovars' access to healthcare



once the Kosovo Women's Network concludes its qualitative research on healthcare providers and policymakers in October 2016.

This report is structured by three stratifications: gender, ethnicity, and residency (urban/rural). The findings derived from the eight indices along with analyses of non-indexed questions are presented under each stratum. This report concludes with survey findings and areas for further research. Annexes include a more detailed description of the survey research methodology (Annex 1) and index question matrices (Annex 2).

#### 2. RESEARCH METHODS

The report is based on mixed methods research design including a national household survey of 1,309 Kosovars (52 percent women and 48 percent men) conducted by faculty and students at the University of Pristina to better understand the experiences of Kosovar citizens with the healthcare system; stakeholder interviews with key informants were also conducted to inform and contextualize the survey responses.

#### 2.1 Survey Data Collection Methods

The survey was conducted from mid-May to mid-June of 2016 throughout Kosovo, in both urban (42 percent) and rural areas (58 percent). The sample is representative of all ethnic groups in Kosovo. The selection was done using Multistage Random Sampling Method. For further information, please see Annex 1.

#### 2.2 Stratifications of Analyses

The researchers analyzed the survey data using six stratifications: gender, ethnicity, residency (urban/rural), age, region, and education level. <sup>1</sup> The findings were not analyzed by socioeconomic status as the survey data on socioeconomic status were not internally consistent.<sup>2</sup> This report only presents the gender, ethnicity, and urban/rural analyses, as they yielded the most useful results. Age, region, and education level analyses can be summarized as follows:

- 1. Age was generally not correlated with access to healthcare.
- 2. The analyses of region presented disparities, with the capital region of Pristina and the Serbian-majority region of Mitrovica generally faring better than the other five regions, but the results are difficult to interpret without further data on the hospitals and providers.
- 3. There was a positive correlation between education level and access to healthcare. More educated patients had better access and report receiving better care.

<sup>&</sup>lt;sup>1</sup> Education is presented in terms of number of years of schooling due to changes in the length of high school in Kosovo; thus, 0-7 years can be understood as elementary school, 8-11 as high school, 12-14 as a university degree, and 15+ as a graduate degree and/or more.

<sup>&</sup>lt;sup>2</sup> Internal consistency reliability is a measure of how well different questions on the survey measure the same construct or idea. Survey respondents were asked for their individual monthly income and their household monthly income. About 54 percent of respondents reported their individual income to be higher than their household income. Thus, socioeconomic data were not reliable and were not analyzed.



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## 2.3 Creation of Indices

The survey instrument contained 190 distinct questions. The researchers grouped the questions into eight indices that correspond with the key research questions presented above. The purpose of an index is to reveal trends across questions by assigning scores to different cohorts in the population surveyed. For example, one cohort we analyzed was rural women. To create the index, we compiled all of the questions that related to service utilization, and we assessed how rural women answered those questions. Depending on how they answered those questions, they were assigned a score. We repeated the analysis for rural men, urban women, urban men, and so on for each cohort. Thus, we can compare how each group answered across many questions.

This report includes eight indices total as shown in Figure 1. The primary indices are barriers to access, service utilization, awareness of patient rights, and quality of care. The barriers to access index was further delineated by types of barriers: financial, geographic, and cultural. Quality of care was further assessed using three components that impact quality of care: patient-provider relationship (whether communication between healthcare providers and their patients is patient-centered and equitable), perception of personnel quality (whether patients receive effective and safe care), and availability (whether institutions have and efficiently use proper equipment and supplies).

Within each index, the included questions must be correlated with each other to ensure they are all measuring the same concept. To assess this, the researchers constructed correlation matrices. Questions that did not correlate with the others were excluded from the index, but are discussed in the body of the text. A list of the questions used to construct each index will be presented in Annex 2.



Figure 1. Organization and Definition of Indices.



## 2.3.1 Index Scores

For each of the indices, the minimum possible score is 0 and the maximum possible score is 100. A higher score always represents higher barriers to fully accessing and utilizing the healthcare system. Thus, someone with a score of 0 faces no barriers while someone with a score of 100 faces the highest barriers for each of the indicators that the index addresses.

#### 2.4 Survey Analysis Methods

This report utilizes a 0.05 level of significance and all correlations presented in this report are considered significant at this level. Throughout this report, the reader can assume that the word "significant" is used to mean statistical significance (See Statistical Analysis Methods under Annex 1). Correlations between strata (gender, residency, and ethnicity) and the indices were assessed using one-way Analysis of Variance (ANOVA tests). Except for comparisons of scores between regions, significant differences between various sub-groups in the survey sample were assessed using the Šídák multiple comparisons test. Each table features means scores for each subgroup and the standard error in parentheses.

#### 2.5 Interview Methods

To explore factors affecting Kosovars' access to healthcare from the perspective of healthcare providers, policymakers, and NGO leaders, the Dartmouth team conducted five key informant interviews. These interviews will be included in a larger qualitative data collection process ongoing at KWN currently. For further information, please see Annex 1.

#### 2.6 Limitations and Further Analysis

Limitations stemmed from four categories: survey design, surveying technology, surveyor training, and respondent errors. Survey design was limiting for a few questions where respondents could select only one answer when multiple answers may have applied. Responses to abortion questions may also be inaccurate as the Albanian word for miscarriage and abortion is similar. Another limitation is the heavy focus on reproductive health and family planning, resulting in a more narrow analysis.

The surveying technology used to record the interview responses to the household surveys was KoBoToolbox, a free and open source tool developed for researchers by the Harvard Humanitarian Initiative and Brigham and Women's Hospital. While functional, it is in Beta phase of testing, which resulted in some problems with timekeeping and coding.

Surveyors changed throughout the surveying process as the original students recruited had final exams and thus had to be replaced. Not every surveyor received the same training, creating the potential for inconsistencies. Finally, some surveyors entered the correct region but the incorrect city or town name, which may impacted the rural/urban analyses. This was resolved by using the location of the surveyor's partner.

Respondents may not have been familiar with being surveyed. This resulted in interviews that were conducted with the entire household present, which may have impacted the respondent's honesty. On other questions, self-reported numbers were inaccurate and had to be excluded from further analysis. The most important example of this discrepancy was found in responses to household income, where many people estimated their household income from the last month to be lower than their personal monthly income. Finally, questions may have solicited positive



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response bias, where people are likely to agree with a positive statement by default unless they are pushed or asked to further explain.

## **3. KOSOVO HEALTHCARE SYSTEM**

Kosovo's healthcare system is one in transition. Kosovo inherited a Soviet Semashko healthcare structure from former Yugoslavia, with the state acting as both the purchaser and the provider of health services. This system incentivized specialization, creating many inefficiencies and redundancies. Patients had little agency in choosing where to seek care.

When Kosovo's autonomous status was revoked by Belgrade in March 1989, the health sector became a battleground for conflict between Kosovo's Albanian population and the Serbian government. The Serbian government assumed control of the Kosovo healthcare system while the University of Pristina's medical faculty was closed, disrupting the training of many medical students. Over sixty percent of ethnic Albanian health workers (an estimated 2,400 people) left their jobs because they were either fired, discriminated against, or chose to leave (Percival and Sondorp 2010). The healthcare workers that remained were required to speak Serbian and write in Cyrillic (Percival and Sondorp 2010).

After 1989, many Albanians lost their jobs and consequently lost their insurance coverage. In the following decade, over half of the Albanian population lacked a social insurance card needed to gain access to the public health system. As a result, access to healthcare for the Albanian population suffered during this time period (Percival and Sondorp 2010).

To address this need, Albanian healthcare workers established a parallel primary healthcare system known as the Mother Theresa system. This parallel system operated 96 clinics throughout Kosovo, many in remote areas. Healthcare workers served as volunteers and supplies and medicines were paid for via a parallel tax system. During this time, Albanian healthcare workers also established private facilities such as clinics and laboratories (Percival and Sondorp 2010).

Since the Albanian population could no longer receive medical training in their own language at the University of Pristina, they also established a parallel medical education system. Though this system provided a high level of theoretical knowledge, medical students received limited clinical training due to the lack of access to training sites As a result, a generation of Albanian healthcare workers was left with gaps in their medical knowledge and uneven credentials (Percival and Sondorp 2010).

Despite the efforts of the parallel healthcare system, the health of Kosovo's population declined during the 1990s. Immunization rates dropped—vaccination coverage for children against diseases such as polio fell below 60 percent with some areas falling below 30 percent coverage. The incidence of infectious disease rose, and polio subsequently re-emerged with 52 cases reported between 1990 and 1997 (Percival and Sondorp 2010). The healthcare system was further damaged after armed conflict broke out in 1998. Approximately 90 percent of hospitals and clinics were damaged, and almost all private clinics operated by Albanian doctors were destroyed (Uka and Festina 2013).

Post-conflict reconstruction focused on the introduction of primary health care and rehabilitation of the health infrastructure. The reconstruction was heavily influenced by international donors, who strongly supported a primary healthcare model (Buwa and Vuori 2007). Primary healthcare



was meant to emphasize family medicine and act as a gatekeeper to specialized care, provided at the secondary and tertiary level. In the early 2000s, management of primary care was decentralized to the municipal governments. This resulted in a fragmentation of oversight for public institutions between municipal governments and the Ministry of Health (Buwa and Vuori 2007).

The Kosovo healthcare system is divided into three levels: primary care, secondary care, and tertiary care. Primary health is controlled by the municipalities while secondary health and tertiary health is controlled by the Ministry of Health. Institutions have been systematically designated throughout the country.

Each of the 38 municipalities has a Family Medicine Center where citizens can access primary healthcare. These Family Medicine Centers have at least one doctor and two nurses for every 2,000 people in the clinic's catchment area. The shift toward Family Medicine Centers was intended to strengthen primary care and decrease reliance on specialists for routine healthcare, yet in 2007 Buwa and Vuori reported that this reform had largely failed due of lack of behavioral and attitudinal shifts in patient populations. According to the WHO-Kosovo Head of Office Dr. Skender Syla, in 2016 the primary care model has still not been embraced and continues to struggle.

