**Barriers to enrolling Women Injecting Drugs (WID) and IDU (Injective Drug User) female partners with hepatitis C in Hepatitis C elimination program, Tbilisi, Georgia**

Non Governmental Organization

Hepa Plus

Researcher: Sophiko Gogochashvili

Co-researcher: Maka Revishvili

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# List of Abbreviations

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| --- | --- |
| IDU | Injecting Drug User |
| IDU’s partner | Sexual partner of injecting drug user |
| HIV | Human Immunodeficiency Virus |
| AIDS | Acquired immune deficiency syndrome |
| VCT | Voluntary Counseling and Testing |
| Social worker | Specialist working with injecting drug users and their partners under Harm Reduction Program |
| GFATM | Global Fund to Fighting AIDS TB and Malaria |
| PBEI | Peer based educational interventions |
| Outreach | Social field work |

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# Introduction

This research “Barriers to enrolling Women Injecting Drugs and their partners with hepatitis C in Hepatitis C elimination program, Tbilisi, Georgia” was conducted by NGO Hepa Plus, with funding from Civil Society Institute (CSI).

Hepa Plus is a community organization that brings together community members with hepatitis C. The organization is focused on working with drug users based on harm reduction principle. Since 2011, Hepa Plus has been actively involved in all advocacy campaigns and activities for access to hepatitis C treatment and diagnosis, including development, revision and implementation of a strategic plan for access to hepatitis C treatment and diagnosis.

From 2013 onwards, Hepa Plus has been implementing GFATM project “Provision of HIV preventive services to IDUs and their sexual partners” (sub-sub-recipient). The GFATM project has been implemented in Georgia since 2008. The scope of services provided covers:

* Distribution of sterile injection equipment, mostly needles and syringes, and alcohol swabs (distributed during social fieldwork - outreach activities, as well as on site in service centers);
* Distribution of condoms and educational materials;
* Free anonymous testing for HIV, hepatitis B/C and syphilis;
* Various medical, psychological and legal consultations;
* Peer based educational interventions (PBEI);
* Overdose prevention through first aid training and distribution of Naloxin drug;
* Case-by-case approach and management.

**Epidemiological situation in terms of Hepatitis C**

Hepatitis C is one of the most challenging and large-scale diseases in the modern world. 71 million suffer from chronic hepatitis C worldwide; most people with chronic infection develop hepatic cirrhosis or cancer; every year up to 399,000 people die from liver diseases related to hepatitis C; in Georgia approximately 150,000 people suffer from chronic hepatitis C. Most of them are not aware of their disease; more than 95% of people suffering from this disease can be treated with anti-virus drugs. As a result, the rate of mortality from hepatic cirrhosis and cancer may reduce;

Currently, there are no vaccines against hepatitis C, but efforts continue in this direction.[[1]](#footnote-1)

Georgia is one of the countries with high prevalence of hepatitis C. Georgia has the highest incidence of hepatitis C[[2]](#footnote-2) among the countries in Eastern Europe and Central Asia. Based on the results of seroprevalance study of hepatitis C conducted by the Disease Control and Social Healthcare Center in 2015-2016, hepatitis C is prevalent among general population (Anti HCV 7.7% and RNA 5.4%)[[3]](#footnote-3). Reasons for the high incidence of the disease have not been properly studied. One of the reasons could be the collapse of healthcare system in 90s, as well as negative impact of low quality healthcare services on safe injection practices, poor control and epidemiological surveillance of infections and blood safety in medical institutions over years. All these factors, coupled with widespread syringe exchange among IDUs, lead to higher incidence of hepatitis C in general population[[4]](#footnote-4).

Despite the scarcity of epidemiological surveillance data, it has been proven that IDUs are at a high risk of hepatitis C. Based on the data of Behavioral Surveillance Survey - BSS conducted in 2014-2015, 66.2% of IDUs are infected with hepatitis C[[5]](#footnote-5).

Hepa Plus report showed that 100% of people with hepatitis C were involved in risky behavior in the past, and most of them still continue to do so no matter whether they are aware or not of the risks associated with such behaviors[[6]](#footnote-6).

