

# **Patient education and counseling guide**

**For adults infected with Hepatitis C**

**MSF OCB**  
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# 1. Background

## 1.1. The burden of Hepatitis C

About 150 million people are chronically infected with hepatitis C virus, and more than 350 000 people die every year from hepatitis C-related liver diseases<sup>1</sup>, most of which are caused by liver cirrhosis and hepatocellular carcinoma (HCC). An estimated 27% of cirrhosis and 25% of HCC can be attributed to hepatitis C worldwide<sup>2</sup>. Due to absence of reliable epidemiological data, disease prevalence rates globally remain uncertain and HCV-related mortality is likely underestimated in low and middle Income countries (L&MIC)<sup>3</sup>. The highest prevalence is found in Egypt (15-20%) and Asia (China 3,2%, Pakistan 4,8%<sup>4</sup>).

Furthermore, around the globe an estimated 16% of people living with HIV/AIDS are infected with hepatitis C<sup>5</sup>. Co-infection of HIV and HCV has negative mutual implications for patients<sup>6,7</sup>. Not only does HIV accelerate the progression of HCV, but patients with HIV-HCV co-infection also run a significantly increased risk of overall mortality as compared to patients mono-infected with HIV.

## 1.2. Fast developing treatment possibilities and access

Currently, 59% of the world's population has no access to HCV diagnosis and even less to HCV treatment<sup>8</sup>. Although the effectiveness of treatment of HCV in developing countries with Pegylated interferon plus ribavirin (PEG-IFN/RBV) has been demonstrated<sup>9</sup>, the treatment has been seen as too complex, expensive and poorly effective, resulting in little incentives for guideline development in L&MIC and leading to lack of screening and low country demand.

Luckily drug development for HCV is progressing rapidly, with new direct-acting antiviral medications capable of essentially curing HCV<sup>10</sup>. These new hepatitis C treatments aim to improve on the older treatment regimes in a number of ways. They can be taken orally rather than injected; the side-

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<sup>1</sup> World Health Organization. Fact Sheet 164, July 2013.

<sup>2</sup> Perz JF, Armstrong GL, Farrington LA, Hutin Y, Bell B. The contributions of hepatitis B virus and hepatitis C virus infections to cirrhosis and primary liver cancer worldwide. *J Hepatol* 2006 ; 45:529- 38

<sup>3</sup> Branch AD, Van Natta ML, Vachon M-L, Dieterich DT, Meinert CL, Jabs D a. Mortality in hepatitis C virus-infected patients with a diagnosis of AIDS in the era of combination antiretroviral therapy. *Clin Infect Dis*. 2012 Jul;55(1):137–44

<sup>4</sup> Shepard CW, Finelli L, Alter MJ. Global epidemiology of hepatitis C virus infection. *Lancet Infect Dis* 2005; 5:558-67

<sup>5</sup> Easterbrook P, Sands A, Harmanci H. Challenges and priorities in the management of HIV/HBV and HIV/HCV coinfection in resource-limited settings. *Semin Liver Dis*. 2012 May;32(2):147–57.

<sup>6</sup> Chen T-YY, Ding EL, Seage Iii GR, Kim AY. Meta-analysis: increased mortality associated with hepatitis C in HIV-infected persons is unrelated to HIV disease progression. *Clin Infect Dis*. 2009 Nov 15;49(10):1605–15.

<sup>7</sup> Deng L-P. Impact of human immunodeficiency virus infection on the course of hepatitis C virus infection: A meta-analysis. *World J Gastroenterol*. 2009;15(8):996

<sup>8</sup> Access Campaign. Diagnosis and treatment of hepatitis C: a technical landscape. 2013, Geneva

<sup>9</sup> Chronic Hepatitis C treatment outcomes in low and middle income countries : a systematic review and meta-analysis. *Bulletin of the WHO* 2012; 90:540-550.

<sup>10</sup> New HCV Interim Recommendations available. *Medscape*. Feb 07, 2014

effects of the medication are likely to be significantly reduced; and treatment has a shorter duration. These improvements should both increase uptake of treatment and facilitate retention in care. At the same time, action is being taken to clear the path for generic manufacturing of the drug, which could result in substantial price reductions<sup>11</sup>.

### **1.3. Patient support as part of the package of care**

In MSF projects, the term *patient support* covers all the activities aiming at empowering the patient in front of his illness and treatment, beyond the purely medical aspects of care<sup>12</sup>. These activities of support should be based on discussion, search for support and solutions to the difficulties the patient is facing. Patient support activities have four main goals:

- Understanding and acceptance of the patient's illness and treatment
- Recognition of the consequences of his/her illness in his/her daily life (family, emotional and sexual, friendships, professional, etc.)
- Adaptation of his/her behavior and lifestyle in accordance with the situation
- Involvement and responsibility of the patient in the treatment

Patient support needs to comprise activities offering education and information, but also emotional and social support and thus combines health promotion with mental health support.

Challenges that are faced in order to expand access to HCV treatment to low-resource settings are very similar to the ones faced 10 years ago for upscale of HIV treatment<sup>13</sup>; not only the challenges regarding the cost and the development of better drugs, but also regarding patient support.

Like for HIV, upscale of HCV treatment will need maximum retention in care and improvement of the community and the patient's literacy regarding the disease and treatment. Counseling and education, done by nurses, lay counselors or patient experts, among other actions, has been proven effective for ART adherence<sup>14</sup>. For HCV, similar treatment literacy programs, counseling and peer support are expected to yield the same beneficial outcome.

The new international recommendations for HCV treatment stress the need for patient education and counseling<sup>15</sup>. Recommended fields of focus are prevention of infection and transmission, and lifestyle advice. In order to fight stigma, ensure adherence, prevent worsening of the patient's condition and prevent transmission or reinfection, patient support activities are crucial, and need to be organized alongside the clinical follow-up.

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<sup>11</sup> MSF Access campaign, November 2013 Downloaded from <http://www.msfaccess.org/about-us/media-room/press-releases/gilead-attempt-secure-patent-hepatitis-c-drug-opposed-india>

<sup>12</sup> MSF-OCB, The patient support component in HIV/AIDS projects, 2009

<sup>13</sup> Nathan Ford et al., Expanding Access to Treatment for Hepatitis C in Resource-Limited Settings: Lessons from HIV/AIDS in *Clinical Infectious Diseases* 2012;54(10):1465-72

<sup>14</sup> Scanlon and Vreeman, Current strategies for improving access and adherence to antiretroviral therapies in resource-limited settings, in: *HIV/AIDS - Research and Palliative Care* 2013;5 1–17

<sup>15</sup> Recommendations for Testing, Managing, and Treating Hepatitis C, Infectious Diseases Society of America (IDSA) and American Association for the Study of Liver Diseases (AASLD) Downloaded from <http://www.hcvguidelines.org> (p10-11) on 19 Feb 2014

Furthermore, treatment with DAA's (like Sofosbuvir) instead of Peg Interferon will allow for lighter and more standardized patient counseling and education with a focus on adherence and lifestyle change as no major side effects like depression or psychosis are to be expected. This will also facilitate task shifting from clinicians to nurses or lay counselors, allowing for scale-up and decentralization, thereby bringing the treatment closer to the people.