Secondary care is accessible at any one of the seven regional hospitals. The regions of Ferizaj, Gjakova, Gjilan, Peja, and Prizren each have one regional hospital while the region of Mitrovica has two: one in Mitrovica north--in the city of Mitrovica—and the other in Mitrovica south—in the town of Vushtrii. Mitrovica is a region in the north of Kosovo with the largest Serbian minority population. Due to the political situation in Kosovo, there are essentially two separate public healthcare systems operating in parallel in the region: the widely used public system and another that operates in Serbian populated areas but is still fully funded by the government of Kosovo (OSCE, *Parallel Structures in Kosovo* 2003). This has created the dual hospital situation in the region of Mitrovica. According to the OSCE, the Mitrovica hospital, in Mitrovica north, also serves as the main (tertiary) healthcare institution for Kosovo Serbs from across Kosovo. The total number of regional hospitals remains at seven since the Kosovo University Hospital, in Pristina, provides dual services by providing both secondary care for Pristina and tertiary care for all Kosovo.

Tertiary care is only available in the Kosovo University Hospital in the capital of Pristina (Muzik and Uka 2013). There are three additional institutions associated with KUH--the medical school, the university clinical center, and the clinical services unit.

Alongside the public health institutions, there are numerous private clinics and hospitals throughout Kosovo that offer both specialized and general care (Kosovo Health Sector Strategy 2009). Private institutions have continued to remain a popular alternative to the public health institutions for a variety of reasons. For health care personnel, private institutions are a way to supplement their public sector incomes. For patients, private institutions do not require referrals from Family Medicine Centers, and thus patients may move directly to specialty care (Buwa and Vuori 2007). Motivations for seeking public or private care will be more fully discussed in Section 5, *Utilization*. However, under the current system, both providers and patients who can afford it are incentivized to continue seeking private care and thus perpetuating the split system.



Many structural problems remain in achieving a fully integrated healthcare system. Kosovo's status as an internationally recognized, sovereign nation is still not confirmed. As of 2016, over one hundred nations have recognized Kosovo as a nation, but Kosovo is still not member of the United Nations. Thus, it is not officially a member of the World Health Organization (WHO), although the WHO does function in the country using a different legal structure (Syla 2016). The ongoing transition from the centralized socialist model, limited utilization of the primary healthcare model, the parallel healthcare systems, and Kosovo's status issues all present challenges.

### 4. DEMOGRAPHICS

#### 4.1 Country Demographics

Kosovo is a young country, with a median age of 28. The life expectancy for a citizen at birth is 70 years, lower than that of citizens in the average European Union state (Statistical Office of Kosovo 2011). About 46 percent of the nation lives in poverty, with 12 percent in extreme poverty (World Bank 2011). Kosovo is a multi-ethnic society, with a large Albanian majority. The poverty rates reported above may under-represent Serb, Roma, and some other ethnic minorities as they are based on the 2011 Kosovo National census which excluded northern Kosovo, where a majority Serbian population lives, and was boycotted by some southern Serbian and other minority populations. The Roma, Ashkali, and Egyptian populations are often grouped together and discussed as a collective presence in the country. They are widely viewed as the most impoverished communities. They live on the fringes of society, often without the identity papers that would entitle them to the benefits available to other citizens: social welfare, unemployment, even schooling (George 2009, UNICEF).

In 2014, Human Rights Watch reported that these minority communities continue to suffer discrimination. The Ministry of Social Welfare changed the eligibility criteria for social assistance in a way that effectively prevents many Roma, Ashkali, and Egyptian families from accessing social benefits. The 2010 Strategy for Integration of Roma, Ashkali, and Egyptians "continues to exist on paper only, with the government failing to allocate necessary funds to implement the strategy," (Human Rights Watch 2014).

Kosovo is a majority Muslim country, where about 95.6 percent of the population identifies as Muslim. The other most common religions are Roman Catholic (2.2 percent of the population), and Orthodox (1.5 percent of the population) (CIA n.d.).

The median age for men was 27.9 while the median age for women was 28.6. Youth unemployment numbers remain high with 55.3 percent of youth ages 15-24 unemployed. Unemployment is slightly higher among young women at 63.8 percent than young men (52.0 percent) (CIA n.d.). The World Bank estimates that the total unemployment rate is above 30 percent, with a weak labor participation rate of 40.5 percent. The gender ratio for the total population is 1.06 men to one woman (World Bank 2015).

Since the end of the war, Kosovo has made significant progress as measured by health indicators. Infant mortality rate in 2000 was at 29 deaths per 1,000 births, and it has dropped to 11 deaths per 1,000 births in 2016 (Action for Mothers and Children 2016; Arur 2013). Although the infant mortality rate has improved significantly since 2000, it still remains higher than the



European Union average—11 deaths per 1,000 births versus 4.1 deaths per 1,000 births (Arur 2013). From the end of the conflict in 1999, there has been no recorded outbreak of communicable, vaccine-preventable diseases, like measles. However, significant health challenges remain.

#### 4.2 Sample Demographics

In Table 1, the demographics of the survey sample population, disaggregating respondents by gender, residency, ethnicity, education level, religion, region, age, and marital status are presented.

Strata	Women	Men	Total	Strata	Women	Men	Total
Residency				Regions			
Urban	280	272	552	Ferizaj	65	63	128
Rural	396	361	757	Gjakova	63	64	127
				Gjilan	64	71	135
Ethnicities				Mitrovica	114	105	219
Albanian	470	434	904	Peja	52	54	106
Serbian	92	103	195	Pristina	184	152	336
Roma, Ashkali, Egyptian	48	40	88	Prizren	134	124	258
Bosnian	28	27	55				
Gorani	14	14	28	Age Groups			
Turkish	22	14	36	16-24 Years	148	146	294
Other	2	1	3	25-34 Years	152	112	264
				35-44 Years	130	102	232
Education Levels				45-54 Years	121	109	230
0-7 Years	113	32	145	55-64 Years	84	94	178
8-11 Years	223	122	345	65+ Years	41	70	111
12-14 Years	215	352	567				
15+ Years	125	126	251	Marital Status			
Don't Know	0	1	1	Single	168	188	356
				Married with certificate	398	373	771
Religion				Married without certificate	55	44	99
Islam	566	513	1079	Co-habitating	1	0	1
Catholic	13	9	22	Engaged	24	15	39
Orthodox	89	104	193	Divorced	4	4	8
Atheist/no faith	2	4	6	Widowed	26	9	35
Agnostic/unsure	3	2	5				
Prefer not to respond	3	1	4	Total	676	633	1309

#### Table 1: Unweighted Sample Statistics

## 5. UTILIZATION OF HEALTHCARE SERVICES

Utilization is defined as how citizens use services within the healthcare system, addressing what services citizens are seeking and where in the healthcare system they are seeking them. Utilization of healthcare services thus also includes context about the culture of care in Kosovo by discussing the different types of institutions and why patients choose to use the ones that they do. Two of the main trends in utilization are the limited use of the primary care model and the continued split between the institutions in the public and private sector. This section provides background to the rest of the report by creating a snapshot of the patient's side of the healthcare system.



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As explained by Section 2.1.2. Survey Analysis Methods, an index was created using all the questions that relate to service utilization, such as have you ever gotten a checkup or have you ever been treated for sudden illness. The questions asked to only women were excluded since data existed for only female respondents. Most of the questions ultimately included in the index were focused on primary and preventative care. The only specialties touched upon were gynecology and urology. (See annex 2 for full list of questions).

This index was then used to calculate scores for different cohorts, stratified by gender, residency, ethnicity, education, and region. As is standard throughout the report, the *higher* the score, the *worse* it is. Higher scores represent lower utilization of healthcare services. The possible scores range from 0—full utilization of all healthcare services addressed by the index questions to 100—no utilization of any healthcare services addressed by index questions.

Section 6.1 reports on service utilization and addresses whether patients are using primary and preventative care, and/or specialist care. Section 6.2 discusses the utilization of public versus private institutions based on survey results, interview findings, and a literature review.

### 5.1 Service Utilization Index Findings

The index findings demonstrate a general pattern of underutilization of health services. The mean score for Service Utilization is 76.6, with a range of scores from 22.2 to 100. Gender is significantly correlated with service utilization. Women, with a mean of 74.0, were slightly more likely to utilize healthcare services than men were, with a score of 79.7. Residency, ethnicity, and age were also significant correlates. No significant trends arose when analyzing service utilization by educational attainment.







### 5.1.1 Residency

Urban and rural Kosovars use services at different rates, with rural Kosovars using fewer services than urban Kosovars (p < 0.001). Rural citizens have a mean score of 78.6 while urban citizens have a mean score of 74.0. This trend holds across both men and women, with urban men using fewer services than urban women and rural men using fewer services than rural women (p=0.000 for all). Rural men, with a score of 80.9, are the group least likely to use healthcare services.

#### 5.1.2 Ethnicity

Ethnicity is also significantly correlated with service utilization. Since the majority of the survey respondents are, as is the majority of the Kosovar population, Albanian, we chose to compare the status of all other ethnic groups to Albanians in this section and follow this format for the remainder of the report.

Albanians have a mean score of 77.2. The only group that is statistically different is Serbians, who have a mean score about 10 points lower at 67.9 (p=0.000). While Serbians are not statistically different from other ethnic groups, they consistently score the lowest, and therefore best, on service utilization. Albanians and Bosnians score 77.3 and 77.6 respectively.

Within ethnic groups, both Albanian and Turkish women use more services than their male counterparts. Albanian women score 74.4 to Albanian men's 80.3 (p=0.000). Turkish women score 67.3 to Turkish men's 78.3 (p=0.021).