Hepatitis C treatment in Georgia has been limited for years due to the high price of treatment and diagnosis. However, later in April 2015, with the support of US partners and pharmaceutical company Gilead, unique hepatitis C elimination program was launched in Georgia. Its aim is rapid detection of all infected people, their treatment and minimization of new instances of the disease by means of effective preventive measures.

Even though the state program for elimination of hepatitis C has been operating in Georgia for three years already, with treatment received by more than 45,000 people, currently there are still 100,000 infected people. Therefore, it is important to detect them as soon as possible.

An estimated 19,000 people who tested positive in rapid tests were reported in harm reduction programs. They are not included in the treatment program.

The priority of the program is to enroll these people in the treatment.

Screening tests are free of charge throughout the country[[7]](#footnote-7).

# About the research

**General description of the research**

Although hepatitis C elimination program has been in place for three years, there are still people, IDUs and IDU partners who are not yet included in this program.

There are some obstacles which, despite the program availability, prevent them from being included in this process,

Special attention should be paid to IDUs and IDU partners with hepatitis C who have not yet been included in the program.

**Purpose of the research:**

The purpose of the research is to study the extent of participation of women injecting drugs and IDU men’s female partners with hepatitis C in hepatitis C elimination program, and to identify obstacles preventing this population from taking part in the hepatitis C elimination program. The results of the research will help us identify and respond to their needs on evidence based data. Specifically, plan intervention at the stage of diagnosis of women injecting drugs and their partners to ensure their prompt inclusion in the treatment process.

**Research assumption:**

There are biological, psychological and social factors preventing women injecting drugs and IDU men’s female partners with hepatitis C from enrolling in the elimination program.

**Period of the research:**

This research was conducted by Hepa Plus in the period from 15 November 2017 to 15 July 2018 (8 months). Interviews for the qualitative study were conducted in February-March 2018, and focus group took place in April.

# Methodology

Qualitative study was conducted as part of this research. We used the in-depth interview and focus group discussion method. In-depth interviews were conducted with 30 women injecting drugs and IDU’s female partners, whereas focus group consisted of ten medical specialists who have worked with women infected with hepatitis c for many years.

Audio records of interviews and focus groups were prepared and later transcribed. These audio records are kept in a special lockable drawer which is inaccessible to unauthorized individuals.

**Selection of participants**

A consistent and respondent-oriented selection method was used to select respondents. This means that interview was conducted with all the beneficiaries infected with hepatitis C who were available for the researcher and agreed to participate in the research. Information about the research was disseminated among Hepa Plus beneficiaries. Social workers and VCT consultants offered the beneficiaries who knew about their hepatitis C virus status to participate in the research. Selection continued until the number of people required for the qualitative study was reached.

A representative of hepatitis C community who has an extensive experience of field work participated in interviews with the researcher and acted as a co-facilitator in the focus group.

All potential participants of the research were explained the essence and purpose of the research in accordance with the research protocol. The consultant asked each client to explain what they considered to be risky and inconvenient. After obtaining the participants’ voluntary written consent, the research interviewer asked the participants questions based on the pre-approved questionnaire.

During the in-depth interview, the survey was conducted individually and face-to-face, in a separate room. The interview lasted for 30-45 minutes on average.

Focus group lasted for 2 hours.

**Research tools**

Pre-defined questionnaires were used during the qualitative study, both for in-depth interviews and focus groups. Researchers as well as community representatives with hepatitis C infection and IDU beneficiaries of Hepa Plus took part in the questionnaire development process. In order to improve the questionnaires, the in-depth interview and focus group questionnaires were revised in advance to ensure that they address the issue of the research. These questionnaires are attached to the research report (see appendices 1 and 2).

Participation in the research was voluntary and confidential as participants were provided with incentives. At the donor’s request, the participants were registered according to their IDs. However, only the researcher had access to information provided during the interview and focus group, whereas the donor was provided only with a list of participants.

**Criteria of inclusion in the research**

The following inclusion criteria were used for selecting beneficiaries for interviews.

* More than 18 years.
* Women injecting drugs or IDU woman with drug consumption history.
* IDU man’s female partner.
* Claim that they are infected with hepatitis C and have not yet been included in hepatitis C treatment program.
* Joined the research voluntarily.
* Speak Georgian, as the research was conducted in Georgian and consent forms were issued in Georgian.