## **2. Principles of Patient Support for Hep C**

### **2.1. Integrated within clinical follow up**

This guide is a practical tool for patient support activities in MSF HCV projects. The sessions in this guide are organized alongside the main medical follow-up moments to ensure patients get the appropriate support along the care pathway, while not overburdening patients with countless visits to the health facility.

For HIV projects, the patient support activities for HCV need to be integrated in the HIV circuit, with systematic screening of all HIV-infected patients and integration of HCV counseling and education in the existing counseling flow.

An overview of minimal counseling and education sessions can be found on page 4.

### **2.2. Focus of support on diagnosis and initiation of treatment**

The emphasis of the counseling and education is on diagnosis and initiation of treatment –focus is on prevention of transmission/ reinfection and on assisting the patient to overcome the main personal obstacles for treatment adherence; once the patient has started treatment the counseling addresses lifestyle changes.

Adherence should be routinely monitored at every clinic visit by the clinician through a self-report method such as a recall question on missed doses in the last week or a visual analogue scale – Refer to the Patient education and counselling handbook for more info on adherence self-reporting. Two possible self-reporting questions are in the patient adherence plan; the counselor/ clinician can choose one of the two questions at follow-up counselling sessions. Patients with identified adherence or other problems are flagged by the clinician and referred to the counsellor.

### **2.3. Problem-solving around adherence or lifestyle steps to enhance behavior change**

Behavior change and treatment adherence is encouraged through the application of some basic principles of techniques such as *motivational interviewing*. The counselor will work through a standard set of challenges to ensure adherence and lifestyle adaptations. For each adherence or lifestyle goal the counsellor will explore together with the patients what could be possible obstacles for reaching this goal, and will identify an adherence and lifestyle plan. The idea is not coerce the patient into change but rather explore the patient's ambivalent feelings towards change and make him or her 'flip' – drawing out the patient's motivation for change rather than imposing external motivations. For more information about the principles and strategies of motivational interviewing, see [www.motivationalinterviewing.org](http://www.motivationalinterviewing.org)

## **2.4. Ensuring a comprehensive package for injecting drug users**

A substantial amount of infections happens through sharing of needles and other drug injecting paraphernalia among intravenous drug users (IVDU). Hepatitis C treatment should be embedded in a comprehensive package of interventions like opioid substitution and needle exchange programs<sup>16</sup>. Each project will have to set up or map out the existing services and partners that provide this support. Identification of IV drug users can be done by the counselor or nurse, who can then refer the patients to the adapted services.

The guideline suggests when to screen for IV drug use and when to refer the patient; it does not describe any specific patient support activities for IV drug users.

## **2.5. Additional tools and strategies for retention in care**

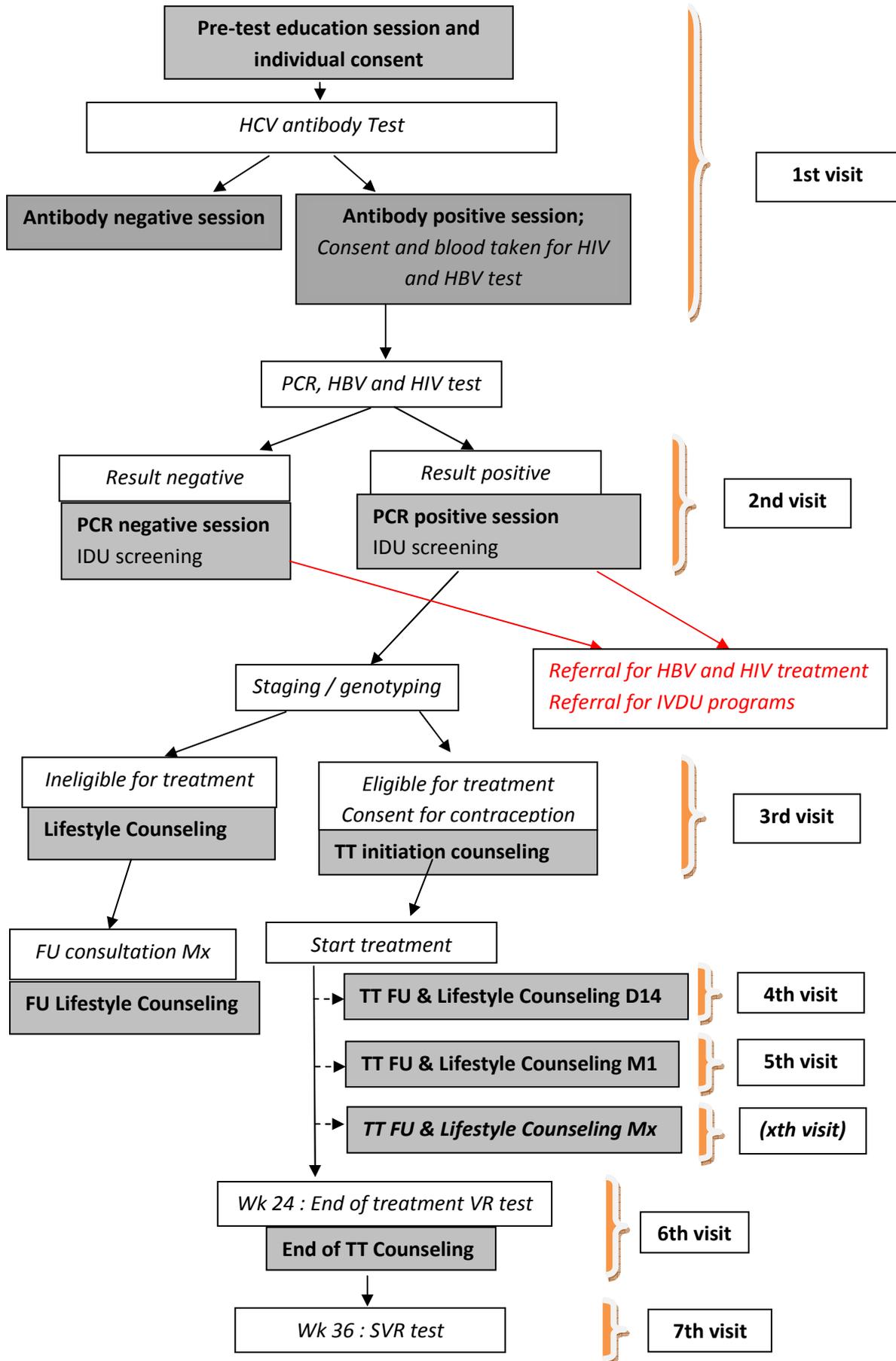
We recommend some additional tools and activities to be used / set up in the project, in order to allow maximum effectiveness of the patient support component:

- Patient tracing: Patients missing appointments should be traced and motivated to return back to care and continue treatment. Definition of a missed appointment is to be established in the project, eg. a no show for 1 day/ 2 days/ one week after the scheduled appointment. Tracing can be done by phone, SMS or home visits. This activity requires an appointment book to correctly identify patients who missed an appointment and a communication flow between the tracer and health care worker to share the outcomes of the tracing.
- Service promotion activities to promote screening and testing for Hepatitis C can be set up in the community to target specific risk groups.
- According to the project's context, a transport reimbursement scheme can be considered.