Ethnicities	Women	Men	Both Genders
Albanian	74.36	80.29	77.23
	(0.739)	(0.620)	(0.496)
Serbian	65.98	69.87	67.89
	(1.446)	(1.444)	(1.033)
Roma, Ashkali, Egyptian	73.46	72.89	73.21
	(1.315)	(2.245)	(1.225)
Bosnian	75.69	79.44	77.61
	(2.403)	(1.874)	(1.539)
Gorani	72.44	62.04	69.15
	(2.763)	(8.044)	(3.354)
Turkish	67.25	78.28	71.30
	(2.622)	(3.481)	(2.308)

 Table 2: Service Utilization Mean Scores Stratified by Ethnicity and Gender (with Standard Errors in Parentheses)

#### 5.1.3 Age

Generally, as age increases, both male and female respondents are more likely to use services. There are statistically significant differences between the oldest groups (55-64, 65+) and the youngest (16-24) (p=0.000). This makes sense in a global context as older citizens are more likely to need medical services than younger citizens.



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### 5.2 Findings in Depth: Checkups and Screening

While some questions about checkups and screening were included in the Utilization index, the findings on preventative care are particularly noteworthy and thus merit further discussion. General health checkups and preventative care remain significantly underutilized across the general Kosovar population. More than half of the respondents (53.9 percent) have never had a general checkup. A slightly higher percentage of men (48.7 percent) than women (43.8 percent) have had a general checkup. Urban Kosovars (49.0 percent) were more likely to have had a checkup than rural Kosovars (44.3 percent).

Different ethnic groups behave very differently when it comes to checkups. Serbians are by far the most likely to get checkups, with 79.0 percent of Serbians reporting that they have had a general checkup as a preventive visit. Gorani have the lowest likelihood of having a checkup, at 32.1 percent.

As age increases, people are more likely to report having had a general health checkup. Only 35.9 percent of 16-24 year olds have had a general checkup. This percentage steadily increases as age increases, reaching a high with 66.2 percent persons 65 and older who have had a general checkup.

Although checkups were rare, of those who reported having a general health checkup and remembered when their last one was, most had done so recently. Over 90 percent had their checkup within the past five years (90.8 percent). The plurality, 35.1 percent, report having had a checkup in the past six months. Another 29.0 percent had a checkup within the last year, and 26.8 percent report getting a checkup between two and five years ago.

Screenings are even less common than checkups. Survey responses show a general lack of understanding about which medical procedures constitute screenings. There were several screening questions on the survey including three about colon cancer, two about breast cancer, and two about pap smears/cervical cancer screening, with the latter two asked only to women.

Overall, all of the questions consistently show very low use of screenings. Approximately 97.4 percent of the respondents have never been screened for colon cancer and 95.3 percent of respondents have never had a colonoscopy. Of the 4.7 percent of the respondents that have had a colonoscopy, only about one third of them had one in the past five years.

Among female respondents, 91.0 percent report never having had a breast cancer screening. Women were also asked if they had ever heard of a mammogram, and if they responded affirmatively, were asked whether they had ever had one. About 44.2 percent of women had never heard of a mammogram. Of the 55.8 percent that had heard of a mammogram, only 18.1 percent had received a mammogram screening in the past three years.

Among female respondents, 90.4 percent report never having been screened for cervical cancer. Women were later asked if they had ever heard of a pap smear and if so, had they ever gotten received one. About 60 percent of women had heard of pap smears. Of the female respondents who had heard of pap smears, 37.5 percent had received such a screening. Among all female respondents, 22.8 percent of women had received a pap smear and thus at least 22.8 percent of female respondents have been screened for cervical cancer. The discrepancy between the percentage of women who report having been screened for cervical cancer (9.6 percent) and the



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percentage that report having a pap smear (22.8) shows the lack of knowledge surrounding what constitutes screening and what the purpose of various medical tests are.

Low screening rates are not driven purely by a deficit of knowledge. Dr. Visare Nimani, Program Specialist at UNFPA in Kosovo, described capacity issues that further depress screening rates. Most public family medicine centers are not able to provide mammograms; therefore a woman has to use the secondary level of the healthcare system. This arrangement effectively separates breast cancer screening from other preventative care, which is provided at the primary care level (Nimani 2016). A similar pattern is true with pap smears. First, only gynecologists may conduct pap smears, which often forces women to utilize secondary care rather than primary care as not all family medicine centers employ gynecologists. The only institution with the capacity to analyze pap smears is the pathology institute in Pristina. Pap smear samples must be transported to UCCK for analysis and results conveyed back to the regional center, creating a slow and inefficient process (Nimani 2016). The only other option for women is to go to private labs to have their test results read. Neither process makes screening easy for women.

#### 5.3 Pharmaceutical Use

The survey asked both about obtaining prescription drugs with a prescription and without a prescription. While obtaining drugs with a prescription was coded into the index as a positive response, obtaining drugs from a pharmacy without a prescription drug use was not included in the index as it is more difficult to categorize. People are not using the healthcare system as it is intended and without follow up questions, it is impossible to know what sorts of drugs people are obtaining without a prescription and what motivates this behavior. One explanation is drug abuse, but another equally plausible explanation is citizens are seeking treatment when they cannot access, or afford, a doctor's consultation.

The majority of citizens have obtained drugs both with and without a prescription—79.7 percent of Kosovars have obtained drugs with a prescription while 63.5 percent of Kosovars have obtained drugs without a prescription.

Nonprescription obtainment is not reported equally across gender, residency, and ethnicity. Men (71.2 percent) are more likely to obtain, or admit to obtaining, drugs without a prescription at least once than women are (63.0 percent). Urban respondents are more likely (72.3 percent) than respondents from rural regions (63.2 percent) to obtaining drugs from a pharmacy without a prescription.

Different ethnic groups vary greatly in the rate at which they obtain drugs without a prescription. Albanians are the least likely to do so, with only 65.2 percent of Albanians ever obtaining drugs without a prescription. Roma, Ashkali, and Egyptian, Turkish and Serbian respondents are more likely to have obtained drugs without a prescription at 89.6 percent, 88.2 percent, and 87.1 percent of the respective populations responding affirmatively.

Higher levels of education correspond with a higher likelihood of having obtained drugs without a prescription. Citizens who have 0-7 years of schooling report a 54.8 percent rate of obtaining drugs without a prescription. This number rises to 61.7 percent for those who have 8-11 years of education, 70.1 percent for those with 12-14 years of education, and reaches a peak at 74.0 percent of people with 15+ years of education admitting to receiving drugs without a prescription.



The Center for Public Policy and the Social Sciences

## 5.4 Health Insurance and Payment

According to the Act on Health, first passed by the government of Kosovo in 2004, public health insurance is a right for all citizens. In 2016, this has still not become a reality. Without public health insurance in place, some companies have begun to offer private health insurance. A minority of citizens, about six percent of respondents, have chosen to purchase private health insurance. Of that six percent, two-thirds of the insured are men and one-third of them are women. The insured are split 50-50 between rural and urban, but the gender divide is very different in rural and urban areas. In rural areas, about 80 percent of the insured are men and 20 percent are women. In urban areas, the insured are about 50 percent male and 50 percent female. While this private insurance may provide some financial relief, it should not need to exist as everyone should be covered under the Kosovo Health Insurance Fund.

#### 5.5 Service Utilization Discussion

One trend that emerged throughout data analysis is the gap that exists between stated belief and subsequent action or practice. Preventive health care is not widely practiced in Kosovo. When asked if regular checkups were a waste of money, only 4.3 percent of the respondents agreed or strongly agreed with the statement. Yet, over half the respondents have never had a checkup. Likewise, 85.7 percent of the respondents state that if they were sick they would go to the doctor. Yet for 25.9 percent of the respondents, there was at least one instance in the past year where they needed to consult the doctor but did not.

Another trend that emerged was the frequency and persistence of the belief that certain services were unnecessary. When asked why they did not get prenatal care, 23.8 percent of women cited the belief that prenatal care was unnecessary. These findings suggest that Kosovar women would benefit from additional health education programs.

As discussed above, rates of screening and preventive care utilization in Kosovo are low, though most people believe these services are important. An additional factor to consider is the culture surrounding screening and general health checkups in Kosovo. Ms. Aliu states "when it comes to prevention care, it's not a habit in our society... We tend to visit the doctor when we have to. We have no other way. But, regularly visiting the doctor, just consulting, or going to general check-ups, that's not a habit" (Aliu 2016).

Furthermore, the culture around screening and preventative care, particularly for women, is impacted by societal views of acceptable behavior. When it comes to reproductive health, Ms. Aliu explains, "Visiting [the] OB/GYN for just [a] regular check-up is still ... kind of a taboo for a lot of women, especially young women. I mean, we can see the women who attend our resource centers, women we work with, or even my own network of friends where they just don't think it's necessary if you're not sexually active or if you're not married yet or if you don't have any partner yet." She emphasizes that the low service utilization rates are often due to a "mentality that it's not necessary.... rather than [a lack of] opportunities to get care" (Aliu 2016).

In sum, in order to improve screening rates and preventative care utilization, the quality of the services must be improved in addition to changing the population's attitudes towards utilizing these services.



#### 5.6 Public versus Private Healthcare System

As discussed previously, the healthcare system in Kosovo remains split between public and private healthcare institutions. When asked for their preference, 59.2 percent of respondents indicated a preference for public facilities. The next most common choice was private institutions, chosen by 32.3 percent of respondents. An additional 8.5 percent responded they have no preference between the two types of institutions. When asked why they hold these preferences, the reasons were very different for those who selected public institutions versus those who selected private institutions.

Responses	Public	Private
It's less expensive	69.64%	0.69%
It has better quality care	12.59%	79.02%
It's closer to me	7.65%	0.77%
I know people there	3.09%	2.88%
It has the specific type of care I need	4.14%	12.50%
Other	2.89%	4.14%

Table 3: Reasons for Public or Private Preference

For the majority of respondents who prefer public institutions, cost is the most important factor-69.6 percent say they prefer public facilities because they are less expensive. The next most common response was that public facilities provide a better quality of care. For those who chose private facilities, they overwhelmingly cite better quality care as the reason they prefer private facilities. The next most common answer is that private facilities have the type of care needed.

