



“PATIENTS’ VOICE PROJECT”

Needs Analysis Research Report



December 2016



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A- EXECUTIVE SUMMARY

The report contains findings of the survey that took place in October 2016, along with 3 focus groups that took place in November and December 2016. In the main section, the outstanding topics are discussed. The annexes contain the graphics based on the survey results as well as focus group notes.

Based on the findings from the survey and the focus groups, the following results have emerged:

- There is lack of awareness among the members of the community regarding patients' rights
- When the rights of a patient is violated, members of the public are not aware of the existing mechanisms, if there any, that allow them to file their complaints
- If a complaint is filed, the results are usually not satisfactory
- Patients have a tendency to use private hospitals, even though they are more expensive

Based on these findings, there is immediate need for awareness raising and training activities on patient rights and how patients can file complaints if they are not thoroughly satisfied.

A health system without patients at its centre is unthinkable. Patients' rights are one of the basic human rights across the EU states. The human right to health means that everyone has the right to the highest attainable standard of physical and mental health, which includes access to all medical services, sanitation, adequate food, decent housing, healthy working conditions, and a clean environment.

- The human right to health guarantees a system of health protection for all.
- Everyone has the right to the health care they need, and to living conditions that enable us to be healthy, such as adequate food, housing, and a healthy environment.
- Health care must be provided as a public good for all, and it should be financed publicly and equitably.

In the annexes, all the results from the survey are presented, including the cross tabulation answers divided by gender, education, age, salary, nationality, marital status and location.



B- DEMOGRAPHICS and METHODOLOGY

1- Methodology

a) Questionnaire

The questionnaire was prepared based on the guidelines published in the call for research tender, and all stakeholders agreed on the version that was eventually used. The questions were prepared in multiple choice format with closed-ended questions and the pollster coded the answers accordingly. The surveys were formed for the general public.

b) Focus Groups

The focus group questions were also prepared based on the guidelines in the tender. Three different focus groups took place, including health professionals, media professionals and lawyers, who are all important stakeholders in the area of patient rights.

Overall, the aim of the survey and focus groups was to determine whether the members of the public know their rights about health, and whether they act when they are mistreated. The focus groups took place in order to obtain an in-depth view of the situation and how the major stakeholders feel about the existing situation.

2- Demographics

Based on the statistical information in the northern part of Cyprus, the size for the survey was 847 respondents. Based on this number and 95% confidence interval, the sample size of 847 would give an error level of $\pm 3,36$.

The focus groups with 6-7 people each took place in November and December 2016. There has been a delay due to the gathering of the media professionals due to their busy calendar to meet on a common day.



C- RESULTS

a. Basic Rights, Violations and Complaint Procedures

Two main results emerged from the survey, which were also supported by the focus groups. Many people are not aware of the basic 14 patient rights and, if they are not satisfied with the care they are provided, they do not know how to file a claim and lobby for their rights.

- i. When asked about what they think of the term 'Rights of a Patient', the most popular five answers were:
 - Patients' confidentiality (9.8%)
 - Equal treatment for all (7.4%)
 - The opportunity to accept or deny treatment (5.5%)
 - The right to file a complaint (5.3%)
 - The right for compensation (4.8%)

Such low percentages suggest that the public in general are not aware of their rights as patients. Even though, when asked whether they know what the rights of patients are, 67.9% said 'Yes', in reality, they are not aware what these rights are. Breaking this down in terms of education, the less educated a person is, the less they are aware that patients' rights exist.

This was also reflected through the focus groups. Even when the health professionals were asked about what the patients want, they usually answered that they would like to get treatment and get information. These are obvious answers; however, none of the participants mentioned any other rights or concerns that the patients might have, such as the right to consent or access, alternative treatment methods or personalised treatments, right to compensation, etc.

- ii. When asked about whether they know what universal patients' rights are, the following percentages were reported in the survey:
 - Right to access to health services (14%)
 - Right to file complaints (13%)
 - Right to privacy and confidentiality (11.8%)
 - Right to consent and refusal of treatment (9%)
 - Right to compensation (7.5%)
 - Right to personalized treatment (7.4%)
 - Right to security (7.2%)
 - Right to free choice (6.6%)

These are relatively higher percentages compared to the first question; however, they still remain lower than the desired level of awareness. During the focus group with the health professionals, the first four rights mentioned were:

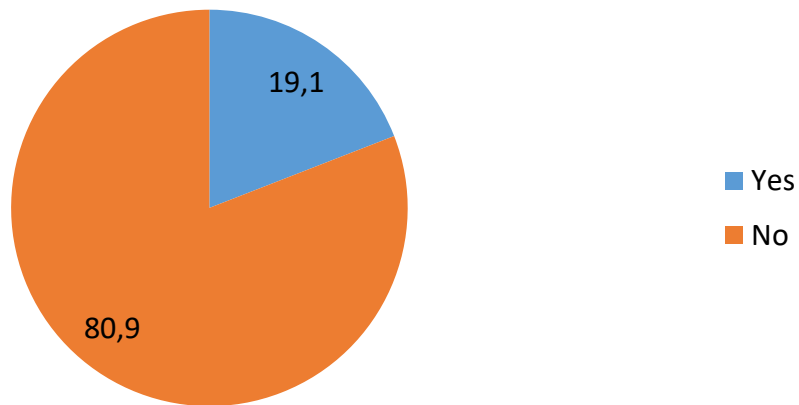
- Right to privacy and confidentiality
- Right to information



- Right to alternative treatments based on coordination among doctors
- Right to security

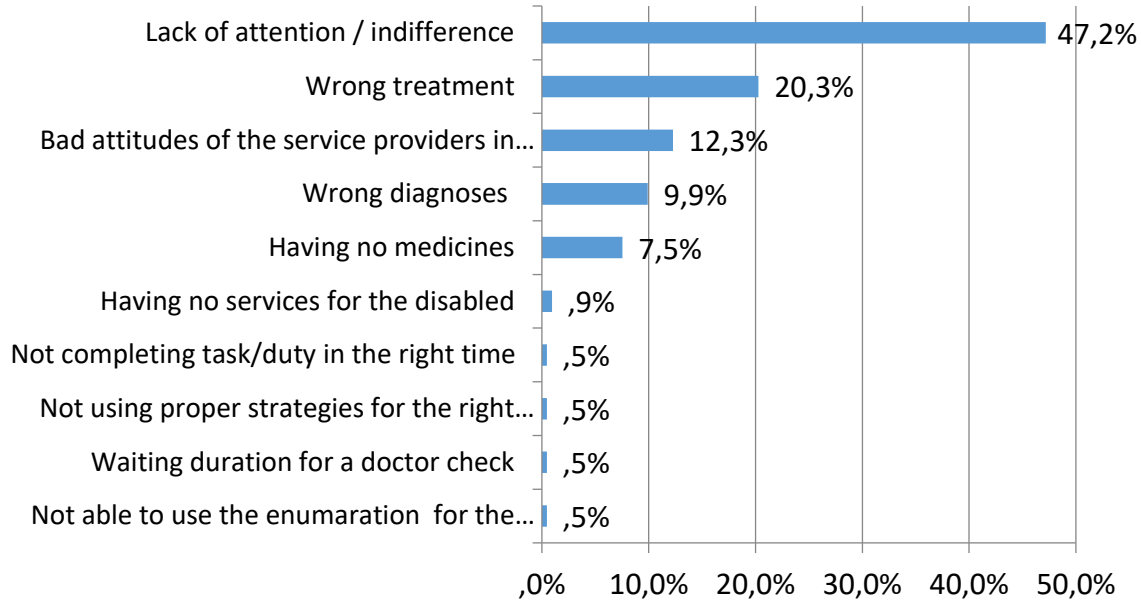
This also proves that even the health professionals are not fully aware of all the rights of the patients. This view is further strengthened by the focus groups with the media professionals and lawyers, who had even less awareness of the basic rights. In short, the lawyers mentioned that patients had no rights in the northern part of Cyprus.

- iii. The next question in the survey is particularly revealing of the existing situation in the northern part of Cyprus. When asked if they had ever filed a complaint based on their dissatisfaction of health services, only 19.1% said 'Yes'. The fact that only 19.1% of patients had ever filed a complaint about mistreatment is a clear indication that they do not know how to lobby for their rights and the right mechanisms to complain do not exist.