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<sup>16</sup> European Monitoring Centre for Drugs and Drug Addiction. *Hepatitis C treatment for injecting drug users*. 28/5/2013 downloaded from <http://www.emcdda.europa.eu/topics/pods/hepatitis-c-treatment>

### 3. Flow of counseling sessions



## Notes on the patient flow

1. The grey boxes represent the counseling and education sessions. Their content is outlined further in this guide. The white boxes in between represent key medical moments (a medical act or the receipt of a test result). Each project should identify who will offer the patient education and counselling as it can be a clinician, a nurse, a lay counselor or an external service if trained. Some of the medical interventions (eg. anti-body test, negative PCR result,...) don't need a separate clinician consult but can be integrated in the counseling sessions.
2. The red arrows refer to follow-up in *or* outside the MSF structure such as HIV treatment programs and care or support for IV drug users such as opioid substitution and needle exchange programs.

## 4. Monitoring and evaluation

Monitoring and evaluation of patient support activities is essential to follow up its implementation and to adapt the services accordingly.

- The numbers of sessions performed (as opposed to percentages) are important to monitor counselor work load. This data can be gathered through a monthly tally sheet whereby workload per day per counsellor can be identified.
- The quality of counseling sessions should be monitored through regular observation of sessions, review of counselling notes in the patients' files and case discussions<sup>17</sup>.
- The coverage of sessions will show if patients receive the support that is set forward. Targets for the coverage percentages are proposed– whose feasibility needs to be looked into and evaluated in each project.

| Indicator  | Target | Numerator   | Denominator   |
|--|--------|---|---|
| Percentage of patients who accepted the antibody test  | 90%    | Number of pre and post-sessions / Anti-body tests done  | Number of patients who were proposed an antibody test |
| Percentage of patients who received the PCR result   | 90%    | Number of PCR result sessions   | Number of samples sent to lab for PCR                 |
| Percentage of patients eligible for treatment attending the treatment preparation session                | 90%    | Number of treatment preparation sessions  | Number of patients eligible for treatment             |
| Percentage of patients not eligible for treatment attending 1 <sup>st</sup> lifestyle counseling session | 90%    | Number of 1 <sup>st</sup> lifestyle counseling sessions for patients not eligible for treatment | Number of patients not eligible for treatment         |
| Percentage of patients attending 1 <sup>st</sup> TT follow-up and lifestyle counseling session           | 90%    | Number of 1 <sup>st</sup> treatment follow-up and lifestyle counseling sessions                 | Number of patients eligible for treatment             |
| Percentage of patients not eligible for treatment attending 2 <sup>nd</sup> lifestyle counseling session | 80%    | Number of 2 <sup>nd</sup> lifestyle counseling session for patients not eligible for treatment  | Number of patients not eligible for treatment         |
| Percentage of patients attending 2 <sup>nd</sup> TT follow-up and lifestyle counseling session           | 80%    | Number of 2 <sup>nd</sup> treatment follow-up and lifestyle counseling session                  | Number of patients eligible for treatment             |

<sup>17</sup> Médecins Sans Frontières, *Patient education and counselling. Handbook for HIV/TB infected adult patients*, March 2012

Source of verification: counseling tally sheet (see Annex 3 p31) for numerator and medical data for denominator.

## 5. Content of counseling sessions

| 1a. Pre-test education session |   |              |   |
|--------------------------------|---|--------------|---|
| <b>Target group</b>            | Patients eligible for screening   |              |   |
| <b>Objectives</b>              | To provide the basic information on HCV infection, transmission and treatment<br>Obtain consent for anti-body testing |              |   |
| <b>Timing</b>                  | At referral for HCV screening   | <b>Mode</b>  | Group + individual consent<br>Or fully individual |
| <b>Duration</b>                | 10 minutes + 30 minutes test  | <b>Tools</b> | HCV flipchart                                     |

## Introduction

- Introduce yourself
- Explain the objective of the session

### 1. What is HCV or hepatitis C? **CARD 1**

The word 'hepatitis' means inflammation of the liver. Hepatitis C is an infection, caused by a virus called Hepatitis C virus. Although hepatitis C also affects other parts of the body, your liver is the organ most affected. Your liver is an essential organ with a lot of important functions: it removes bad substances from your blood and it makes sure you have enough sugar, vitamins and hormones to keep your body functioning.

### **CARD 2**

- The first six months, the infection with the Hepatitis C virus is called **acute infection**. Most people don't notice any symptoms. During this time, the body can sometimes get rid of the virus on its own, because our immune system, the soldiers of our body, fights off the virus. We say the virus is cleared. In this case, treatment will not be needed. About 1 person out of 5 will clear the virus.
- Most people will develop a **chronic infection**. You may not notice any symptoms for several years, as hepatitis C develops slowly. If your hepatitis C is chronic, in three out of four cases, you will have only very mild to moderate damage to your liver over time.
- However, in one out of four cases, chronic hepatitis C can lead to more serious problems and the liver will not be able to perform its functions anymore: a patient can develop cirrhosis, liver failure and liver cancer over a period of 25 to 30 years.

### 2. How is HCV transmitted? **CARD 3**

- HCV can be transmitted through contact with infected blood. You can only contract HCV if you come into direct contact with an infected person's blood. HCV can live outside of the body for days to weeks and is infectious even after blood has dried.
- Syringes and other injection equipment, toothbrushes, razor blades, manicuring tools or other sharp objects and tattooing or body piercing materials can contain the hepatitis C virus. Very often the infection is transmitted through contaminated medical equipment like needles.
- Women who are infected can transmit the virus to their children during pregnancy or delivery.
- *Although it's rare, transmission through unprotected sex is possible so you should protect yourself and your partner by using condoms.*

### 3. How can you prevent hepatitis infection? **CARD 4**

You should avoid contact with unsafe blood, even dried blood. Always make sure that medical and dental equipment is clean and safe, that syringes haven't been used and that razor blades are new.

You should avoid using injections when it is not needed. Most of the time, taking pills is as effective as having an injection.

### 4. What is the treatment for HCV?

People who cleared the virus after 6 months do not need treatment.

For patients with a chronic infection, making some changes in the lifestyle is the most important. They should avoid drinking alcohol and smoking and should make sure they eat enough fruit and vegetables and not too much fat food. This way, liver damage can be

prevented and an infected person increases the chance to stay healthy.

Hepatitis C can be treated, but this treatment is not necessary for everybody. This means some people will not be put on treatment, even with chronic infection.

Treatment is available in this health center for patients who need it. It consists of a combination of two types of pills that need to be taken daily for 6 months. The treatment will get rid of the virus and prevent more liver damage.

**5. What is the testing procedure?**

HCV testing is done in **2 steps**.

- A first test is an antibody test. This test will look if your immune system has had to fight against HCV. If the result is positive, it means that you have been infected with hepatitis C in the past, and that you may still be infected. It does not mean that you are chronically infected. In case your results are negative, it is advised to take another test within six months. That is the time it takes for the virus to be visible in your blood.
- If your first test is positive, we move to the second step, to check if you have the chronic infection. This test takes some more time. If this test is positive, it means you have chronic HCV and you might need to take the treatment to avoid getting ill.

We want to offer you the first test now, but it is your right to say you do not want a test. Your results are confidential and will not be shared with anybody else.

-----  
**6. Ask for consent\***

-Can you tell me what hepatitis C is?

-How is hepatitis C transmitted?

-You are free to decide to take the test. Do you agree to take the HCV test?