Rural citizens are more likely to prefer public institutions than urban citizens are with 62.1 percent of rural citizens citing a preference for public compared to 54.7 percent of urban citizens. Different ethnic groups behave differently as well. A majority of Albanians prefer public institutions, 59.6 percent, to private institutions, 31.8 percent. The same is true across all minorities, Roma, Ashkali, and Egyptians, Bosnians, and Gorani, except for Serbians. Serbians have a strong preference for private facilities with 53.3 percent expressing a preference for private facilities.

Educational attainment is correlated with preferences for private healthcare institutions as higher levels of education translated into a higher preference for private institutions. This reflects the trend that the more educated, and likely wealthier, someone is, the less likely they are to seek out public institutions for healthcare services.

Respondents were asked how often they visited a public or private healthcare institution in the past 12 months. Unfortunately, this question was governed by skip logic—if a respondent



answered that they had never had a general checkup, they were not asked how many times they had visited a healthcare facility in the past 12 months. Thus, the following numbers do not include those who skipped a general health check-up but sought healthcare for other purposes. Of asked, the median number of visits to a public health facility is two in the last year. The median number of visits to a private health care facility is one.

#### 5.6.1 Divide between Public and Private Sector Discussion

In Kosovo, the public and private systems are supposed to function separately and independently. By law, doctors are forbidden to refer patients from the public sector to the private sector. In practice, such referrals happen regularly. It is common for doctors to work in both sectors, at the same time. Salaries from private clinics supplement public income. Every interviewee commented on the practice, with one interviewee remarking, "It's so grave that sometimes someone is a director of one clinic and also [the director] of a private one" (Hoxha 2016). Employment in both sectors creates a conflict of interest and perverse incentives, both ultimately worsening the care that patients receive.

An example brought up multiple times was how the conflict of interest for dually employed doctors may impact equipment availability. Doctors have an incentive to refer patients to their private clinic-- thus they have an incentive to be indifferent to the status of the public facilities. One interviewee suggested that when public equipment is broken, the doctor will refer you to a private clinic, usually his or her own. When asked whether she saw this as something that comes about because so many doctors are working in both a public facility and their own private clinic, Dr. Nimani paused, slowly answering "Yes... Unfortunately, yes." Another interviewee offered a similar example but took it one step further, discussing instances where public hospital equipment is destroyed so the private hospital can benefit (Hoxha 2016).

When profit comes before patients, the consequences are dire and health outcomes are worse. In Kosovo, this may be seen in family planning. Almost 10 percent (9.9 percent) of women responded that they had had an abortion. This rate is far higher than the global average rate of abortion in developing nations (Guttmacher Institute 2016). This finding may reflect reporting bias, however. Contraceptive use is low, with only 19.2 percent of all respondents, and only 12.1 percent of women, reporting contraceptives use. Dr. Nimani, the head of office for UNFPA Kosovo, offered one potential explanation: "... in 99 percent of cases, gynecologists have private clinics so they are not very interested in promoting family planning. That's why we shifted our focus in promoting family planning methods more through family medicine doctors, because they don't have private clinics, they are always family doctors and do not have their private interest in terms of not promoting [contraceptives]". When asked to clarify what she meant by private interest, Dr. Nimani explained that abortions were more lucrative for doctors than prescribing birth control is so thus doctors, especially in private clinics, are incentivized to not educate patients (Nimani 2016).

As the public and private systems continue to coexist, there must be better regulation and enforcement. Currently there is good, and bad, in each system, but patients are ultimately the victims of provider conflicts of interest in both systems.



## 5.7 Conclusion

The patterns of utilization in Kosovo help define and contextualize the levels of access to healthcare and healthcare habits that citizens currently have. The next three sections, Barriers, Quality, and Awareness further explain these patterns, specifically addressing what may be preventing citizens from accessing quality healthcare in Kosovo.

Use of healthcare services is overall still low, especially for primary and preventative care. Further research should focus on what services people are using, in what sector, and at which level. This survey did not differentiate between public and private service providers nor did it ask many questions about specialty care. A better understanding of where services are provided will allow targeted reform that creates tangible results. Another potential area of further research relates to increasing the utilization of preventive services and additional analysis of the causes of underutilization. Further research will also be able to better explain the use of pharmaceuticals without prescription and whether they are being abused or used for legitimate medical purposes.

As shown throughout the section, knowledge is not always what prevents service utilization. The questions soliciting respondent's opinions showed that often they know what *should* be done. Acting upon that however is another issue. As Dr. Syla, the head of the WHO in Kosovo explained, "Well, this is always [how it is] with many other issues. Also many people know that smoking is very harmful but they do not behave with this knowledge. ... The fact that they are at this stage of awareness means that we should work more," (Syla 2016). This offers an optimistic perspective that the barriers addressed in subsequent sections can be overcome with hard work and cooperation between providers, the Ministry of Health, and NGOs. The seeds of change have been planted.

## 6. GENDER

Given that one of the key research questions was to explore the gender gap, one of the biggest surprises of the analysis was the apparent lack of disparities between men and women in their access to healthcare. Many of the indices showed slight differences or no difference in the way the women and men access their healthcare. This could be because the surveys were often conducted with the entire family present so this could have affected the accuracy of these results. The one notable exception to this pattern is found on questions tapping into cultural barriers.

## 6.1 Decision making

Important decisions in the household are still overwhelmingly made by men. A majority of women respond that either their husband or their father has the final say when an important decision is to be made. "Husband" was selected by 46.9 percent of female respondents while "father" was selected by 12.4 percent of female respondents. Just 7.3 percent of women report that they have the final say in an important decision. In contrast, a majority of men respond that they (33.6 percent) or their father (25.6 percent) has the final say.

While men still largely have the final say in questions about healthcare decisions, a patriarchal hierarchy is not quite as apparent. The index includes a question on who decides whether the respondent should go to the doctor. The majority of both men (77.2 percent) and women (62.74 percent) answer that they decide for themselves whether they should go to the doctor. However, the family hierarchy is still clear when looking at the frequency of the next most common



response. For women, the next most common decision maker is their male partner, with 22.8 percent of women saying he makes the decision for her to go to the doctor. For men, the next most common answer is also their (female) partner, but only 6.5 percent of men responded in this way.

A similar question, excluded from the index, is who decides whether children should go to the doctor. In the survey sample, 25.9 percent did not have children. All subsequent responses are only from those with children. Almost half of the female respondents (46.3 percent) report that their husband or male partner decides whether children should go to the doctor. For men, there is a tie with 31.5 percent responding that the decision is theirs and another 31.5 percent responding that their female partner makes the decision.

Finally, respondents were asked whether the decision to use contraceptives was mostly a joint decision, their decision, or their partner's decision. The vast majority of men and women, 79.8 percent of women and 70.7 percent of men, respond that it is a joint decision. However, in situations where it is not a joint decision, the male most often has control. A far higher percentage of men, 20.0 percent, respond that the decision to use contraceptives is theirs. Only 7.0 percent of women say it is their decision. Likewise, a higher percentage of women, 13.2 percent, say it is their partner's choice while only 9.2 percent of men respond similarly.

#### 6.2 Prioritization

When asked who in the family would be prioritized if only one person could be sent for a regular checkup, the respondents overwhelmingly (72.2 percent) said "no one, we are all the same." However, respondents almost always ranked men, male children, and older men more highly than their female counterparts. Men were especially likely to behave in line with this pattern.

#### 6.3 Cultural Barriers Discussion

While limited research on this type of barrier exists in Kosovo, many of our expert interviews confirmed the survey findings while emphasizing how patriarchal and hierarchical structures and traditions in Kosovo may impact citizens' access to healthcare. For example, Mrika Aliu, Executive Director of Action for Mothers and Children shared a story from a Health Resource Center run in partnership with her organization. When women visit one of the Health Resource Centers, women are sometimes asked to complete a questionnaire of basic information. According to Ms. Aliu, when women are asked personal health questions such as the date of their last menstrual cycle, they sometimes respond with statements such as "Well, I don't know because my husband knows" or "I cannot tell you that because I have to ask my husband." Ms. Aliu followed up on these statements by clarifying that, "In Pristina, it might be a bit different, but if you go outside of Pristina, you can still see that influence of men when it comes to decision making about family planning, about delivery mode, about anything related to women's healthcare," (Aliu 2016).

Dr. Skender Syla, Head of the WHO Kosovo Country Office, echoed Ms. Aliu's statements. He also mentioned that cultural barriers depend on several factors that may overlap including living in rural areas, lower levels of education, especially for women, low socioeconomic status and whether or not the woman is employed (Syla 2016).



The Center for Public Policy and the Social Sciences

Ms. Aliu also stated that cultural barriers could arise if women sought care at private rather than public institutions. While women can receive certain services free of charge at public institutions, some women will seek care at private hospitals, in which case "finances become a barrier for a lot of women" as in Kosovar society, men are still seen as the breadwinners and even if women work, they may "have to give that money to men" and may not always be "independent in managing their own finances" (Aliu 2016). In most cases, women do not work so that is when finances merge with cultural norms to become a barrier for them (Aliu 2016). Since cultural norms are deeply rooted in society, their impact is likely pervasive, making it difficult to disentangle cultural barriers from other barriers to accessing healthcare.

## 9. RESIDENCY

Kosovo has seen a rapid shift in the urban-rural divide in the last few decades. More economic opportunities in the cities have lead to the rapid depopulation of the villages, while the capital of Pristina has seen its population increase by tenfold in the last sixty years. Even so, majority of the population—about 62 percent—lives in rural areas. According to the Statistical Agency of Kosovo, rural populations also consume less than urban populations, and they spend differently. An average urban family annually spends about 8,000 euros, about 800 euros more than a rural family. What is interesting is that in rural areas, there is more spending on food and transport, but less on health and education (Kosovo Agency of Statistics 2015). This is reflected in disparities between urban and rural populations in their access to healthcare.