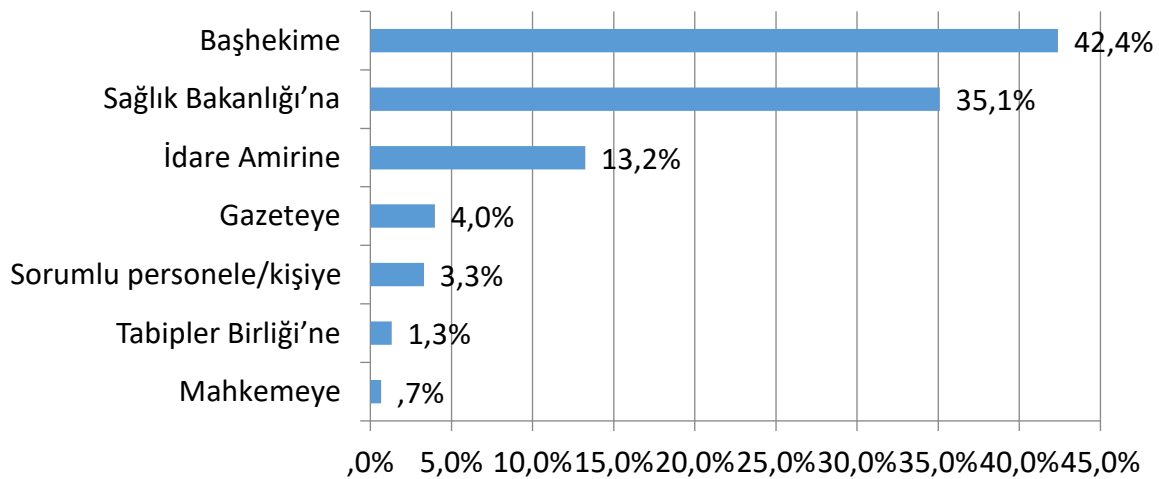


iv. When asked about what they had filed a complaint about, the answers were as follows:



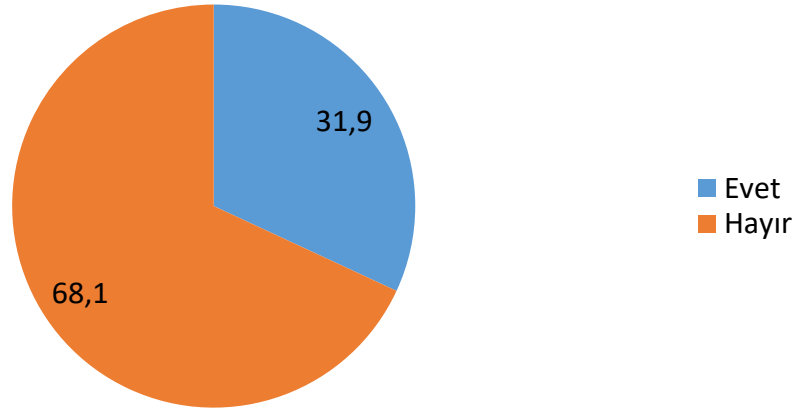
The biggest complaint with 47.2% was the lack of proper care and not receiving enough attention from the healthcare professionals. This is followed by getting inappropriate treatment with 20.3% and also the negative attitude of healthcare professionals.

Out of the 19% people who had filed a complaint, 42.4% went to the Chief Doctor of the hospital, followed by 35.1% to the Department of Health.





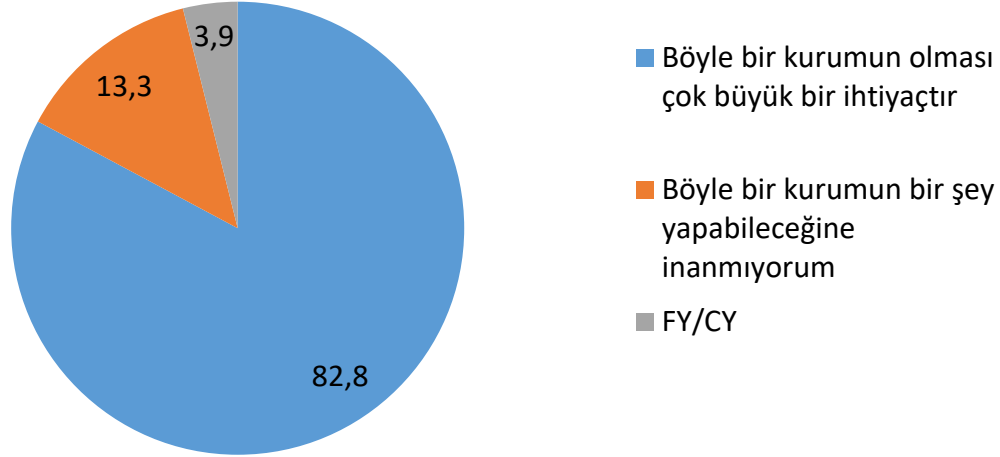
This approach is not very healthy or effective. When asked during the focus groups, health professionals also confirmed that the hospitals should have a complaints unit to handle these issues. Some of the health professionals also think that this unit should be part of a health related association such as The Universal Patient Rights Association (to ensure independence), and, if legal action is required, lawyers should be consulted. This inefficiency is evident from the percentage of complaints that have actually been resolved, which is only 31.9%:



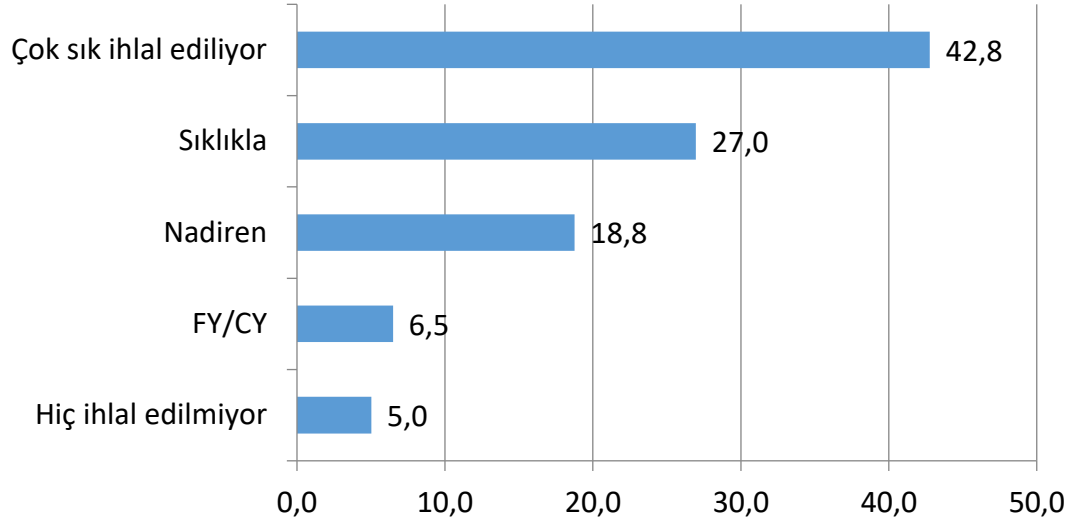
Therefore, out of the small percentage of complaint cases of only 19.1%, only one third of them have been resolved. Also, not all of the complaints are resolved favourably; only one third of the complaint resolutions were satisfactory, so about one ninth of all complaints (roughly 10%) resulted in a favourable solution to the complaint. This is an extremely unsatisfactory situation. This view of the healthcare system was also verified during the focus group with the health professionals, as they confirmed that minimal attention is given to the complaints and there is not a proper mechanism to handle them.



- v. When members of the public were questioned through the survey about whether there is a need for an association or unit to defend patient rights, there was an overwhelming 'Yes' response, with 82.2%.



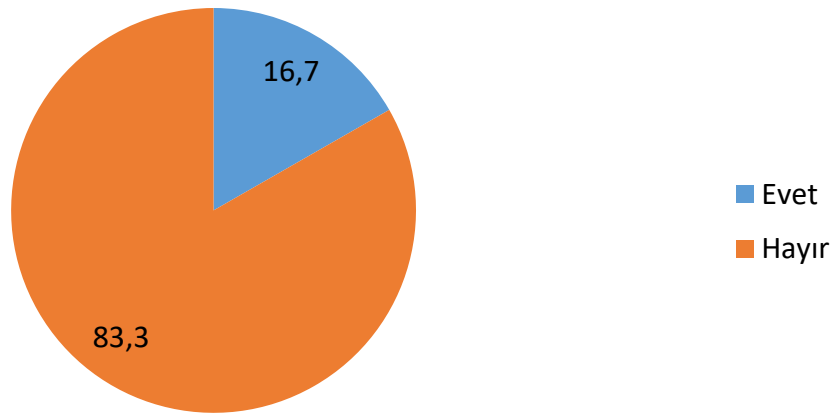
- vi. The lawyers, media professionals as well as health professionals were also asked whether they think there are patient rights violations in the northern part of Cyprus. They all agreed that violations exist and, according to the health professionals, most violations exist in terms of respect for patients' time. Some patients in the state hospital, especially those coming from outside of Nicosia, are often made to wait for hours, with no satisfactory results in the end. Also, since the database of the state hospital was reset in 2012, all the patients' data before this date was lost; therefore, patients do not have access to their previous information anymore. The media professionals also pointed out that there are differences in the treatment that people with higher economic opportunities enjoy versus the ones with lower opportunities and also in terms of treatment that people in cities get versus people in rural areas. These rights violations were also reported by the survey participants, where 69% of the sample population believed that the patient rights are violated often or very often:



This high percentage confirms that many violations exist; however, people do not generally file complaints due to the lack of suitable mechanisms or because of their disbelief that the complaints will be resolved favourably.

b. Raising Awareness regarding Patient Rights and Legal Framework

- i. When asked about whether they had ever received information about patient rights, the survey participants reported the following:

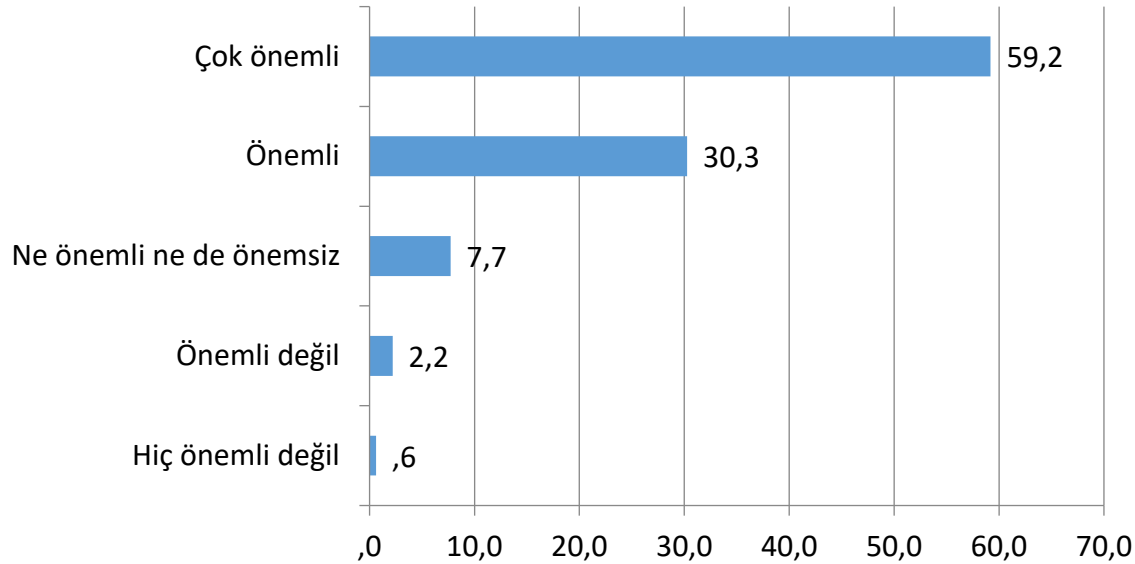


So, only about 16.7% of the members of the public had ever received information about patient rights. Out of this small percentage of people, 21% had received the information from online newspapers, 14.6% from television programmes, and 14.2% from health institutions, such as hospitals. Therefore, this is a clear indication that there is a need for training and raising awareness through official sources to ensure the correct information is disseminated. Even when



cross tabulated by education, it was found that only 24% of university graduates had received information regarding patient rights.

An extremely high percentage of survey participants think there should be awareness raising on patient rights, with 89.5% rating this as important or very important:

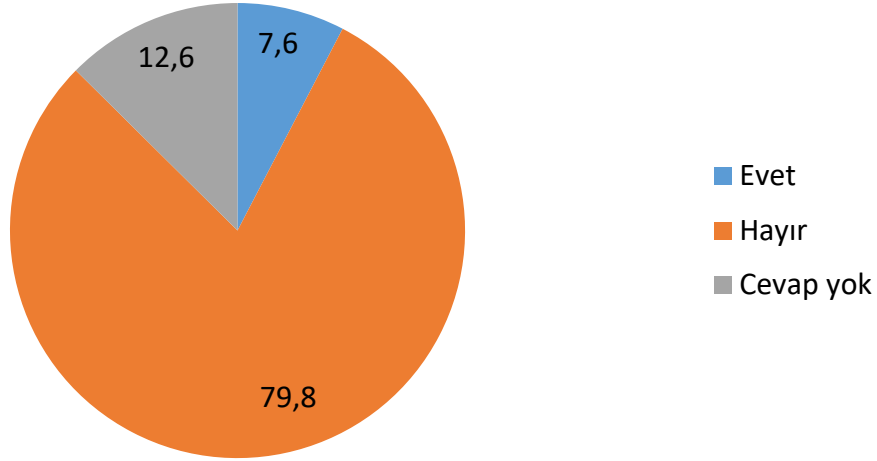


Thus awareness raising should be implemented in relation to this very important topic as soon as possible.

Also, when questioned as to whether they, or someone they knew, had faced patient rights violations, only 28.7% said that they sometimes face violations with 22% saying they often face violations, as they are not fully aware of what their rights are.

During the focus groups, the participants were questioned about what kind of awareness raising activities should take place in order to direct the public's attention towards patient rights. The health professionals responded that there should be training by the Department of Education in schools, the Department of Health and hospitals. Also, in cooperation with the Department of Health, doctors, nurses and health professionals should be trained, who can in turn educate the public. The health professionals also felt that associations working in the area of health should arrange training in rural areas in cooperation with existing civil society organisations (CSOs) in the area. The health professionals also felt that billboards and flyers could be a good way to start raising awareness. The health professionals also felt that social media could be a good channel to spread awareness regarding patient rights, as the public uses the social media channels often.

The survey participants also had a question about any legal action that they might have taken based on the patient rights violations that they themselves or someone they knew had faced, and only 7.6% said 'Yes'.