**7. Explain the test procedure**

- The first step to knowing whether you are infected with hepatitis C is the test we will perform today. Test is done right here, with a finger stick test, just taking a very small drop of blood. You will know the result after 20 to 30 minutes.

**8. Perform the anti-body test.**

*\*If the pre-test education session was done in group, part 6, 7 and 8 will be done as a separate session, individually.*

| 2a. Anti-body negative session   |  |              |               |
|--|--|--------------|---------------|
| <b>Target group</b>  | Patients with negative anti-body test  |              |               |
| <b>Objectives</b>  | To provide the meaning of the negative result<br>To reinforce the prevention message |              |               |
| <b>Timing</b>  | Right after the anti-body screening, same session.                                   | <b>Mode</b>  | Individual    |
| <b>Duration</b>  | 10 minutes   | <b>Tools</b> | HCV flipchart |
| <p><b>1. Sharing of the result</b></p> <ul style="list-style-type: none"> <li>- The result of the test is negative. This means that at the moment, there is no sign in your blood that you have been exposed to the hepatitis C virus.</li> </ul> <p><b>2. Window period</b></p> <ul style="list-style-type: none"> <li>- It takes some time for the antibodies to become visible in the blood. This means that in case you were recently exposed to the virus, the antibodies might not be visible yet while you do have an acute infection. I therefore advise you to take the test again in 6 months to make sure you are not infected.</li> </ul> <p><b>3. Risk reduction plan <b>CARD 3</b> and <b>CARD 4</b></b></p> <ul style="list-style-type: none"> <li>- Do you remember the ways of transmission of the hepatitis C virus?</li> <li>- What can you do in your daily life to make sure you do not become infected?</li> <li>- Do you feel that you might encounter difficulties in applying one of these precautions?<br/><i>(Explore medical treatment through injections, drug use, sharing of razor blades and manicure tools,...)</i></li> </ul> <p><b>4. Closing of session</b></p> <ul style="list-style-type: none"> <li>- Ask if the patient has any more questions.</li> </ul> |  |              |               |

| 2b. Anti-body positive session |   |              |                                       |
|--------------------------------|---|--------------|---------------------------------------|
| <b>Target group</b>            | Patients with positive anti-body test   |              |                                       |
| <b>Objectives</b>              | To provide the positive result<br>To explain the procedure for further HCV testing<br>To obtain consent for HBV and HIV testing |              |                                       |
| <b>Timing</b>                  | After the anti-body screening, same session.  | <b>Mode</b>  | Individual                            |
| <b>Duration</b>                | 20 minutes  | <b>Tools</b> | HCV flipchart<br><i>HIV flipchart</i> |

### **1. Sharing of the result**

The result of your test is positive. This means that you have been exposed to the hepatitis C virus. There is a chance that your body has cleared the virus, and that you are no longer infected. It is also possible that you have a chronic infection, which could slowly affect your liver.

### **2. Testing of household members**

- Can you tell me what was said about the ways of transmission of the virus? (verify and complete knowledge)
- People living very close run the risk of transmitting the virus to each other, because in rare cases blood contact may occur.
- It is recommended that you invite your household members also for testing to be sure that nobody else in your family is infected. Can you invite them for an HCV test? What could keep you from talking to your family?

***Make a note in the patient's file about who should come for testing; follow up at next session***

### **3. Explain the Further HCV testing procedure**

We need to take further tests to establish whether you have a chronic hepatitis C infection. For these tests we will need to take some blood and send it to the lab.

### **4. Explain Further testing for HBV**

- Since HCV is transmitted through contact with contaminated blood, you could also be infected with other viruses that are spread through blood contact, like hepatitis B and HIV. As these other infections might have an influence on the hepatitis C infection and could make the treatment more difficult, it is important to know whether you are infected.
- We would therefore like to take some blood to send for testing for hepatitis B. If you are not vaccinated against hepatitis B we can give you the vaccine after testing.

### **5. Explain Further testing for HIV**

- As we said before, another virus that can be transmitted through blood is HIV. What do you know about HIV?
- HIV is a virus that attacks this immune system (the CD4 cells): slowly the body will become weaker. Even if you are feeling well, the virus is causing damage in your body. All kinds of diseases will be able to enter: fever, diarrhea, TB, mouth sores. Without treatment, the virus will continue to damage the immune system and eventually, an infected person will die.
- There are 3 ways of transmission of HIV:
  - o 1. through sexual contact
  - o 2. from a mother to her child during pregnancy, delivery or breastfeeding
  - o 3. through contact with infected blood
- There is no cure for HIV but there is a treatment that can control the virus. For this treatment to work best, it is important to know as soon as possible whether one is infected.

### **6. Consent**

- It is your choice to take the tests. All results are confidential and will not be shared with anyone else. Do you agree to take the tests?
- Please come back to the clinic for follow-up in .... weeks

### 3a. PCR negative session

|                     |  |              |               |
|---------------------|--|--------------|---------------|
| <b>Target group</b> | Patients with a negative PCR test  |              |               |
| <b>Objectives</b>   | To provide the negative result<br>To reinforce the prevention of message |              |               |
| <b>Timing</b>       | At 2 <sup>nd</sup> visit, after PCR test results                         | <b>Mode</b>  | Individual    |
| <b>Duration</b>     | 10 minutes   | <b>Tools</b> | HCV flipchart |

#### 1. Sharing of the result

The result of the blood test is negative; this means that you do not have a chronic hepatitis C infection, and that your body managed to clear the infection. You no longer have HCV.

#### 2. Risk reduction plan **CARD 3** and **CARD 4**

##### Explain the goal:

Your infection cleared by itself, but it is however very important to ensure you do not to become infected again.

##### Identify barriers:

Can you tell me the ways the virus is transmitted?

Is there anything that might be difficult for you to avoid?

Have you ever used injections for other than medical reasons?

##### Make a plan:

-One of the big sources of infection is through medical procedures that are unsafe. To be sure, you should avoid using injections when it is not needed. Most of the time, taking pills is as effective as having an injection. The medication goes into the blood stream and attacks the disease through the blood; injections do not work faster or better.

*-For suspected IV drug users: talk about the importance of use of clean needles and other tools and refer to the appropriate services.*

#### 3. Proposal of Hep B Vaccination

- Hepatitis C can only be prevented through avoiding contact with blood. For hepatitis B there is a vaccine.

- Have you been vaccinated? In case no, would you be willing to take the vaccine?

***Refer to consultant for vaccination if necessary***

#### 5. Closure of session

Ask if the patient has any more questions.

### 3b. PCR positive session

|                     |  |              |               |
|---------------------|--|--------------|---------------|
| <b>Target group</b> | Patients with a positive PCR test                      |              |               |
| <b>Objectives</b>   | To provide the positive result and prepare for staging |              |               |
| <b>Timing</b>       | At the 2 <sup>nd</sup> visit, after PCR test results   | <b>Mode</b>  | Individual    |
| <b>Duration</b>     | 20 minutes   | <b>Tools</b> | HCV flipchart |

#### 1. Introduction

Introduction of the counsellor and objective of the counseling session

#### 2. Share the positive result

We found the Hepatitis C virus in your blood. This means that you are chronically infected with HCV.

#### 3. Assess the patient's knowledge on hepatitis C

Can you tell me what you know about hepatitis C?