The following inclusion criteria were used for selecting focus group participants:

* More than 18 years.
* Experience of working with female patients infected with hepatitis C.
* Experience of working with IDU female patients.
* Awareness about the elimination program.

The research design was submitted to the Ethics committee in the healthcare research union and was assessed positively.

**Limitations:**

The qualitative study method does not make it possible to cover a large part of the studied population. Therefore, we cannot state that the statistical reliability of the data reaches the 95% threshold.

Given that the research population, specifically, respondents participating in the interview represent hidden population (there was no wide choice available when selecting women injecting drugs; in addition, IDU men’s female partners were often unwilling to disclose their own status), a consistent selection method was applied which means that interview was conducted with all beneficiaries who were available to the researcher and agreed to participate in the research despite the risks associated with the in-depth interview (talking about sensitive and very personal issues)., Medical specialists who deal with hepatitis C patients participated in focus groups. However, during the discussions it was difficult to focus on Women injecting drugs and on IDU men’s female partners with hepatitis C as sometimes women with hepatitis C do not speak to their doctors about drug consumption. It is more difficult to find out if her partner is an injecting drug user.

It was also difficult to differentiate the reasons cited by IDUs, IDU’s female partners and the women who have no similar experience.

**Data processing**

During the processing of research results key terms were classified and then reviewed based on a synthetic method. Logical and systematic analysis of the research subject helped to reveal factors which prevent cohorts participating in the research - Women injecting drugs and IDU men’s female partners with hepatitis C - enroll in the hepatitis C elimination program. The findings of the research helped to form a systematic understanding of the research subject and reach specific conclusions.

**Key findings**

1. **In-depth interview**

A number of findings were made based on the analysis of in-depth interviews:

in most cases, women participating in the research stated that they were going to enrol in the elimination program in the near future. However, most of them find it difficult to specify exact dates. In some cases, women find it difficult to state one specific reason as to why they have not yet enrolled in the program. However, when looking more into the details, we can identify certain factors which are more or less common for respondents participating in the research.

Opinions of medical specialists participating in the focus group to a certain extent reflect the findings made during the in-depth interview with respondents. However, there are some opinions which are expressed only by medical specialists.

* 1. **Duration and possible causes of infection**

As reported by most beneficiaries, they had presumably been infected long before they learned about their status. However, the duration of infection in the data is reported according to how long the respondents have known about their status of infection. This period ranges from 1 to 14 years:

It appears that most of the respondents have learned about their status during the last three years, i.e. after the elimination program has been launched (17 out of 30 respondents), which might be partly due to the active screening of hepatitis C in the country. Respondents often state that they have learned about their status after getting their test results in the mobile clinic, or during elective surgery. Interestingly, Women injecting drugs expected that they could be infected while IDU’s female partners ruled out any chance of infection and were shocked to learn about their status.

Importantly, 40% of respondents stated that they had been infected by their spouses. Although it is known that there is a low risk of sexual transmission of hepatitis C, there are still many cases when family members are believed to be the possible source of infection. In one of the cases, a respondent thought that his child was the source of infection.

50 % of respondents are injecting drug users who believe that they were infected by exchanging syringes or other injection equipment; interestingly, many IDUs think that drug itself can be infected, i,e. the infection can be transmitted through drugs. 2 out of 30 interviewed females share this opinion believing that they were infected through heroin. One of the female respondents says: “When I took a dose of heroin, they told me then it had a germ in it and I could get infected with hepatitis C. Those doing heroine always have C. It happened back in 2002. In 2004, I was arrested and I knew for sure that I was infected. Before I was arrested, I did drugs with a butterfly catheter. My friend told me I shouldn’t do it because she had C. I told her I knew about it and that I also had C. I used her syringe. I knew about all those trends from drug addicts. The test was done on Pavlov street. They went their for test and professors confirmed their earlier suspicion that heroin was infected”.

7% out of the remaining 10% say that they were supposedly infected by dentists, as they did not have any other risky manipulations or behaviors.