#### 9.1 Financial Barriers

Kosovars from rural regions face slightly higher financial barriers when accessing health care than urban Kosovars do (p = 0.001), and this disparity is mostly driven by rural women who face significantly more financial barriers than urban women do (p = 0.002); in contrast, there is not a statistically significant disparity between rural and urban men (p = 0.122).

When asked if obtaining money for medical care and services was a problem, 45.3 percent of rural women reported it was, while only about 30.4 percent of urban women said the same, resulting in a 15 percentage point difference. For men, there was only a three percentage point difference between rural men (39.7 percent) and urban men (36.2 percent) when asked if getting money for healthcare was a problem.

#### 9.2 Geographic Barriers

Urban citizens face lower geographic barriers than their rural counterparts, on the whole. However, it is important to consider which level of the healthcare system citizens are attempting to access, something not asked about in the survey. Kosovo's healthcare facilities are distributed in a systematic way. There are primary care clinics in every one of the 38 municipalities, a secondary hospital in each of the seven regions, and a tertiary hospital only in the capital city of Pristina. Given this decentralized organization, no Kosovar should have significant geographic barriers in accessing primary care. However, the same cannot be said for more specialized care.

This difference in geographic access was reflected in the different modes of transportation used by respondents to reach the healthcare facility. The plurality of both urban and rural citizens used a personal car—47.6 percent of urban respondents and 64.1 percent of rural respondents. However, the second most popular options diverge significantly. The second most common



choice for urban respondents is travel on foot, which was selected by 37.1 percent of respondents. This sharply contrasts to the number of rural respondents who selected the same option: only 8.3 percent of rural respondents chose walking as their mode of transportation when traveling to a healthcare facility. Instead, the second most common choice for rural respondents, selected by 19 percent of the rural population, was bus or minibus, likely used when personal vehicles were unavailable.

#### 9.3 Cultural Barriers

Rural Kosovars, with a mean score of 14.8, face slightly higher cultural barriers than urban Kosovars who have a mean score of 11.2 (p = 0.000). In an urban context, men and women are not statistically different from each other. However, rural men and rural women are different, with rural women facing higher barriers than rural men.

#### 9.4 Patient-Provider Relationship (PPR)

As with all prior indices, rural and urban Kosovars score differently (p = 0.0277). Quality of PPR is slightly worse for rural Kosovars (53.8) than urban (51.4) Kosovars. Across both rural and urban regions, women maintain a higher quality relationship with their healthcare providers than do their male respondents. Urban men, with a mean of 56.7, score significantly worse on PPR quality than do urban women, with a mean of 46.9 (p=0.000). Similarly, rural men, with an average PPR score of 55.8, have worse quality relationships with their providers than rural women, with a score of 51.9, do (p=0.007).

When comparing among genders, rural women have worse quality of relationship with healthcare workers than urban women do. However, there is no significant difference between rural and urban men's scores.

#### 9.5 Perceived Personnel Quality

There is no significant difference in how rural and urban respondents perceive the quality of their healthcare providers. Both groups scored about 23 on the PPQ index. However, when analyzed by both gender and residency, there are significant differences between groups. Urban men respond that their healthcare providers are of a relatively lower quality than do urban women. The same difference in perception does not exist for rural men as compared to rural women. Urban men also perceive their healthcare providers to be of a slightly lower quality when compared to rural men. However, the same is not true of their female counterparts.

#### 9.6 Awareness of Rights

Urban Kosovars, scoring 34.8 on awareness, are significantly more aware of their rights than are rural Kosovars, with a score of 42.5, (p=0.000).

#### 9.7 Conclusion

Each index score consistently demonstrated that residents of rural regions have more limited access to the healthcare system than do their urban counterparts. This shows that residency is a significant factor when determining if a Kosovar will have access to healthcare. Improving access in rural regions of the country, across of the dimensions explored here, will serve well the entire population of Kosovo. Likewise, encouraging greater utilization of the primary healthcare model may alleviate some of the barriers identified by the Kosovar respondents in this analysis.



Primary care centers are strategically located to minimize geographic barriers and may help prevent more costly health care in cases where citizens wait until the later stages of an illness or disease to seek treatment. By increasing usage of wellness checkups for all at the primary care level, cultural stigma and the related cultural barriers may be reduced.

### **10. ETHNICITY**

Kosovo's population features a large Albanian majority and several ethnic minority groups such as Bosnian, Serbian, Turkish, Ashkali, Egyptian, Gorani, and Roma peoples. Accordingly, each of the eight indices described previously were analyzed by ethnicity. As explained in Section 3.3. Survey Analysis Methods, each index was created using all the questions that related to the topic. The questions asked to only women were excluded since data existed for only female respondents. (See annex 2 for full list of questions).

Each Index was then used to calculate scores for different cohorts, stratified by gender and ethnicity. As mentioned previously, the *higher* the score, the *worse* it is. Higher scores represent lower utilization of healthcare services. The possible scores range from 0—zero barriers, optimal quality, and full awareness—to 100—high barriers, very low quality, and minimal awareness.

#### 10.1 Financial Barriers

Ethnicity is highly correlated with financial access. Albanians face an average Financial Barriers score of 15.7. Once again, since the majority of the survey respondents were Albanian, the status of all the other ethnic groups is compared Albanians.

Serbians have an average score of 9.52 and thus face lower financial barriers than Albanians (p = 0.004). However, not all Serbians are better off than Albanians. Serbians who live in Mitrovica are significantly better off than Serbians living anywhere else in Kosovo. Serbians who live in Mitrovica average an extremely low financial barriers score of 0.9. For Serbians living anywhere else in Kosovo, the average financial barrier score is 22.5.

Bosnians, Roma/Ashkali/Egyptians, and Gorani all face significantly higher financial barriers than Albanians do (p = 0.000 for all). The magnitude of the discrepancies is large; the financial barrier index score of non-Serbian, non-Turkish ethnic minorities is at least twice that of Albanians.



Ethnicities	Women	Men	Both Genders
Albanian	16.24	15.18	15.73
	(1.018)	(1.009)	(0.717)
Serbian	9.167	9.830	9.521
	(1.789)	(1.774)	(1.261)
Roma, Ashkali, Egyptian	40.12	50.52	44.79
	(3.745)	(4.006)	(2.806)
Bosnian	48.61	24.07	36.34
	(4.918)	(2.925)	(3.312)
Gorani	54.81	53.57	54.17
	(5.699)	(6.117)	(4.194)
Turkish	21.59	6.731	16.07
	(4.490)	(2.924)	(3.258)

Table 4: Financial Barriers Mean Scores Stratified by Ethnicity and Gender (with Standard<br/>Errors in Parentheses)

When looking within ethnic groups, Bosnians and Turkish women face significantly greater financial barriers than their male counterparts do. Bosnian women face significantly higher barriers with a mean Financial Barriers score of 48.6 compared to Bosnian men's 24.1 (p < 0.001). Likewise, Turkish women score 21.6 to Turkish men's 6.73 (p = 0.028).

The score differences between genders of the same ethnicity create a different pattern of financial barrier scores among men than among women. Bosnian men with a mean score of 24.1, are much closer in mean score to Albanian men, 15.2 and no longer statistically different (p = 0.382). Only Roma, Ashkali, and Egyptian men, with a score of 50.5, and Gorani men, with a score of 53.6, are significantly different from Albanian men (p < 0.001 for both).

#### 10.2 Geographic barriers

Albanian respondents score a mean of 38.3 on the Geographic Barriers index. Overall, Serbians (30.6) face the lowest geographic barriers (p < 0.001) While statistically different from Serbians, Albanians are not much worse off, scoring about 8 points higher. Bosnians and Turks score similarly to how Albanians score. Roma, Ashkali, and Egyptians are worse off than Albanians with a score of 48.8 (p = 0.002). However, Gorani are significantly worse off than all other groups with a score of 83.3 (p < 0.001). Among the ethnic groups, Gorani live in the most rural areas of Kosovo, which likely explains why they score the worst in terms of geographic access.

When more closely analyzed, Serbian women (36.6) face significantly higher geographic barriers than Serbian men (25.2) (p = .001). While Serbian women still score the lowest among females, the gap between Albanian women and Serbian women is not significant.

It is possible that mode of transportation has an impact on the disparities in geographic access between ethnicities as transportation patterns differ widely among the ethnic groups in Kosovo. A majority of the Roma, Ashkali, Egyptian population (50.8 percent) and the majority of the Bosnian population (68.2 percent) walked the last time that they visited the doctor and less than fifteen percent used a personal car. In contrast, over 60 percent of the Albanian respondents used



a personal car the last time they went to the doctor, and less than 20 percent walked. Among Goranis, the most geographically disadvantaged group, none reported using a personal car. Two-thirds said they took a taxi, and 22 percent walked.

 Table 5: Geographic Barriers Mean Scores Stratified by Ethnicity and Gender (with Standard Errors in Parentheses)

Ethnicities	Women	Men	Both Genders
Albanian	39.17	38.31	38.76
	(1.066)	(1.099)	(0.765)
Serbian	36.59	25.16	30.58
	(2.764)	(1.802)	(1.668)
Roma, Ashkali, Egyptian	49.39	48.02	48.77
	(4.151)	(4.740)	(3.123)
Bosnian	40.48	32.10	36.36
	(5.356)	(4.362)	(3.512)
Gorani	84.52	82.05	83.33
	(6.182)	(7.362)	(4.783)
Turkish	37.12	36.90	37.04
	(4.665)	(5.880)	(3.653)

## 10.3 Cultural Barriers

The cultural barriers faced by citizens are highly correlated with ethnicity (p = 0.000). Albanians, the benchmark group, have a mean of 13.1. The Serbian population has the overall lowest mean, a score of 8.4, (p = 0.002). Albanians score the second lowest with a mean score of 13.1 as previously mentioned. Roma, Ashkali, and Egyptians score a mean of 13.7 while Bosnians score a 20.4, Turkish score a 21.0 and Gorani with a 47.4, score the worst. Bosnians, Turks, and Gorani all face significantly higher cultural barriers than Albanians do (p = 0.016, p = 0.048, p < 0.001 respectively). Among the ethnic groups, the Gorani are considered the most culturally conservative which may explain why their scores are much higher than those of the other ethnic groups.