If necessary, complete with the following, using **card 1** and **card 2**:

- A person with hepatitis C may not have symptoms for many years, and some people never develop symptoms. Hepatitis C can attack very slowly.
- Although hepatitis C also affects other parts of the body, your liver is the organ most affected. Your liver is an essential organ with a lot of important functions: it is like your body's dispatching center: it removes bad substances from your blood and it makes sure you have enough sugar vitamins and hormones to keep everything functioning.
- The virus will make the liver hard and becomes less elastic. So it will be more difficult for blood and other fluids to flow freely through the liver. A person with chronic HCV experiences health complications when his liver is no longer able to carry out important tasks. In the long hepatitis C can lead to more serious problems including cirrhosis, liver failure and liver cancer over a period of 25 to 30 years.

#### 4. Your care pathway: HCV staging

Not everybody infected with HCV needs to be put on treatment. The disease only progresses in some infected people; for others, they will be HCV+ but not have a lot of consequences for their health. Only the patients, who have to some degree liver damage, need to be put on treatment. The treatment is not easy and does not work for everyone; this is why we do not put all HCV positive people on treatment. Sometimes, it is better to live with the virus.

In order to take this decision, we need to look at your liver, to see whether the virus is doing some damage. Therefore we will refer you to ..... where some tests will be performed. We will receive the results ..... days after the tests are done, so we ask you to come back to the clinic for a follow-up consultation. If the tests indicate that the virus is attacking your liver

than you will start treatment, if not, then you will receive further support as to how to adapt your lifestyle and ensure you can live a healthy life with the virus.

## 5. Make an adherence Plan

*Fill out the conclusions in the patient's adherence plan – see Annex 1 p26*

### **My reasons to stay healthy:**

Hepatitis C is a disease that affects your life, but with some effort and changes in your lifestyle and for some adherence to medication you can live a healthy life.

First of all, what is important in your life? What can motivate you to stay healthy?

### Adherence step 1: Identify a support system

#### **Explain adherence goal:**

It can be a big help if you have someone close to you who is aware that you have hepatitis C. Sharing some of the things you experience can relieve the burden. The other person will be able to help you remember to take your medication if needed or to respect your appointments at the clinic.

#### **Identify barriers:**

Is there anyone you have told about your previous test result?

What makes you reluctant to tell people about this result or the treatment?

#### **Make a plan:**

Which words could you use to talk about this? Who is most likely to offer support?

### Adherence step 2: Prevention of transmission

#### **Explain lifestyle goal:**

To protect the people around you, it is important to make sure they don't become infected

#### **Identify barriers:**

What do you remember about the ways the virus is transmitted?

Could you tell me which of your habits could pose a risk of transmission?

Have you ever injected drugs? Or have you ever used injections not for medical reasons?

#### **Make a plan:**

How could you make sure not to share razor blades or toothbrushes? Is there a specific place you can keep yours?

*For suspected IV drug users: talk about the importance of use of clean needles and other tools and refer to the appropriate services.*

### Adherence step 3: Planning for future appointments

#### **Explain adherence goal:**

During the coming months you will need to come regularly to the clinic for medical follow-up and counseling about lifestyle adaptations.

#### **Identify barriers:**

How do you get to the clinic?

In the past, have you encountered any difficulty in coming to the health center?

What could prevent you in the future from respecting your appointment?

#### **Make a plan:**

Is there anyone in your household who can help you out when something interferes with your appointment?

How can you make sure you remember the appointment?

Would you agree if a community health worker contacts or visits you if you miss an appointment?

*Write down the correct phone number and address, also the number of a contact person.*

#### **6. Proposal of Hep B Vaccination**

- Hepatitis C can only be prevented through avoiding contact with blood. For hepatitis B there is a vaccine.

- Have you been vaccinated? In case no, would you be willing to take the vaccine?

#### **7. Closure of session**

Check if patient has any further questions and make a new appointment; refer the patient to the consultant for Hep B vaccine.

***Note: HIV positive patients will need further counseling***

*Please refer to the patient counseling and education guideline for HIV/Aids<sup>18</sup>, for guidance on announcement of a positive result and basic HIV information.*

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<sup>18</sup> Médecins Sans Frontières, *Patient education and counselling. Handbook for HIV/TB infected adult patients*, March 2012

| 4a. Lifestyle session   |   |              |               |
|---|---|--------------|---------------|
| <b>Target group</b>   | Patients who have positive PCR test and who do not correspond to the treatment criteria   |              |               |
| <b>Objectives</b>   | To explain the reasons for non-eligibility<br>To ensure prevention and medical follow-up: lifestyle, prevention of transmission and vaccination |              |               |
| <b>Timing</b>   | After staging / at 3 <sup>rd</sup> visit<br><br>Clinician should refer for lifestyle counseling after each medical follow-up visit              | <b>Mode</b>  | Individual    |
| <b>Duration</b>   | 20 minutes  | <b>Tools</b> | HCV flipchart |
| <p><b>1. Introduction</b></p> <ul style="list-style-type: none"> <li>- Introduction of the counsellor</li> <li>- Check what doctor told the patient and asses how the patient feels</li> <li>- We performed several tests to see how the disease has progressed and what the effects are on your liver. Based on the results the doctor has decided that at this point it is not necessary to put you on treatment.</li> </ul> <p><b>2. Reasons for non-eligibility</b></p> <ul style="list-style-type: none"> <li>- What do you remember about how the virus affects the body? <ul style="list-style-type: none"> <li>A. As we discussed in the previous session, HCV acts very slowly. In the majority of infected people, the virus remains stable and doesn't cause any severe damage to the liver or other organs. As you do not have any sign of major liver damage are not put on treatment. By taking some basic precautions it is possible to control HCV and not become ill.</li> </ul> </li> </ul> <p>Can we discuss some of these precautions?</p> <p><b>3. Review adherence step 1 and step 2</b></p> <p><b>4. Make a lifestyle plan <span style="background-color: red; color: white; padding: 2px;">CARD 8</span></b><br/> <b><i>Fill out the patient's lifestyle plan</i></b></p> <ul style="list-style-type: none"> <li>- <u>Lifestyle step 1: Keeping a healthy diet</u><br/> <b>Explain lifestyle goal:</b><br/> Your eating habits are important to keep your liver well.<br/> Remember we discussed the functions of the liver. One of these is to remove all bad substances from the body. What you eat and drink has direct consequences for your liver. the best thing to keep your liver healthy is to take care of your body weight and to have a well-balanced diet:<br/> The first thing to keep your liver healthy is to take care of your body weight and to have a well-balanced diet, like in the plate on this image: Eat plenty of fruit and vegetables and whole-wheat grains. Limit meat and avoid as much as possible food high in fat or sugar. Drink plenty of water throughout the day and exercise to keep your body in good shape.</li> </ul> |   |              |               |

**Identify barriers:**

What do your meals look like currently? Who does the cooking at home?

How easily could you change something in your diet, for example eating more fruit or vegetables?

At what moments do you tend to eat greasy or sweet snacks?

**Make a plan:**

How could you discuss food preparation at home? Which alternatives could you suggest?

How can you make sure you limit fat intake and ensure enough vegetables and fruit?

What could be a healthy snack?

- Lifestyle step 2: avoiding alcohol and drugs

**Explain lifestyle goal:**

Hepatitis can become worse if the patient drinks alcohol. To keep your liver healthy, it is best to avoid alcohol as much as possible.