* 1. **Extent of stigmatization (speak openly about their status or not, or feel that they will be judged by the community)**

“Very few women openly speak about their status because of the stigma and lack of education. They think it is a disaster so only very close friends know about it. I spoke to a very close friend about it and she also told me that she had to report her status due to her work, otherwise she would not do it. She needed help. When some of her friends learned about it, she felt very stressed. I calmed her down saying that I also had the infection. This had a calming effect on her, her mood changed instantly. Before that she was very hysterical”, 45 year old IDU’s female partner said. She has been infected for 12 years and this issue still causes her great pain. She says that when her family learned about her infection, they asked her to keep her personal care items, towel, utensils and other things separately. She still feels very hurt when she thinks about it.

As we can see from the research, IDU respondents are less likely to perceive themselves stigmatized. They are ready to state their status openly thinking that it is normal and should not be surprising to anyone whereas IDU’s female partners believe that after disclosing their status they will be looked down on as people using drugs or having other risky behaviors. The community will not understand it. That is why they try to conceal their status, sometimes even from their family members.

30 year old IDU’s female partner who learned about her infection one year ago, says: “People make you feel like you're a leper. At times, I felt so ashamed when I heard people talking about someone who had C. I have never told them that I carried C. Even if I’m cured, I’ll remember it forever. The people are so inadequate, they can tell you things you’ll never be able to forget; I hope I won’t need to consult a psychologist after the treatment”. Stigmatization often prevents them from seeking treatment. A 48 year old IDU woman says: “I have many infected friends but I cannot bring home to them that it is confidential. They refuse to apply to these centers. Those who were not in prisons do not want anyone to know about their C infection. One of the women’s husband is infected but she is still afraid of applying to the centre”.

* 1. **Awareness about treatment and its results**

As we can see from the interview, respondents are better informed about the results of treatment than about the process of treatment. As they are not yet enrolled in the treatment process, they do not know exactly where they should go, which tests they will have to take. They just know that they will need to pay additionally for the tests though they do not know exactly how much they will have to pay. IDU respondents depend on their social workers. They say that they will start treatment but they are going to ask their social worker where they should apply to and what they should do. Some of them think that they can do all necessary tests and take medications in the service centers of the harm reduction program where they have been tested before.

The significant part of the research deals with the positive and negative effects described by the research respondents. The main positive effect is that the virus disappears, a person is cured and can live without any fear; 70% of respondents say they know people who have been cured and felt happy as a result. 42 year old IDU woman whose husband participated in the elimination program says: “My husband says he feels much more energetic now”. Half of the respondents say they heard only good things about the elimination program. They are also satisfied with the quality of services: “Those who received the treatment were very satisfied with the service: instructions, reference, and attention”.

Some of the respondents spoke about the negative effects of the treatment, such as physical weakness, mood swings or increasing agitation, insomnia. One of the described negative effects was also the fact that no alcohol could be consumed during the treatment because it could damage the liver; respondents spoke about cases when their acquaintances or relatives were unable to endure the treatment and had to leave it halfway.

52 year old IDU woman: “One of the women was feeling weak, sweaty and had a fever. I also know a man who joined the program. I asked him how he felt and I could see that he was very pale. The body gets slowly adapted to it”.

45 year old IDU’s partner says: “Some people say that their nervous system deteriorated, they had nervous disorders, headache and stomach ache so I try to avoid it. It destroys the immune system but it’s better than having a tumor. People with tumor have to go through chemo to survive whereas with treatment of hepatitis C lasts just a few weeks. It’s very good. I think our country was fortunate enough to be a part of the program”.

As we can see from the quote above, despite the fact that 30% of respondents speak about negative effects, they still emphasize that most of the infected people have been cured. It is very important.

* 1. **Factors preventing inclusion in the program**

Based on the findings of the research, we can note several obstacles. First of all, it should be mentioned that there are objective reasons for not participating in the treatment. One of the respondents was pregnant, which was a physical obstacle to enrolment in the elimination program. One of the respondents also said that her veins were so much damaged due to the use of injection drugs that it was impossible to draw blood from her veins. This was an obstacle for starting the treatment.

Factors preventing inclusion in the elimination program which were identified during the research can be divided into the following categories:

Financial - one fourth of respondents stated they could not join the elimination program due to financial problems. This problem is especially relevant for IDUs and for the respondents who have more than one family members with hepatitis C infection. It is noteworthy that the respondents who state that financial problem prevents them from starting the treatment, cannot say exactly what types of tests are required for enrolment in the program. They also do not know the approximate amount they will need to pay for starting the treatment.