Within ethnic groups, gender continues to play a role in the cultural barriers that one faces. Albanian women face statistically higher cultural barriers than Albanian men do (p=0.028). Serbian women also face statistically higher barriers than Serbian men (p = 0.042). Bosnian men and women have the most significant difference in scores with Bosnian women scoring a 28.4 to Bosnian men's 11.7 (p = 0.008). Among Gorani, Turkish, and Roma, Ashkali, and Egyptians, there is no statistically significant difference between men and women.

**Both Genders** 

13.07

(0.511)

8.36

(0.912)

13.66

(1.567)

20.38

(3.177)

47.44

(6.514)

20.96

(3.640)

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Table 6: Cultural	<b>Barriers</b>	Scores	<b>Stratified</b>	bv	Ethnicity and	Gender
				- 2		

### 10.4 Patient-Provider Relationship (PPR)

Gorani

Turkish

When the data are stratified by ethnicity, there are two main clusters, one around a score of approximately 50 and one around a score of approximately 65. Respondents in the lower cluster, who score better on their patient-provider relationship, are composed of Albanians, Turks, and Roma, Ashkali, and Egyptians who score 52.3, 51.8, and 47.0 respectively. Neither group in this cluster is statistically different from Albanians. Respondents in the higher cluster, who score worse on patient-provider relationship, are composed of Serbians, Bosnians, and Gorani who score 59.4, 69.4, and 64.3 respectively. All are statistically different from Albanians (p = 0.0000, p = 0.0000, p = 0.036).

55.80

(8.856)

22.32

(5.012)

32.81

(6.231)

18.75

(4.954)

When gender differences are examined within ethnic strata, women and men tend to behave differently. For Albanian and Roma, Ashkali, and Egyptian women, the overall trend of women reporting better patient provider relationships than their male counterparts holds. Albanian men score 55.9 compared to Albanian women's score of 49.1 (p=0.000). Roma, Ashkali, and Egyptian men score 62.1 while their female counterparts score 43.2; this 18.9 point gap between Roma, Ashkali, and Egyptian men and women is the largest gap between any of the ethnic stratifications (p=0.000).

In contrast, for Serbians and Gorani, the trend is reversed. Serbian men (56.5) have better scores on PPR quality than do Serbian women (62.3; p=0.046) and Gorani men, score 55.8 to Gorani women's 70.2 (p=0.030). The survey findings did not show a significant difference between Bosnian men and Bosnian women.



Ethnicities	Women	Men	Both Genders
Albanian	49.07	55.89	52.34
	(0.953)	(0.840)	(0.650)
Serbian	62.33	56.54	59.41
	(2.243)	(1.793)	(1.448)
Roma, Ashkali, Egyptian	43.20	62.12	51.75
	(2.406)	(2.427)	(2.012)
Bosnian	70.99	67.84	69.44
	(2.403)	(4.016)	(2.328)
Gorani	70.24	55.83	64.24
	(3.410)	(5.193)	(3.276)
Turkish	43.69	52.56	46.98
	(4.796)	(3.914)	(3.423)

 Table 7: Patient-Provider Relationship Mean Scores Stratified by Ethnicity and Gender (with Standard Errors in Parentheses)

### 10.5 Perceived Healthcare Personnel Quality

Serbian, Bosnian, and Gorani people perceive healthcare personnel quality differently than Albanians do. Albanians perceive higher personnel quality than the other ethnic groups, scoring a 22.6 compared to Serbians at 31.7, Bosnians at 32.0, and Goranis at 34.7. Roma/Ashkali/Egyptian and Turkish people are not statistically different from Albanians.

When comparing by gender and ethnicity, Serbian women score a 37.3 while Serbian men score a 27.2 Therefore, Serbian women report significantly worse personnel quality than Serbian men do (p < 0.001). The Roma, Ashkali, and Egyptian women (17.4) rate their healthcare providers more favorably than their male counterparts (25.8) do (p = 0.001).

Table 8: Perceived Healthcare Personnel Quality Mean Scores Stratified by Ethnicity and
Gender (with Standard Errors in Parentheses)

Ethnicities	Women	Men	Both Genders
Albanian	22.33	22.93	22.63
	(0.710)	(0.662)	(0.486)
Serbian	37.34	27.22	31.73
	(1.823)	(1.295)	(1.149)
Roma, Ashkali, Egyptian	17.35	25.89	21.17
	(1.166)	(2.238)	(1.269)
Bosnian	32.45	31.60	32.02
	(3.264)	(1.752)	(1.833)
Gorani	36.16	32.03	34.66
	(2.041)	(4.812)	(2.219)
Turkish	25.15	14.32	21.21
	(2.915)	(1.707)	(2.155)



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## 10.6 Availability of Healthcare Services

The majority of ethnic groups cluster around an availability score of about 30. There is no statistical difference between Albanians, Serbians, Roma, Ashkali, and Egyptians, Bosnians, or Turks, who score 39.1, 41.1, 33.8, 38.5, and 32.8 respectively. The Gorani ethnic group is the sole outlier. They score significantly worse, with a mean of 56.3, than any other ethnic group (Albanian: p = 0.005, Serbian: p = 0.036, R/A/E: p < 0.001, Bosnian: p = 0.024, Gorani: p = 0.002).

Within the index, this disparity is partly driven by the Gorani population's increased concern for the availability of emergency care. About 32 percent of Goranis responded that they do not think that they would be able to get care easily if they had an emergency. In contrast, only about seven percent of Albanians, ten percent of Serbians, one percent of Roma/Ashkali/Egyptian, 12 percent of Bosnians, and three percent of Turks shared this concern.

The disparity in scores is also likely driven by the Gorani population's concern that the equipment they need may not be available. About 80 percent of the Gorani population reported this as a concern. While the Gorani were the most likely to be worried that the equipment they needed was not available, this concern was shared widely among the population as a whole. About 50 percent of Albanians, 40 percent of Serbians, 40 percent of the Roma, Ashkali, and Egyptians, 60 percent of Bosnians, and 45 percent of Turks reported the same concern that equipment they need may not be available.

On the whole, respondents agreed that waiting times are long. A plurality of the respondents, 45.3 percent, either agreed or strongly agreed that duration times for seeing a doctor are longer. Another 28.1 percent neither agreed nor disagreed while only 24.7 percent of people disagreed or strongly disagreed.

#### 10.7 Awareness of Patient Rights

When analyzed by ethnicity, most ethnicities' awareness aligns with Albanian awareness. Albanians score an average of 38.6 for awareness. Serbians with a score of 45.3, Turkish with a score of 45.6, and Roma, Ashkali, and Egyptians with a score of 33.6 are slightly different from Albanians but not statistically so. In contrast, Bosnians and Goranis, are significantly less aware of their rights (p < 0.001 for both) Bosnians scored an average of 62.0. Gorani were the least knowledgeable about their rights with a score of 73.2 (p < 0.001).

However, within ethnicity there are stark gender-driven disparities. Among Serbians, women are far less aware of their rights than men are. Their scores, 59.8 for Serbian women and 32.4 for Serbian men, differ by almost 30 points (p < 0.001). For Bosnians, the opposite is true, with Bosnian women far more knowledgeable about their rights than Bosnian men. Bosnian women score 52.4 on Awareness while Bosnian men score 71.9 (p = 0.013). When these gender discrepancies are taken into account, the women rank differently than the overall population did when split by ethnicity. Serbian women and Gorani women are the only groups significantly different from Albanian women (p < 0.001, p = 0.037 respectively).



## 10.8 Conclusion

The overall trend in indices scores when analyzed by ethnicity indicates that minority ethnic groups have more difficulty accessing care than the majority Albanian population. In particular, the Bosnians and Gorani score poorly on nearly all of the indices examined in this report.

The sole exception to the generally lower-performing minority ethnic groups is the Serbian population in Kosovo. Serbians tend to score approximately as well or better than the Albanians on each of the indices. One reason for this may be the parallel healthcare system that exists in Mitrovice, the northernmost region in Kosovo where a large portion of the nation's Serbian population resides. The Serbian government funds this parallel system, thereby allowing Mitrovica Serbs to have better access to medical care. Accordingly, the ethnic conflicts of the past continue to play a role with regards to accessing healthcare for Kosovo's population.

#### **11. KNOWLEDGE AND RIGHTS**

Patients' rights are intended to ensure the ethical treatment of all patients by codifying what patients are entitled to and guaranteed under the law. The relationship between doctor and patient relies upon the patient's trust that the doctor is knowledgeable and an expert in health. The relationship has a natural element of hierarchy that leaves the patient in a more vulnerable position. Therefore, understanding how aware patients are of their rights, how well respondents understand the healthcare system, and whether patients are able to assert their rights, are all important to understanding how healthcare is delivered in practice.

#### 11.1 Knowledge Barriers

A lack of knowledge about how to obtain healthcare services may prevent people from seeking healthcare. Thus, lack of information can also be a barrier to receiving care. In the survey, the only questions asked about potential information barriers were related to reproductive health services. Despite the limited scope of the questions, the data strongly supports the existence of barriers created by a lack of knowledge about the healthcare system or services.

The majority of survey respondents, 61.6 percent, indicated that they did not feel they had adequate access to sexual and reproductive healthcare services. The most common reason that people did not feel they had access, cited by 65.5 percent of respondents, was that people did not know where to access these services. This response was consistent with results of a later survey question wherein 76.3 percent of respondents indicated that they did not know where to get family planning information and services. While women were more likely to know where to go (27.9 percent of women compared to 19.1 percent of men), neither group performed well.

This confusion was echoed when respondents were asked if family medicine centers provided gynecological and reproductive health services or if such services were only available from gynecologists. Family medicine centers do provide such services as family medicine doctors are capable of providing birth control and most reproductive health services. Furthermore, some family medicine centers have gynecologists in residence. Respondents were almost equally split between the three options: 35.3 percent said family medicine centers could provide gynecological and reproductive health services, 34.0 percent said such services could be provided by only gynecologists, and 30.7 percent of people said they did not know. Overall,



knowledge about reproductive health services is very low and may prevent people from seeking such services.