Using drugs is also a heavy burden for your liver as it has to remove a lot more toxins. The best thing would be to avoid all recreational drugs.

**Identify barriers:**

Let us have look together at your alcohol habits:

1. Have you felt you should cut down on your drinking or drug use?
2. Have people annoyed you by criticizing about your drinking or drug use?
3. Have you ever felt bad or guilty about your drinking or drug use?
4. Have you ever had a drink or used drugs first thing in the morning to steady your nerves or to get rid of a hangover?

Do you feel it is possible for you to diminish alcohol intake/ drug use? How ready do you feel to quit, on a scale from 1 to 10 (where 1 is not feeling ready at all, and 10 is feeling absolutely ready)?

**Make a plan:**

⇒ Two or more yes at screening suggests a potential problem of alcohol abuse and specialized care might be needed. Refer to the appropriate services

What would you need to feel stronger about quitting or diminishing drinking? (*If you used the scale, 'What would be needed to bring you from a score 5 to 7?' (or 6 to 8, etc) )*

- Lifestyle step 3: tobacco use (for smokers only)

**Explain lifestyle goal:**

There is evidence that smoking increases the damage to your liver. To ensure that the treatment has the desired effect and to prevent further damage, it would be advisable to stop smoking.

**Identify barriers:**

How many cigarettes do you smoke a day?

Do you feel the urge to smoke right after you wake up?

Have you tried to quit before? What might be holding you back to stop smoking?

**Make a plan:**

How ready do you feel to quit smoking?

What could help you to feel more ready to stop?

What could be a way to put your thoughts off smoking? What are some activities you can do when you feel the urge?

Who could be your buddy to stop smoking? Either someone who will quit the same time, or someone you can talk to when you feel the urge for a cigarette.

For some people, it helps to define a specific day to stop smoking and throw away any remaining cigarettes. Which could be your stop-smoking day?

### Review adherence step 3: Future appointments

*Make an appointment for follow-up according to the timeframe for medical follow-up.*

### 5. Closure of session

Ask if the patient has any more questions.

Give a copy of the patient's adherence plan to the patient and put one in the patient's file.

## 4b. Treatment initiation session

|                     |  |              |               |
|---------------------|--|--------------|---------------|
| <b>Target group</b> | Patients who are eligible for HCV treatment  |              |               |
| <b>Objectives</b>   | <p>To explain the reasons for eligibility</p> <p>To explain the importance of the use of contraception</p> <p>To develop a plan for good adherence</p> |              |               |
| <b>Timing</b>       | After clinician announced the staging result   | <b>Mode</b>  | Individual    |
| <b>Duration</b>     | 20 minutes   | <b>Tools</b> | HCV flipchart |

### 1. Introduction

-Explain the goal of the session

### 2. Treatment education

- In the past period we did some tests, to see how the virus was progressing. The doctor estimated that it is important for you to take the treatment, because there is already some damage to the liver. The treatment should get rid of the hepatitis C virus. The treatment will take 6 months. We will know for sure whether the virus is gone through a test 12 weeks after the end of treatment.

- There are 4 important points you need to know before starting treatment.

#### Medication schedule **CARD 5**

The treatment for hepatitis C lasts 6 months. For this treatment, you need to take 2 different types of medication: Ribavirin and Sofosbuvir. Sofosbuvir is taken once a day. Ribavirin should be taken in the morning and in the evening, with food. It is very important that you take the pills every day, and that you take the treatment the full 6 months.

#### Missed doses

It can happen that you forget to take a dose. In this case, skip it and continue the schedule

as before. Don't take a double dose to compensate for the time you forgot.

Side effects **CARD 6**

The treatment has minor side effects. You might feel fatigue, some headache and nausea. If side effects persist ask your doctor for advice. Do not interrupt the treatment.

Self-medication **CARD 7**

The medication for hepatitis C should not be combined with other pills without medical approval because some drug interactions can be dangerous. Always consult your doctor first, before taking any other treatment like antibiotics, paracetamol or any herbal treatments.

**3. Review motivation to stay healthy**

What was your main motivation to stay healthy?

**Identify barriers:**

Which other questions do you have about hepatitis C or about the treatment?

Can you share some of the doubts you might have about starting the treatment?

**Make a plan:**

Do you feel ready to start treatment today?

*In case no: **book for other session***

**4. Revision and further development of adherence plan**

Revision of steps 1, 2 and 3

Adherence step 4: contraception **CARD 9**

The medication is very effective to combat the virus, but during the treatment until 6 months after treatment, you should not become pregnant / your wife should not become pregnant as the drugs can cause deformations of the fetus. This means taking contraception for at least a year. If you are planning to have a baby in the near future, we advise you to wait with the treatment until after the birth (women)/ after conception (for men). We will take a pregnancy test to be sure you are/ your wife is not pregnant, and in the course of the treatment, we will repeat the pregnancy test several times.

**Identify barriers:**

Are you already on family planning?

If no, how do you feel about starting family planning now or how will your partner feel about this?

Which FP methods do you know and what would be your preferred method?

**Make a plan:**

In case female patient accepts: refer to the consultant

In case of male patient: identify how patient will address this with partner and make an appointment for the patient to come with the wife for pregnancy test and contraception.

Adherence step 5: Creation of a medication schedule

**Explain adherence goal:**

The treatment for hepatitis C consists of taking two different pills. Ribavirin is taken in the morning and in the evening, with food. Sofosbuvir is taken once a day.

**Identify barriers:**

What does a regular day look like for you? How about the weekend?

**Make a plan:**

What would be the best time for you to take your medication?

Is there anything in the daily routine that you can link to taking your medication?

Adherence step 6: remembering to take medication

**Explain adherence goal:**

It is human to forget to take medication. But there are some tricks that make it easier for you to remember the drugs.

**Identify barriers:**

What difficulties have you previously faced with remembering to take medication (like antibiotics or other)? How have you previously reminded yourself to take this medication?

**Make a plan:**

What reminders you can use to remember taking the medication (ex cell phone alarm or involve family members)?

Adherence step 7: Storage of medication and keeping extra doses

**Explain adherence goal:**

It is important to identify a convenient place at home to store your drugs, where they are kept safe, dry and not too warm. Also, you should carry some with you in case you do not return home in time to take them.

**Identify barriers:**

What could be your difficulties in storing medication or keeping extra doses with you

**Make a plan:**

Where can you store your medication safely?

Where could you carry an extra dose of drugs in case you don't make it home in time? What can you keep them in (plastic bag or container)?

Adherence step 8: Dealing with side effects

**Explain adherence goal:**

The medication you take fights the hepatitis C virus. It is possible that there are some side effects. Although this medication does not have many side effects the type and the severity of the side effects depend on each person. Some common side effects are fatigue, headache and sometimes nausea (Sofosbuvir). Some people become anemic (they have a lack of red blood cells in the blood which makes you feel tired and weak) after a couple of months (Ribavirin).

**Identify barriers:**

How do you feel about the possibility of side effects? What will you do when some of these appear?

**Make a plan:**

If headache persists or you feel very weak, please come back to the clinic and talk about it with the doctor, who can advise you what to do. Do not decide to stop treatment without medical approval.

What could you do when you feel tired? Is there a way to schedule short naps during the day?