Biological - there are cases when women refrain from treatment due to the possible side effects of medications: 43 year old IDU’s female partner who has been aware for 14 years about her infection with hepatitis C, says: “I am very eager to receive treatment but I am afraid of side effects. The treatment should be available in hospital settings where doctors can attend to a patient in the course of treatment. I have tried to start treatment many times but something is stopping me. I know I will be okay but I fear that the treatment can damage other organs”.

44 year old IDU woman says: “I have not yet started treatment because the medication I will have to take for treatment causes depression. I am prone to depression, so I do not need any complications. I have recently learned that the medication was changed. One person told me that it could lead to suicide if you have psychiatric problems. However, he was treated in France”. Such rumors may become a reason for not enrolling in the treatment program. However, it is rarely cited as a reason by respondents.

Social - it appears that social barriers sometimes become an impeding factor. Respondents demonstrating a high degree of stigmatization still tell their family members and medical personnel about their infection. They do not tend to speak openly about the virus but they believe that this will not be an impediment in the course of treatment. They say that if they make up their minds, they will surely go to a medical institution.

Psychological - the most important barrier revealed during the research. More than 50% of respondents say that the problem lies only in them and if they make up their mind, they will undergo treatment.

Most beneficiaries say that they will start treatment in the near future. However, it should be mentioned here that they are unable to specify exact dates, or explain what they are going to start the treatment.

The fact that hepatitis C has no symptoms is cited as one of the reasons for not starting treatment. The respondents believe that treatment is not urgent and necessary as they do not experience any inconvenience. They also emphasize that they will start treatment once they make up their minds.

* 1. **Main motivation for starting treatment**

Most of women participating in the research are worried about their own health, both hepatitis C and other diseases which cannot be treated due to hepatitis C. 22 year old IDU’s partner says: “The motivation for me is my health. I am too young to give up on my life. I will take treatment and I will be fine”.

One of the important motivations is family and responsibility for family members. Very often women say that they should stay healthy for the sake of their children and family, as they have minor children. My family needs me, I need myself”, - 53 year old IDU’s partner says.

Safety of family members and other people around them is also cited as one of motivations for treatment. Given the risks of hepatitis C transmission, respondents want to be healed so that not to be a threat to other people. “I care for my relatives, I do not want them to be infected”, - 47 year old IDU’s partner says.

In rare cases, respondents say that they do not care about their own health and the fact that they have used injecting drugs for so many years is proof of that.

Only in one case a respondent said that he had no motivation for treatment. “I do not feel any inconvenience so I am not going to take treatment”, 37 year old IDU woman said.

The motivation is also the high market price of medication. Respondents know that they cannot afford to buy the expensive anti-virus medication.

* 1. **Extent of awareness about hepatitis C**

During the interview respondents were asked questions about possible sources of their infection with hepatitis C, about the course of the disease and actions necessary to relieve the disease.

Most respondents were aware of the ways hepatitis C is transmitted. IDUs with hepatitis C were informed by various NGOs about the ways of transmission of hepatitis C and HIV/AIDS. In addition, IDUs inform each other about the risks of transmission through injection. However, sometimes this information is not true being more of a myth (for instance, the story that a drug itself can carry a virus and transmit hepatitis C), and/or it is incomplete. IDUs believe that the virus can be transmitted through exchange of syringes but will not be transmitted through shared utensils. Thus, respondents sometimes say that they used to exchange injection equipment, cotton and utensils believing that this was not a risky behavior.

It appears that most of IDU’s female partners started to look for information about hepatitis C after they became infected. They received information from diagnostic centers where they were diagnosed or, in cases where diagnosis was made in mobile clinics, they were later enrolled in service centers implementing the harm reduction programs. There they attended trainings and received individual consultations. They also searched the Internet for information.

Most respondents know what actions may cause complication of hepatitis C, including, among other things, consumption of alcohol and certain types of food products.

Although many respondents participating in the research did not know the meaning of the term “elimination” and did not equate hepatitis C elimination program with hepatitis C treatment program, most of them knew about the treatment program. However, some respondents were not interested in receiving information about the elimination program as they believed that in case of need they could use the services of NGOs. Thus, they can go to a social worker who will help them with all the procedures necessary for enrolment in the program.