## 11.2 Patient Rights Abuses

In addition to their awareness of rights, respondents were also asked about specific instances of rights abuses. Questions addressed discrimination by gender (Q1), misdiagnosis (Q2), deception (Q3), lack of consent (Q4), breach of confidentiality (Q5), and sexual misconduct (Q6). Each positive response reflects the violation of a patient's rights. The responses revealed a number of concerning findings.

While the following percentages are low, it is highly unlikely that the respondents are the only Kosovars who have grappled with such abuses of their rights.

#### Table 9: Questions on Patient Rights Abuses

Question:	Response:
1. Strongly agree, agree, neither, disagree or strongly disagree? In my lifetime, I feel I have been discriminated against by a healthcare worker because of my gender.* (Asked only to women)	<ul><li>1.9 percent agrees or strongly agrees</li><li>6.8 percent neither agrees nor disagrees.</li></ul>
2. The doctor or gynecologist diagnosed you with cancer without running any tests.*	Yes: 1.04 percent
3. The doctor told you that it was essential for you to have surgery, but you later found out from other doctors that you did not need surgery.*	Yes: 3.75 percent
4. Doctors took your blood to do an HIV/AIDS test without your consent.*	Yes: 0.72 percent
5. A healthcare worker spoke about your disease or treatment in front of other patients or to other patients.*	Yes: 3.2 percent
6. The doctor or nurse touched you in an inappropriate sexual way that did not seem necessary as part of the procedure.*	Yes: 86.0 percent

When citizens were asked if they ever felt discriminated against due to their gender, 91.3 percent of the respondents either disagreed or strongly disagreed. The 1.9 percent of survey respondents reporting discrimination against them because of their gender, when extrapolated to the general



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population, may represent as many as 34,200 cases of gender discrimination across the Kosovar population.

Blatant misdiagnosis remains, as shown in questions 2 and 3. One percent of survey respondents reported that their doctor diagnosed them with cancer without running any tests. About four percent of the population report that their doctors recommended unnecessary surgery as well. This happened to approximately twice as many women as it did to men. Finally, women were more likely men report that their healthcare provider touched them in an inappropriate way.

While these percentages seem relatively small, the fact that any segment of the population suffered these abuses is noteworthy. Anecdotal evidence of such abuses is widespread, indicating that the survey may have failed to capture more extensive rates of provider abuse of patient rights. At minimum, the statistical evidence from this national household survey is sufficient to raise concerns and motivate further research.

#### 11.3 Confidentiality

The patient's right to confidentiality is defined as the right of the patient for a doctor, nurse, pharmacist, or other healthcare personnel to keep information about the patient or the patient's health confidential. The survey and interviews showed that this right remains not known fully known by patients nor respected by healthcare personnel.

When respondents were asked whether they have the right for doctors to keep information about them and their health confidential, 21.5 percent of the respondents responded that they did not have a right to confidentiality. Women are 5.1 percentage points more likely than men to know that they have a right to confidentiality.

Citizens of urban regions are also more likely to know their right to confidentiality—83.9 percent of urban respondents answered affirmatively, compared to 80.0 percent of rural respondents. Rural males are the least knowledgeable on this topic, with only 72.3 percent of them responding that they have a right to confidentiality.

When the data are stratified by ethnicity, strong discrepancies in knowledge of the right to confidentiality are evident. As earlier stated, the average percentage of "yes" responses across the population is 78.47. Albanians have slightly better knowledge than the national average, with 80.1 percent of Albanians affirming their right to confidentiality. Every minority, other than Turks, scored lower than Albanians on knowledge of their rights to confidentiality. Serbians and Gorani had especially poor knowledge of the right to confidentiality with only 50.3 and 53.6 percent of respondents respectively affirming this right.

As was true for the rights earlier discussed, education was positively associated with knowledge of the right to confidentiality. Those with the highest level education were most likely to respond correctly, with 84.8 percent saying they had a right to confidentiality. The least educated were over 10 percentage points less likely to respond correctly. Likewise, the younger population was most likely to respond that they had a right to confidentiality. The youngest survey respondents, aged 16-24, responded yes 84.7 percent of the time while the oldest respondents, 65 and older, responded yes only 71.6 percent of the time.

Patient knowledge is only one side of the equation as providers must also respect the patient's right to confidentiality. This was tested twice in the survey and also discussed in interviews.



When asked if the doctor keeps their personal information confidential and does not share it with anyone, 66.2 percent of the patients agreed or strongly agreed that their information was kept confidential. Accordingly, 34.8 percent of the population either disagrees or does not know if their information is confidential.

Informant interviews further contextualized the data, with interview subjects concluding that doctor-patient confidentiality is neither widely understood nor respected. Provider violation of patient confidentiality focused around two themes: lack of understanding and improper record keeping. The biggest barrier among providers mirrors the barrier among the general population—as one interviewee phrased it "You know, this is our tradition and they [the provider] might speak to another nurse [while other people are in the room]. Confidentiality, as a concept, is not very much promoted or respected" (Syla 2016). Since doctors do not practice confidentiality, patients are "Either … not aware or they think it is normal that the information should be given to other[s] or be revealed" (Nimani 2016). Without providers making an effort to maintain confidentiality, less thought is given to private and secure record keeping, another side of keeping patient information confidential. When patient data, via patient health cards or intake forms, are collected, they are not always secured. According to some interviews, it may be left in an open room where anyone can access it (Aliu 2016).

Another issue that strongly impacts confidentiality, but is not fully controlled by either the patient or by the provider, is the role that family—spouses, parents or extended family—may play in the healthcare process. It is common for family to be involved in the patient's healthcare appointment and for the patient to have little privacy (Syla 2016).

A fear of breached confidentiality may be a factor dissuading individuals from seeking care, especially in a country the size of Kosovo where as one interviewee puts it "Everybody knows somehow someone, directly or indirectly. So on one hand, it is very hard to keep the confidentiality... There are some reservations in terms of ... women, especially young women, coming especially from other cities to Pristina because they know the city is very small everyone knows or if you enter the hospital everyone will somehow find out that you went to gynecologist for example ... Unfortunately very often the healthcare providers are speaking among themselves with the names and that is a big problem." (Nimani 2016). Until confidentiality becomes a priority, demanded by patients and prioritized by providers, it is unlikely to naturally change.

## **12. CONCLUSION**

As healthcare in Kosovo continues to develop, the findings of this report provide quantitative support for much of what has been known only anecdotally thus far. Progress has been made in Kosovo, yet much remains to be done. Ethnic minorities and rural residents in particular have consistently lower access to quality healthcare. The current structures of the healthcare system create mixed motives for doctors, with an incentive to privatize their practice perhaps delivering better quality care but also making that care less accessible for many.

## 12.1 Areas of Further Inquiry

This report offers a first cut at a rich data set with great potential. There are a few areas that we feel particularly merit further investigation:

- The impact of socioeconomic status on access to and utilization of healthcare
- Further investigation of non-prescription obtainment of prescription drugs



- Deeper investigation of what services are sought at each level of the healthcare system

In this data set, socioeconomic data are not internally consistent. Therefore, it was not possible to analyze any findings by socioeconomic level. Socioeconomics are likely to have a strong impact on healthcare access and actions. Thus, it would be interesting to know what that impact is.

Further investigation into the non-prescription obtainment of prescription drugs is vital to figure out what must be done to address it. Currently, the data points to the problem but cannot explain it. Understanding what drugs are being obtained, under whose recommendation, and why is critical. Illegally obtaining antibiotics based on a self diagnosis is a very different problem than illegally obtaining narcotics for an addiction.

A shortcoming of the current data is the lack of delineation between each level of the public and private healthcare system. Some questions contain an explanation of where that service would be obtained, for example, checkups at the primary care level, but often it is not clear. Understanding how often people enter at the secondary or tertiary care level, despite current laws against it is important.

#### 12.2 Policy Steps

Based on research findings, a few areas are particularly important for policy intervention. Ethnicity was consistently correlated with differences in utilization of and access to health care. Therefore, incorporating minorities more fully into the healthcare system is important. This may include shifting the national conversation on which minorities are most disadvantaged; in our data set, it was Bosnians and Gorani who were most likely to have negative outcomes. Traditionally, people speak of the Roma, Ashkali, and Egyptian populations as the most marginalized groups in society but our data did not bear this out.

Residency also served as an indicator of access to healthcare. Rural populations consistently reported facing more challenges in accessing and utilizing the healthcare system. The interplay of factors present in rural regions, such as more traditional cultural norms, lower educational achievement, minority status, and lower incomes for example, makes it difficult to target what must be done. However, one solution to this is to begin more house visits to rural residents bringing healthcare to them rather than requiring them to travel. A second important step will be the national healthcare system providing expanded financial access.

A second area for intervention is in use of the primary care system for preventative and entry level care. The low levels of general health checkups underscore the poor utilization of preventive health services. Knowledge questions show that people remain confused about what services can be obtained at which level. Kosovo health policy has firmly enshrined the primary care model; however, neither the providers nor the population has fully embraced it. Until these groups are brought into alignment, healthcare access and provision will remain suboptimal.

One of the most difficult, but most important, areas to tackle is the public/private healthcare divide. As discussed above, the dual system creates perverse incentives for providers. As the government continues to reform the healthcare sector, the public/private system continues to pose problems. Further research is necessary to resolve the issues that have resulted in this dual system of healthcare delivery.



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#### APPENDICES

Appendix 1. Survey Methodology

The annex provides further details regarding the research methodology. In order to respond to the research questions outlined in the introduction, the research involved mixed methods, involving: 1) a review of the legal framework to identify remaining gaps in the legal outface and its implementation; 2) a national household survey with 1,309 citizens to understand their experience in accessing the healthcare system; 3) interviews with healthcare providers, policymakers, and NGO leaders. The following sections provide further details.