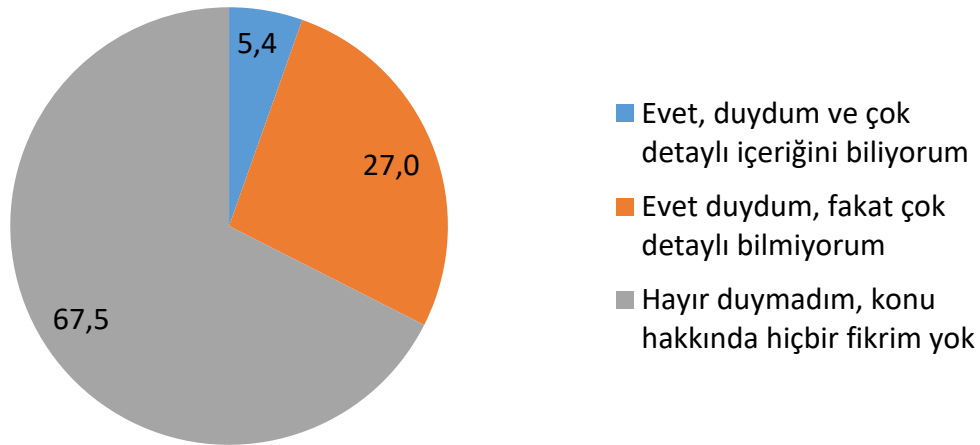


- ii. The focus group including lawyers was asked whether there are laws that protect patient rights. They mentioned there are some laws but they do not completely cover all the violations and most of them are never utilised. When asked whether there are any cases pending against doctors or hospitals, they gave some examples. In most cases, even when there is a decision against a particular doctor, the doctor is usually receives no punishment, and continues his or her job, as there is a shortage of doctors in the country.

When the media professionals were asked about whether they know about any international conventions on patient rights, or Health Laws, they were mostly unaware of these laws. Therefore, they mentioned that the media professionals need to be educated first regarding these laws, so they can pass on their knowledge to the public.



This question was also part of the survey and the results are as follows:

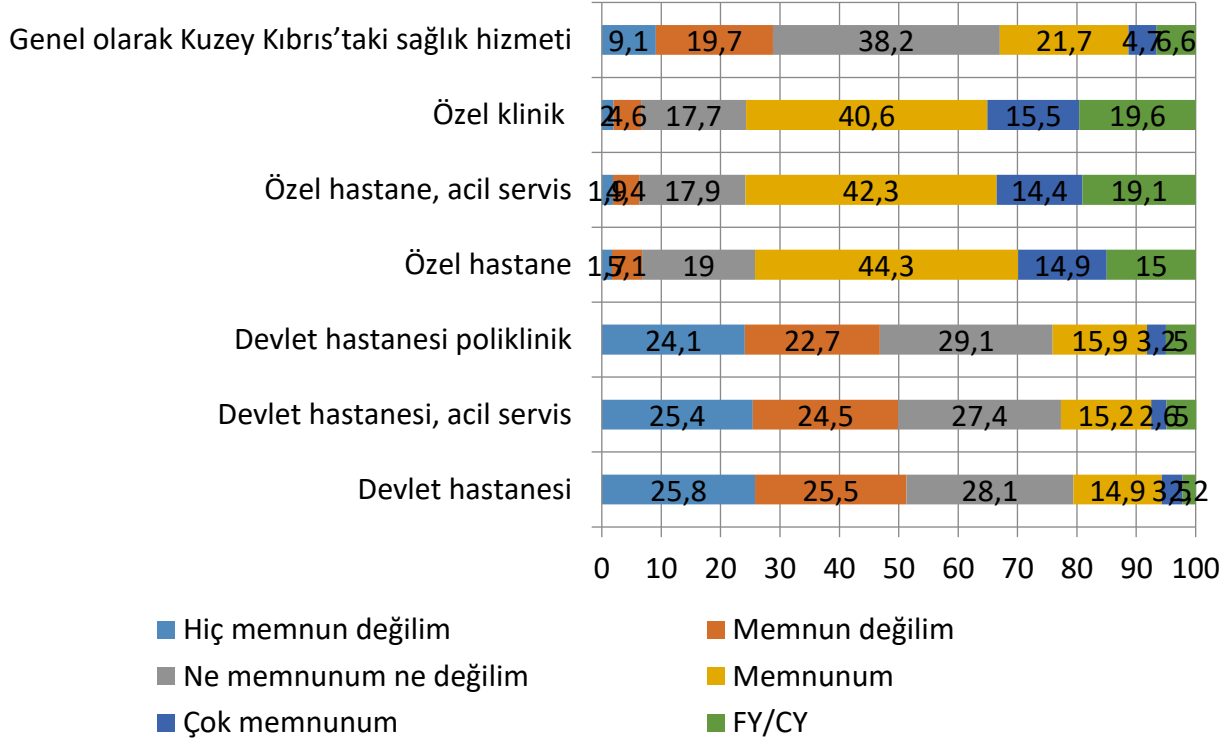


Only about 27% of the public said that they had heard about these conventions, but do not have detailed information. So, this is another area that would benefit from awareness raising.