1. **Focus group**

Based on the nature of the research, it was important to consider not only the opinion of respondents with hepatitis C, but also the opinion of specialists who have a long experience of working with women infected with hepatitis C and to some extent, participate in hepatitis C elimination process in harm reduction services and/or studies.

A focus group was organized to obtain information from medical specialists. We received valuable information from medical specialists about obstacles to enrolment in hepatitis C elimination program, possible counterindications to treatment and needs for additional services.

* 1. **Counterindications to treatment of hepatitis C**

The focus group also noted that although the medications used to treat hepatitis C in the elimination program are less likely to cause side effects and are mostly effective, sometimes treatment is counterindicated due to the following symptoms: headache, stomach ache, nervous disorder, depression, and anemia. It was also mentioned that sometimes side effects from treatment could actually be an abstinence symptom as drug users stop using drugs and/or alcohol during the treatment. This causes symptoms characteristic of abstinence. However, patients, their family members and close friends think it is a side effect from medicine and form a negative opinion of the treatment process.

Specialists note that sometimes expectation of side effects is higher than it is in reality. Patients have preconceived ideas that the process of treatment will be complex, though later they admit that they feel well and have no side effects from the medication.

* 1. **Main motivations for enrolment in hepatitis C elimination program**

During the focus group, specialists described the main factors contributing to the enrolment of patents with hepatitis C in the treatment program. As it was revealed during the in-depth interview, the main motivations here are also the patient’s own health and desire to survive and get rid of the virus as soon as possible, responsibility for the family and children (“my family needs me”). Specialists say that women are more interested in their health than men so they are more motivated to enroll in the program. Women of fertile age (childbearing potential) who learn about the infection during their pregnancy were attributed to a separate group. Their motivation for enrolling in the program is to protect their future fetus from the virus. That is why they intend to undergo treatment after childbirth

Patients are aware that drugs for treating hepatitis C are expensive and that they can receive the drugs free of charge under the state program. It is an additional motivation for them to start treatment, especially for those who knew people infected with hepatitis C before the start of the elimination program and are aware that treatment for hepatitis C is not affordable even to patients from middle-income groups.

* 1. **Obstacles to enrolment in hepatitis C elimination program**

Barriers to enrolment in hepatitis C elimination program which were described by medical specialists complement the barriers described by respondents of the research during the in-depth interview.

According to specialists, one of the obstacles is the fact that tests necessary for enrolment in the elimination program require additional financial resources as IDUs and IDU’s partners are financially vulnerable groups. Their priority is to find/consume drugs. Thus, they cannot afford to pay for treatment.

However, the main obstacle is a psychological factor, i.e IDUs are focused only on using drugs; very often they do not see any need for treatment as hepatitis C has no symptoms.

All specialists note that at the time when hepatitis C elimination program was started, most patients believed that it was a clinical trial to test medications on Georgian population. “They saw on TV news that it was a social healthcare experiment. At first, they were very skeptical to the treatment process, so we had to work much in this direction”, - a hepatologist said.

They were also concerned that at the first stage patients with stage 4 and 3 fibrosis enrolled in the treatment. These patients had acute liver failure, so death rate among them was high. IDUs believed it was caused by the treatment and feared that the treatment could be fatal.

The specialists described common misconceptions among patients with regard to enrolment in the program, for instance, the misconception that the recent growth in liver cancer is the result of treatment or, in the case of IDUs, the belief that use of drugs after treatment could be fatal.

In general, medical specialists who dealt with IDUs, both men and women, share the opinion that it is difficult to obtain IDU’s consent for treatment, that is why they always need a specialist or social worker to accompany them in the course of treatment.

* 1. **Need for additional services**

At the focus group meeting medical specialists mentioned additional services necessary for successful implementation of hepatitis C elimination program.

Required co-funding - so that patients having financial problems could enroll in the program.

Activation of primary healthcare services - active engagement of clinics and family physicians. Specialists believe that any patient coming to a clinic should be informed about the ongoing free screening of general population for hepatitis C in order to disseminate this information to the population.

Specialists think that mass media should play an active role in disseminating the information. In 2015, when the elimination program was just started, more news was reported and broadcast on TV. This issue is still relevant after many years though mass media is now less focused on the elimination program.