Remember to drink enough water, to eat balanced meals and to get enough rest; this will

also help feeling less tired.

We will test your blood several times during treatment to make sure all is well.

**5. Closure of session**

Ask if the patient has any more questions.

Give a copy of the adherence plan to the patient if possible and keep one copy in the patient's file.

## 5. D14 Treatment follow-up and lifestyle session

|                     |  |              |   |
|---------------------|--|--------------|---|
| <b>Target group</b> | Patients who have started treatment                          |              |   |
| <b>Objectives</b>   | Follow-up of adherence plan<br>Provision of lifestyle advice |              |   |
| <b>Timing</b>       | At D14   | <b>Mode</b>  | Individual                              |
| <b>Duration</b>     | 15 minutes   | <b>Tools</b> | Patient's adherence plan, HCV flipchart |

### 1. Introduction

-Introduce yourself and the goal of the session

### 2. Assess adherence

- During the last 7 days, in total, how many times did you miss any of your pills?  
What could have caused you to miss the dose?

**Or**

- During the last month, how much of the prescribed medication did you take? For most people this is not all of them. Can you indicate on the scale? 0% means you did not take any, 100% means you took all of them.

*Show the scale on the patient's adherence plan*

### 3. Review adherence plan

Go through the steps of the adherence plan that was put together during the Treatment initiation-session. Discuss how obstacles were dealt with and review the adherence steps if necessary.

### 4. Make a Lifestyle plan: diet, alcohol, tobacco **CARD 6**

The treatment will be more effective if, apart from taking the pills, you take some other precautions. Our lifestyle has a big influence on our health. If our body stays healthy, it will also be more able to fight the virus. These are a few precautions you can take regarding your diet, and tobacco and alcohol use.

*Refer to the Lifestyle steps of Session 4a. Lifestyle Counselling*

### 5. Closure of session

- Check if patient has any further questions and make a new appointment.

## 5. M1 treatment follow-up and lifestyle session

|                     |  |              |   |
|---------------------|--|--------------|---|
| <b>Target group</b> | Patients who have started treatment and have had at least 1 previous follow-up visit |              |   |
| <b>Objectives</b>   | Follow-up of adherence plan<br>Follow-up of lifestyle plan                           |              |   |
| <b>Timing</b>       | At M1 or after any following medical consultation, when referred by clinician        | <b>Mode</b>  | Individual  |
| <b>Duration</b>     | 20 minutes   | <b>Tools</b> | Patient's adherence and lifestyle plan, HCV flipchart |

### 1. Introduction

-Introduce yourself and the goal of the session

### 2. Assess adherence

- During the last 7 days, in total, how many times did you miss any of your pills?  
What was it that caused you to miss the dose?

*or*

- During the last month, how much of the prescribed medication did you take? For most people this is not all of them. Can you indicate on the scale? 0% means you did not take any, 100% means you took all of them.

*Show the scale on the patient's adherence plan*

### 3. Review adherence and lifestyle plan

- Go through the steps of the adherence plan that was put together during the preparation for treatment-session and lifestyle steps in the lifestyle session. Discuss how obstacles were dealt with and review the adherence steps if necessary.

#### Adherence step 9: Planning for trips

##### **Explain adherence goal:**

For the treatment to work, it is important you take the pills every day. Let's discuss how to deal with unexpected events so that you always have enough pills.

##### **Identify barriers:**

Do you plan to travel in the coming months?

Has it happened that you suddenly had to leave on a trip?

Do you regularly go away to a place that is far away from your Health facility.

##### **Make a plan: CARD 10**

How will you make sure you have sufficient medication when you travel?

If you decide to move far away from the clinic for a longer period, you should attend another health facility for medical follow-up. You should get your file here before leaving and a transfer letter from your doctor. Also keep the phone number of this health facility in

your phone so that you can contact us in case it is needed.

Adherence step 10: Avoiding self-medication

**Explain adherence goal: CARD 7**

For the treatment to work, it is important you don't mix with other medication that was not prescribed here at the health center. There could be some drug interaction that can be dangerous. Especially paracetamol or anti-inflammatory drugs are to be avoided.

**Identify barriers:**

In what cases do you do take medication that is not prescribed?

What type of medication do you take without a prescription?

Would could prevent you from first checking with your doctor, before taking other drugs?

**Make a plan:**

What can you do if you have complaints and you feel you need medication to lighten the pain?

**4. Closure of session**

- Check if patient has any further questions and make a new appointment.

## 6. End of treatment session

|                     |  |              |               |
|---------------------|--|--------------|---------------|
| <b>Target group</b> | Patients who have completed the 24 week treatment                                  |              |               |
| <b>Objectives</b>   | Ensure follow-up for SVR test<br>Ensure continuation of contraception for 6 months |              |               |
| <b>Timing</b>       | After the medical consultation   | <b>Mode</b>  | Individual    |
| <b>Duration</b>     | 10 minutes   | <b>Tools</b> | HCV flipchart |

### 1. Introduction

Congratulate the patient with completion of the treatment.

### 2. Education on need for follow-up test after treatment completion

You completed the full 6 months of treatment. Most probably, you are no longer infected with Hepatitis C. A small percentage of patients however do not respond to this treatment. This is not because they didn't take the treatment well, but because the virus they are infected with, is more difficult to get rid of.

We would like to do a blood test to see whether the virus can still be detected in your blood.

If there is no trace of the virus, we do a final blood test in 3 months. If this final one is clear, it means you are really cured.

Make sure you come back to the clinic for this final test.

***Verify again phone number, address and contact person for defaulter tracing purposes as in adherence plan.***

### 3. Education on need for continuation of contraception

How do you feel about the contraception you were prescribed?

Remember the medication you took, has a strong effect on the fetus in case you (your wife) becomes pregnant. So it is very important that you wait to have a baby until 6 months after finishing the treatment.

### 4. Education on how to prevent future transmission of Hep C

Do you remember the ways of transmission of the hepatitis C virus?

What can you do in your daily life to make sure you do not become infected again?

Do you feel that you might encounter difficulties in applying one of these precautions?

*(Explore medical treatment through injections, drug use, sharing of razor blades and manicure tools,...)*

One of the big sources of infection is through medical procedures that are unsafe. To be sure, you should avoid using injections when it is not needed. Most of the time, taking pills is as effective as having an injection. The medication goes into the blood stream and attacks the disease through the blood; injections do not work faster or better.

### 5. Closure of session

Check if patient has any further questions and make a new appointment after the test results.

# Annex 1: Adherence and lifestyle plan template

Name patient: ..... Date of positive PCR session:.....

Phone number: ..... Address:.....

My motivation to stay healthy / start treatment is:  
 .....

**Adherence step 1: Support system** **Disclosure: ok / not ok**

I have not shared my HCV test result because .....

I will disclose to:.....

If necessary, the person who can help me disclose to my family is .....

Household members to be tested:.....

**Adherence step 2: prevention of transmission**

Possible risk behaviors are .....

I will limit transmission risk by .....

**Adherence step 3: Future appointments** **Agrees to home visit: Yes No**

How will I get to my appointments: .....

Back-up plan if anything interferes with the appointment:.....

How will I remember my appointments: .....

Phone number of contact person: .....

**Adherence step 4: contraception:**

How I will discuss this with my wife/ husband:.....