- iii. Another survey question concerned whether the members of the public thought the health establishments or the government are sensitive about patient rights, and 69.9% of people thought they did not care or they did not care at all. This was the general consensus when cross tabulated across gender, age, education, rural vs urban and household income. This view was also shared by the health professionals during their focus group.

c. General Information

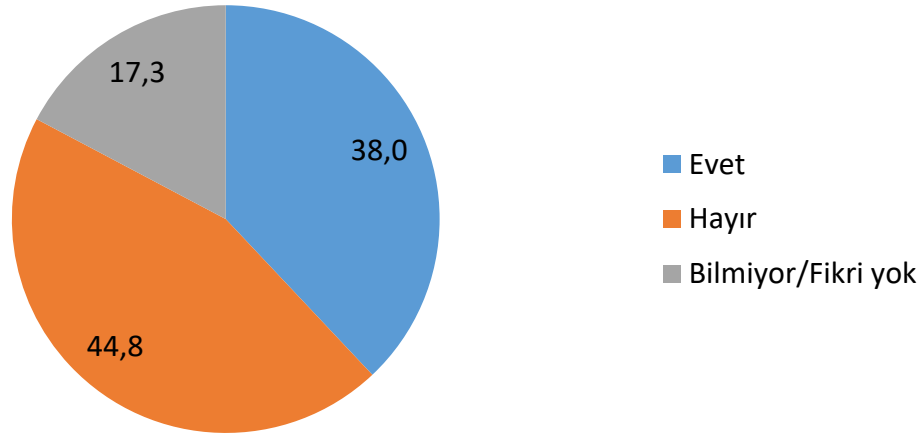
- i. When questioned about whether they go to state or private hospitals in the survey, 26.6% of the participants answered state hospital versus 21.1% who answered private hospitals. When they were asked what their first choice is, the answers were approximately 50% each for state and private, where the 65+ age group favoured the private hospitals with 55.7%.
- ii. When asked about how satisfied they are with the service provided, the following results were recorded:



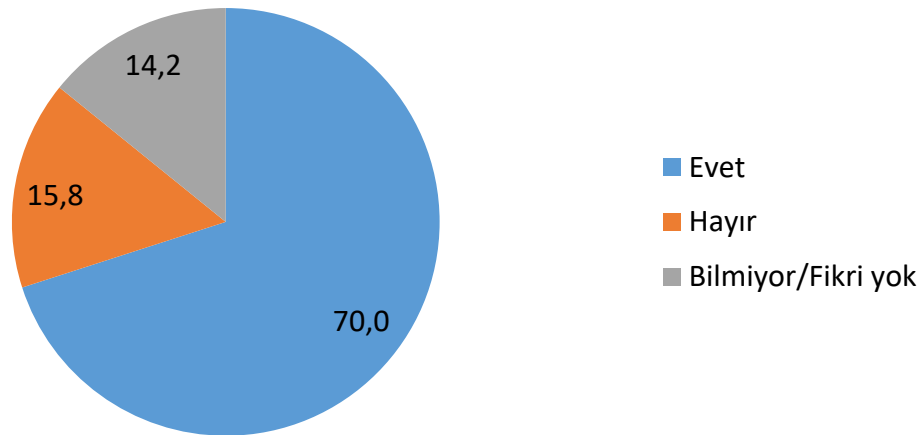
There is clear indication that a higher percentage of people are pleased with the institutions (56%-59% saying I am pleased or very pleased) compared with the state institutions where only about 17% of the people are pleased or very pleased. As expected, as the education level and income increases, the people who are pleased with the service at the state hospitals decreases.



- iii. When the survey participants were asked whether they follow the activities of patient rights related associations, only 38% said "Yes".