Special messages should be created for the patients who know about their status but refrain from enrolling in the program. Social workers should be more actively engaged to increase enrolment in the treatment program.

# Conclusions

* Women injecting drugs and IDU men’s female partners with hepatitis C have sufficient knowledge about the ways of hepatitis C transmission. They are also aware of hepatitis C elimination program.
* The infected women are not aware that hepatitis C elimination program will not last forever and that it will not be available in Georgia in several years.
* Unlike Women injecting drugs with hepatitis C, IDU men’s infected female partners have a higher degree of stigmatization which to a certain extent prevents them from enrolling in the elimination program.
* Unlike men, women with hepatitis C feel more stigmatized. (Similar result was reported by Hepa Plus in research of 2017 - Assessment of knowledge about HIV/AIDS, dependence and behavior among injecting drug users with hepatitis C in Tbilisi).
* IDU men’s female partners state that their main source of information about hepatitis C is the Internet.
* The main source of information about hepatitis C among Women injecting drugs is trainings in service centers implementing harm reduction programs, including leaflets distributed by them and communication with social workers.
* Financial problem is one of the factors preventing enrolment in the elimination program, though it is not the most important one.
* Very often infected women are unaware of the amount of financial resources required for enrolling in the elimination program.
* Psychological factor is considered to be a main obstacle, such as fear of side effects from medication, inability to take a decision and give up drugs.
* The barrier to enrolment in the elimination program could be misinformation from incompetent sources, such as myths spread among IDUs about ways of hepatitis C transmission and side effects of treatment.
* Another barrier to enrolment in hepatitis C elimination is that the issue becomes less relevant and receives lower level of media coverage.

# Recommendations

* More efforts should be put in increasing general awareness of hepatitis C issues, in general, risky behaviors and preventive measures, especially in such groups as Women injecting drugs, IDU men’s female partners and other risky groups.
* The internet should be used as a major source of information about the elimination program.
* Special educational resources should be created in the Georgian language easily understandable to the general population, which will encourage participation in the elimination program.
* Information meetings should be conducted by peer educators, more information should be spread about the condition of women who were involved in the elimination process and have already completed the treatment.
* In order to overcome the stigma towards women with hepatitis C and to prevent the spread of hepatitis C, it is necessary to conduct an information campaign with an emphasis on ways of hepatitis C transmission, such as medical interventions, beauty treatments and physical contact with blood.
* The results of the research should be decoded in a language easily understandable to the general population, and broadcast both on TV and the Internet.
* More efforts should be put in comprehensive healthcare systems to increase awareness of hepatitis C elimination program, such as clinics, medical institutions.
* Information should be spread that hepatitis C elimination program ends in several years, so those wishing to receive free treatment should use this resource as soon as possible.
* Social workers should play a more active role in convincing Women injecting drugs and IDU men’s female partners to take treatment.
* The number of studies about women with hepatitis C infection should increase.

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**Annex 1**

**In-depth interview questionnaire**

Demographic Data:

Personal ID Number:

First Name, Last Name:

Age:

Marital Status:

Status: IDU/IDU’s partner

Education:

Place of work:

Income:

Place of residence:

Have you ever participated in syringe and needle exchange program, or in peer educators’ research? If yes, specify the period.

* When did you learn about your infection with hepatitis C virus?
* How many of your family members know about your infection?
* Describe your sexual practice (number of sexual partners, frequency of using condoms)?
* What do you know about hepatitis C / ways of hepatitis C transmission?
* What other diseases do you know which are transmitted in the same way as hepatitis C?
* Where did you find information about hepatitis C?
* What do you think about the availability of hepatitis C information?
* Which services have you used as IDU, IDU’s partner and/or representative of hepatitis C community?
* How many Women injecting drugs or IDU’s female partners with hepatitis C do you know?
* How many of them speak openly about their status?
* What other services do you think are needed for treatment of hepatitis C?
* Who should assume responsibility for creating/financing these services?
* What do you think needs to be done to reduce the risk of hepatitis C transmission?
* Do you know where you can receive treatment for hepatitis C?
* What do you know about the elimination program?
* Is hepatitis C transmitted by:
* hugging
* kissing
* beauty treatments (which one exactly)
* tooth brush
* shaving accessories
* What would you do if you learned that your friend or family member was infected with hepatitis C?
* How long do you think a person could be infected with hepatitis C without knowing it?
* Can hepatitis C be self-treated?