I am most confident to use the following contraception method:.....

We will not have a pregnancy until..... (date 6 months after end of treatment)

**Adherence step 5: Medication schedule**

Best time to take treatment is:.....(2xRibavirin) and ..... (1xSofosbuvir)

Special attention in weekend or on holidays:.....

**Adherence step 6: Reminders**

My trick to remember the medication is:.....

**Adherence step 7: storage of medication**

I will store my drugs at home in:.....

|   |
|---|
| I will keep extra doses at:.....                              |
| <b>Adherence step 8: Side effects</b>                         |
| When I experience side effects, I will.....                   |
| To prevent fatigue, I will.....                               |
| <b>Adherence step 9: Planning for trips</b>                   |
| When I suddenly have to travel, I will:.....                  |
| If I find myself without medication, I will:.....             |
| <b>Adherence step 10: Avoiding self-medication</b>            |
| When I feel a headache or have other complaints, I will:..... |
| .....   |

|   |
|---|
| <b>Lifestyle step 1: Balanced diet</b>                                |
| Action plan to ensure enough fruit and vegetables:.....               |
| .....   |
| Food / snacks to cut back on are:.....                                |
| I will replace these by:.....   |
| I will discuss diet adaptations with .....                            |
| <b>Lifestyle step 2: Avoiding alcohol</b>                             |
| I will drink no more than ..... doses of alcohol per day              |
| What can help me to drink less alcohol/ use less drugs:.....          |
| Result screening questions: .....                                     |
| <b>Lifestyle step 3: Avoiding tobacco</b>                             |
| My motivation to stop smoking: .....                                  |
| When I feel the urge to smoke, I will do the following activity:..... |
| The person who can support me in my efforts to stop smoking is .....  |

## Follow-up Counselling sessions

**First review of adherence and/or lifestyle on date .....**

Estimate of missed pills/ last 7 days: ..... Cause:.....

**How much of my prescribed medication I took in the past month?**



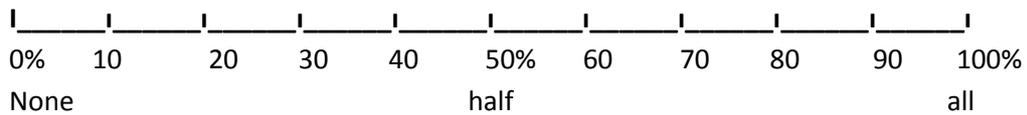
**Remarks:** .....

**Special attention:** .....

**Second review of adherence and/or lifestyle on date .....**

Estimate of missed pills/ last 7 days: ..... Cause:.....

**How much of my prescribed medication I took in the past month?**



**Remarks:** .....

**Special attention:** .....

## Annex 2: Mental Health screening tool for patients to be treated with on Pegylated Interferon

Pegylated Interferon is reported to have some severe psychiatric effects, notably depression, irritability and insomnia. It is recommended that patients, who already suffer from depression on the onset of treatment, are closely monitored and stabilized before being put on Peginterferon.

Moreover, careful monitoring during the period of treatment is needed for all patients on Peginterferon. We provide hereby a standard screening tool for depression (PHQ9), to be administered by the clinician or counsellor at each medical follow-up consultation. **If depression is detected, referral should be made to mental health staff or clinicians, either MSF or external.**

NAME PATIENT: \_\_\_\_\_ Date: \_\_\_\_\_

| <i>Over the last 2 weeks, How often have you been bothered by any of the following problem?</i>  | Not at all | Several days | More than half the days | Nearly every day |
|--|------------|--------------|-------------------------|------------------|
| 1. Little interest or pleasure in doing things   | 0          | 1            | 2                       | 3                |
| 2. Feeling down, depressed, or hopeless  | 0          | 1            | 2                       | 3                |
| <i>If one of the above symptoms are present more than half of the time, go on with the following questions :</i>   |            |              |                         |                  |
| 3. Trouble falling or staying asleep, or sleep so much   | 0          | 1            | 2                       | 3                |
| 4. Feeling tired or having little energy   | 0          | 1            | 2                       | 3                |
| 5. Poor appetite or overeating   | 0          | 1            | 2                       | 3                |
| 6. Feeling bad about yourself or that you are a failure or have let yourself or your family down   | 0          | 1            | 2                       | 3                |
| 7. Trouble concentrating (on things linked with patient's usual activities)  | 0          | 1            | 2                       | 3                |
| 8. Moving or speaking so slowly that other people could have noticed. Or the opposite- being so fidgety or restless that you have been moving around a lot more than usual | 0          | 1            | 2                       | 3                |
| 9. Thoughts that you would be better off dead or of hurting yourself in some way   | 0          | 1            | 2                       | 3                |
| <b>TOTAL</b>   |            |              |                         |                  |

10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all: \_\_\_\_\_

Somewhat difficult: \_\_\_\_\_

Very difficult: \_\_\_\_\_

Extremely difficult: \_\_\_\_\_

if you faced any difficulty, did it occur for two years or more ? \_\_\_\_\_

**A patient is considered as having signs of depression if:**

| PHQ9 score | Provisional diagnosis  | recommendation   |
|------------|--|--|
| 5-9        | Minimal symptoms   | Support and educate to call if worse   |
| 10-14      | Minor to mild depression<br><i>or</i><br><b>chronic depression</b><br>(symptoms lasting for two years) | Support and watchful waiting<br>Reassess in one/two weeks<br><br>Consider starting treatment |
| 15-19      | Major depression   | Refer to clinical officer / psychologist (need for specific treatment)                       |
| > 20       | Severe depression  | Major impairment, need for active treatment  |

- **For major, severe and chronic depression, treatment and follow up consists of:**
  - 1. regular supportive counselling**
    1. Reassure patient about his (her) symptoms, build a trustful and confidential relationship
    2. Evaluate depression (when did it start, release context, etc...)
    3. Asses functional impairment : ask for question 10, be sure all symptoms are lasting for more than two weeks
    4. Reassess patient after one week (counselling session and PHQ9) if PHQ9 <17.
    5. provide regular counselling sessions during medical treatment
  - 2. refer to clinical officer/medical doctor (++ if score > 17)**
    1. small doses of sedating antihistaminic if high anxiety and/or sleeping disorders can be prescribed for a few days, patient's state must be reassessed after one week
    2. Anti-depressant treatment (Fluoxetine, Paroxetine, amitriptyline). Provide all needed information about the treatment, its side effects and length for **at least six months**
    3. Assess the evolution with monthly PHQ9.

## Annex 3 Counseling Tally Sheet

| Session                                 | Pre/Post test | PCR result | Treatment preparation | 1 <sup>st</sup> Lifestyle counseling for not eligible | 1 <sup>st</sup> TT follow-up & Lifestyle counseling | 2 <sup>nd</sup> Lifestyle for patients not eligible | 2 <sup>nd</sup> TT follow-up & Lifestyle counselling |
|---|---------------|------------|-----------------------|---|---|---|--|
| Week ....<br>.../../..... - ../../..... |               |            |                       |   |   |   |  |
| Week ....<br>.../../..... - ../../..... |               |            |                       |   |   |   |  |
| Week ....<br>.../../..... - ../../..... |               |            |                       |   |   |   |  |
| Week ....<br>.../../..... - ../../..... |               |            |                       |   |   |   |  |