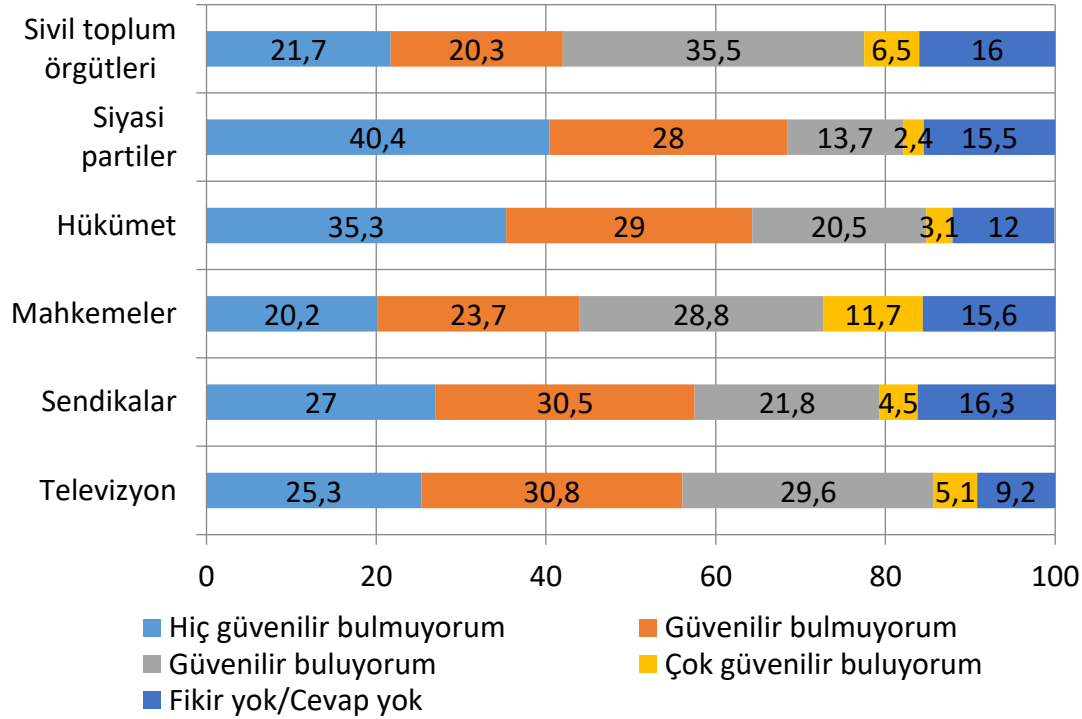
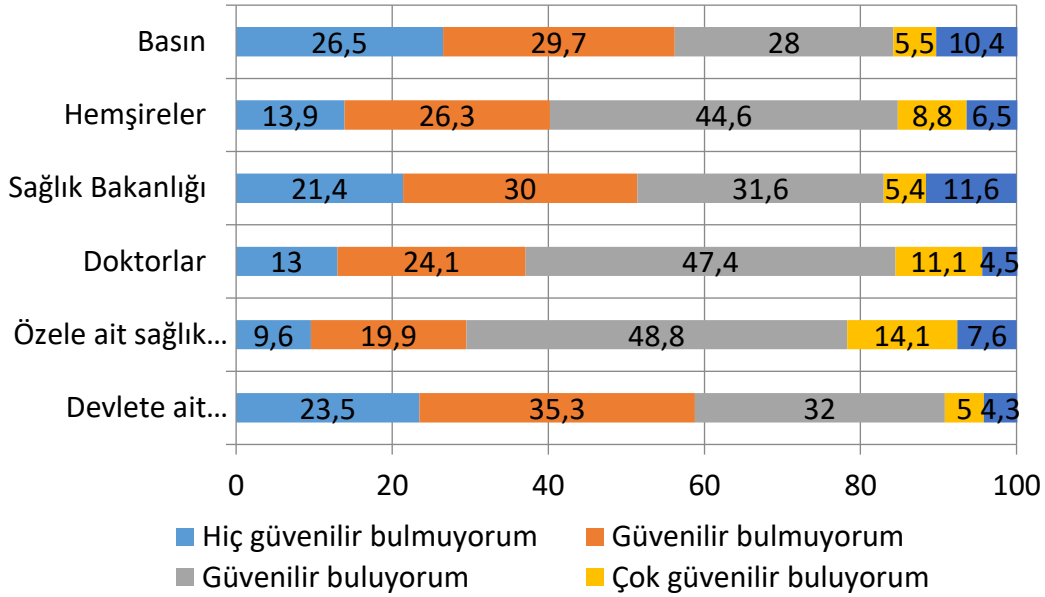
When asked if they would like to support these associations financially or on a voluntary basis, a very high percentage agreed:



- iv. When asked about the four most important problems that the society faces today, the responses were as follows:
- Health system: 22.6%
 - Unemployment: 12.9%
 - Education system: 12.3%
 - Economy: 12%



v. Another important question was who they trusted in terms of institutions:



The least trusted institutions were the political parties, government, unions, media, and Department of Health, in this order. This proves that there are serious trust issues with government and the related institutions.



CONCLUSION and RECOMMENDATIONS

Some very strong trends emerged from the survey and the focus groups. First of all, people are not aware what their rights are, and some of the rights that they are aware of are often being violated. So, there is a need for a twofold approach:

- a. The public needs to be educated about patient rights through training and awareness raising via various channels, such as flyers, billboards and social media
 - b. Patient Rights and working mechanisms should be established for reporting patient rights violations
1. There is a clear need for training. The best way forward is to cooperate with local active NGOs, especially in rural areas, and to provide training to their members, e.g. the Akova Women's Association.
 2. There is also a need to raise awareness regarding patient rights, possibly through the mass media and social media channels.
 3. A functioning and effective complaints mechanism needs to be established to handle the complaints of the patients.