Social factors

* What financial resources do you think are necessary for patients to enrol in the elimination program?
* How does your timetable fit in with the treatment process?
* Will your family members help you in completing the treatment successfully?
* Will your employer agree to create necessary conditions for you to complete the treatment?
* Who will care for you during the treatment?
* Who or what will be the main obstacle for you in starting and completing the course of treatment successfully?
* How important is your enrolment in the treatment for your relatives?
* Do you know people who are enrolled in the treatment program, what do they think about the program?
* Advantages:
* Disadvantages:

Psychological factors

* When you learned about your hepatitis C infection, what did you feel, what did you do and who was the first person you spoke to about this problem?
* When you learned that free elimination program was launched in Georgia, what did you feel, what did you think and who did you share you thoughts with?
* What will be your main motivation for enrolling in the elimination program?

Biological factors

* How do you feel as a person with hepatitis C, do you have any complaints?
* Did you do any confirmation tests or biochemical tests of the liver? Did you get your results?
* Did your behaviour change (consumption of alcohol, chemical substances) after your learned about your C status?

**Annex 2**

**Focus group questionnaire**

***Instruction for the interviewer:*** *Conduct the in-depth interview in accordance with the plan below:*

1. **This part of the questionnaire concerns experience of medical specialists in working with IDUs and IDU partners having hepatitis C virus**

* During your medical practice have you dealt with women infected with hepatitis C, including Women injecting drugs and IDU’s partners? If so, how often?
* How many women with hepatitis C virus do you know (including Women injecting drugs and IDU’s partners)?
* How well are your colleagues informed about hepatitis C?
* In your medical practice, what type of side effects have you observed in patients enrolled in the elimination program?

1. **This part of the questionnaire concerns information about the number of Women injecting drugs and IDU’s partners with hepatitis C virus**

* Of the total number of your patients, how many of your patients are IDUs or IDU’s partners infected with hepatitis C?

1. **This part of the questionnaire concerns enrolment of Women injecting drugs and IDU’s partners with hepatitis C virus in the elimination program**

* How many women with hepatitis C virus do you know (including Women injecting drugs and IDU’s partners) who are enrolled in the elimination program? How many of them speak openly about their status?

1. **This part of the questionnaire concerns factors preventing or contributing to the enrolment of female beneficiaries with hepatitis C virus in the state elimination program**

* In your opinion, what are the biological, psychological and social factors preventing Women injecting drugs and IDU’s partners with hepatitis C from enrolling in the state elimination program?
* What are the factors contributing to the enrolment of Women injecting drugs and IDU’s partners with hepatitis C in the state elimination program?
* Can you remember obstacles described by female beneficiaries with regard to their enrolment in the state hepatitis C elimination program?

1. **This part of the questionnaire concerns source of infection with hepatitis C virus.**

* In your medical practice, what is the main source of infection with hepatitis C mentioned by infected women?
* In your medical practice, what is the main source of infection with hepatitis C mentioned by IDUs and IDU’s partners with hepatitis C?
* How well do you think health and safety standards are observed in the medical field in Georgia?
* What do you think is the most risky medical intervention in terms of hepatitis C transmission?
* What additional services do you think are necessary for successful implementation of the state hepatitis C elimination program?

**Additional Comments:**

1. <http://www.ncdc.ge/Pages/User/LetterContent.aspx?ID=00557b86-25d0-4a83-acaf-10396576fa2d> [↑](#footnote-ref-1)
2. Hepatitis C in Eastern Europe and Central Asia, <http://www.aidsalliance.org.ua/ru/news/pdf/28.10.2015/EECA%20HCV%20EN.pdf> [↑](#footnote-ref-2)
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6. Assessment of HIV/AIDS awareness, dependence and behaver among IDUs with hepatitis C in Tbilisi. M. Gogochashvili M. Sologashvili M. Gogia Revishvili. Hepa Plus, 2017. [↑](#footnote-ref-6)
7. <http://www.ncdc.ge/> [↑](#footnote-ref-7)