**The Survey:** Quantitative data were gathered through a household survey of 1,309 individuals, carried out throughout Kosovo.

**Questionnaire:** The survey instrument contained 195 primarily closed-ended questions. Most surveys, which were carried out via face-to-face interviews, lasted approximately 40 minutes.

**Piloting:** The survey was piloted in advance of the actual survey in rural and urban areas surrounding Pristina. This enabled the research team to see if the survey instrument was properly designed and whether citizens understood it. Slight modifications were made based on the pilot.

**Surveyors:** Surveyors were selected based on their educational background, communication skills, professional skills, ethics and their willingness to be part of the research. KWN involved surveyors from minority ethnic groups and who spoke multiple languages for surveying diverse groups. Surveyors involved a balance of women and men. Women interviewed women, and men interviewed men considering the sensitivity of the topic. A list of surveyors is in the acknowledgements.

**Training of Surveyors:** A two-day mandatory training was organized for all surveyors. The training ensured that surveyors were familiar with the research mandate, survey instrument, sampling method, control procedures, and logistics. Another important part of the training was the importance of safeguarding respondents' security and emotional well-being, as well as how to handle various situations that could arise during surveying, such as family members interfering. Moreover, the training focused on the ethics of surveyors considering the sensitive topic with which the research deals.

**Research Sample:** KWN surveyed 1,309 citizens of all ethnic groups, ages 18 and older. KWN selected a random sample of the Kosovo population. The sample was drawn from rural and urban areas, involving randomly selected sampling points in 132 settlements in 36 municipalities. The sample also is representative of all ethnic groups in Kosovo as the selection was done using the Multistage Random Sampling Method. Stratification of respondents was based on ethnicity and region. Using census data from the Agency for Statistics in Kosovo (ASK) from April 2011, 319 sampling quotas were produced. The sample universe was divided into three sub-sets: Albanian sub-set, Serb sub-set, and "other ethnicities" sub-set. Then the sample was stratified by region and residential profile (urban or rural) of each region.

**Ethnicity:** The sample included Albanians, Kosovo Serbs and Kosovo non-Serb minorities (Turkish, Bosnian, Gorani, Roma, Ashkali, and Egyptian). Stratification principles were the



same for all three ethnic groupings. In order to ensure that there were enough members of certain sub-groups of the population for reliable estimates for that group, KWN oversampled Kosovo Serbs and other minorities. The data was later weighted by ethnicity during the analysis to account for this oversampling.

**Geographic Representation:** The research team conducted surveying in all regions and almost all municipalities of the Republic of Kosovo.

Age and Gender: Respondents from each household, age 18 or above, were selected randomly according to the nearest birthday technique. This naturally results in a proportional distribution of women and men similar to that of the population. According to the ASK (Kosovo Agency of Statistics), 50.3 percent of the population is male and 49.7 percent is female.

**Surveyor Training:** The survey was conducted in June of 2016. Of the 1,309 individuals surveyed, all participants completed the entire interview and survey. As researchers were trained in modern psychological practices, they were asked to observe respondents across several measures, including honesty, comprehension, and comfort. These are important in estimating error and understanding the degree to which respondents answered honestly to such sensitive topics.

**Control:** Two persons not involved in the surveying carried out controls of surveyors. This included random field visits to ensure they were following the sampling methodology and checking the quality of surveyors' work. They also carried out check-backs on a randomly selected sample of 10 percent of completed surveys to ensure accuracy.

**Data collection:** Data was collected on Samsung tablets or smartphones, using KoboToolbox Data Collection software.

**Data analysis:** The Dartmouth College team analyzed the survey data using Stata software. In this report, the data have been weighted by ethnicity in order to address the over-sampling of minority groups (necessary for drawing any existing statistically significant conclusions based on ethnicity). The data has been weighted based on the 2011 national census data, adding an additional 40,000 Serbs believed to be living in northern Kosovo who boycotted the 2011 census, resulting in the following percentages: Albanians 92 percent, Serbs four percent and other ethnic groups four percent.

**Statistical Analysis:** This report utilizes a 0.05 level of significance. Correlations between strata (gender, residency, ethnicity, region, age, and education) and the dimension or aggregate indices were assessed using one-way Analysis of Variance (ANOVA tests). Except for comparisons of scores between regions, significant differences between various sub-groups in the survey sample were assessed using the Šídák multiple comparisons test. For comparisons of scores between regions, mean index scores of a particular region was compared to the mean index scores of the remaining six regions combined using t-tests. Each table features means scores for each subgroup and the standard error in parentheses.

**Index Scoring:** As explained under the Introduction, this report contained indices for each key question. Every question within the index was coded on a 0 to 1 scale, where 0 corresponds with the answer that reflects no impediment to accessing quality healthcare and a 1 corresponds with



the answer that reflects the greatest barrier to accessing quality healthcare. Each index represents the sum of all the questions within it. Each index was then scaled to range from 0 to 100.

## **Report Quality Control and Peer Review**

A diverse team members with differing areas of expertise contributed to quality control as the report was reviewed carefully for accuracy by all team members. The research team circulated the final draft report to members of the Advisory Group, as well as some key respondents for review and quality control. Revisions were made based on their input prior to publishing.

Appendix 2. Index Question Methodology

\*The starred questions were considered in constructing the index, but were not ultimately included due to lack of statistical fit (i.e. lack of variation in responses, too many missing responses because a segment of the population was not asked the question or chose not to answer, etc.). However, the analysis of a selection of these questions is presented in the sections below.

Have you ever visited the doctor for a general health check-up?	Have you ever had a laboratory analysis?
Approximately in which year was the last time that you visited a doctor for a general checkup?*	Have you ever been treatment for a sudden illness?
Have you ever had a regular medical check- up?	Have you ever had cervical cancer screening?*
Have you ever visited the dentist?	Have you ever had a breast cancer screening?*
Have you ever received medication from a pharmacy WITHOUT a prescription?*	Have you ever had a colon cancer screening?
Have you ever received medication from a pharmacy WITH a prescription?	Have you received had a mammogram in the last 3 years?*
Have you ever visited the gynecologist / urologist?	Have you received a pap smear in the last three years?*

Annex Table 1: Questions Used to Construct Service Utilization Dimension Index



Have you ever been treated for a chronic illness?*	A colonoscopy is a test that allows your doctor to look at the inner lining of your large intestine (rectum and colon). He or she uses a thin, flexible tube. A colonoscopy helps find ulcers, colon polyps, tumors, etc. Have you ever received a colonoscopy?
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What was the main reason for not consulting a doctor?	Is getting money needed for medicine a big, little, or no problem?
Is getting money needed for medical care and services a big, little, or no problem?	What are the reasons why you do not feel that you have access to reproductive healthcare? [Recoded for answer choice "It's too expensive"]
Do you have private health insurance?*	

Annex Table 3: Question	s Used to Construct the	e Geographic Barriers Dimension Index
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Approximately how long did it take you to get to the facility (door to door)?	What are the reasons why you do not feel that you have access to reproductive healthcare? [It's too far away]*
Is distance to the facility a big, little, or no problem?	The last time you went to a health facility how did you get to that facility?*
Is transportation a big, little, or no problem?	



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Is getting permission to go for medical advice or treatment a big, little, or no problem?	Who decides whether you should go to the doctor?
Is not wanting to go alone a big, little, or no problem?	What are the reasons why you do not feel that you have access to reproductive? [Family will not allow or Unacceptable for me to have these types of services]
The last time you went to a health facility did you need to ask permission from relatives in order to go?*	Who decides whether children should go to the doctor?*
Annex Table 5: Questions Used to Construct	t Patient-Provider Relationship Dimension Index
I feel very comfortable being examined by my physician. [Strongly agree, agree, neither, disagree or strongly disagree]	Has a doctor or nurse ever explained to you how the different forms of birth control work?
In my last visit, the doctor explained things to me clearly in words that I could understand. [Strongly agree, agree, neither, disagree or strongly disagree]	Did your healthcare worker tell you about multiple options for family planning?
In my last visit, I feel the doctor spent adequate time addressing my concerns. [Strongly agree, agree, neither, disagree or strongly disagree]	Did the health worker tell you about the potential effects, side effects or problems you might have with different family planning methods?
During medical visits I am always allowed to say everything I think is important and to ask questions. [Strongly agree, agree, neither, disagree or strongly disagree]	Do you feel comfortable talking about sexually transmitted diseases and HIV/AIDS with your physician?

Annex Table 4.	<b>Ouestions</b>	Used to	Construct	Cultural	Barriers	Dimension	Index
	2	0.000000	0011011 1101	0	200000	2	



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## Annex Table 6: Questions Used to Construct Perceived Personnel Quality Dimension Index

	I feel doctors respect me and treat me well. [Strongly agree, agree, neither, disagree or strongly disagree.]
My doctors keep my personal information confidential; they don't share it with anyone. [Strongly agree, agree, neither, disagree or strongly disagree.]	My doctors are very competent and well trained. [Strongly agree, agree, neither, disagree or strongly disagree.]
My doctor provides complete and accurate information about treatments and medication. [Strongly agree, agree, neither, disagree or strongly disagree.]	When I received medical care, I had full privacy (no one came in and out of the room except the doctor/nurse). [Strongly agree, agree, neither, disagree or strongly disagree.]
A healthcare worker made a mistake with your diagnosis. [Strongly agree, agree, neither, disagree or strongly disagree.]	The doctor or nurse made an inappropriate or offensive comment to you when you were seeking or receiving care.

Annex	Table 7:	Questions	Used to	Construct	Availability	Index
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Is it a big, little, or no concern that the medicine you need may not be available?	Is it a big, little, or no concern that there may be no equipment available that you need?
	I usually wait for a long time when I visit the doctor. [Strongly agree, agree, neither, disagree or strongly disagree.]



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How much do you think you know about your legal rights to health services?	Do you have a legal right to health insurance?
Do you know how to file a complaint if you are dissatisfied with the quality of medical care that you receive?	



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