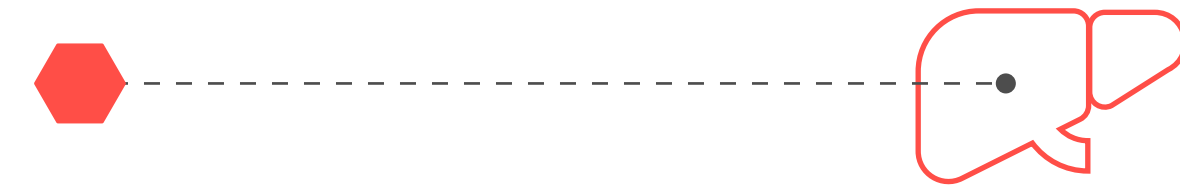


# **Understanding Hepatitis-C & its dynamics in Punjab, India.**

# What is Hep-C?

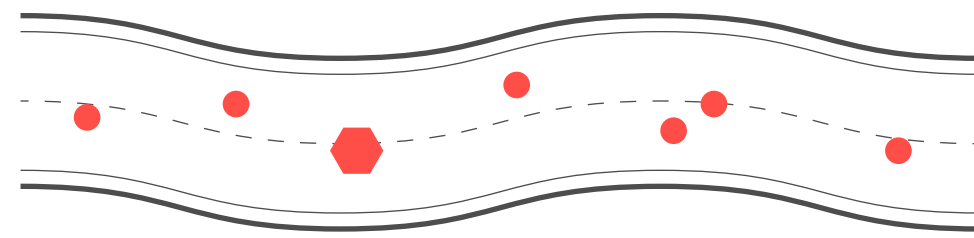
Hepatitis-C is a virus that attacks the liver. It remains dormant for years, sometimes up to 20 years before showing up visibly on the body.



## TRANSMISSION

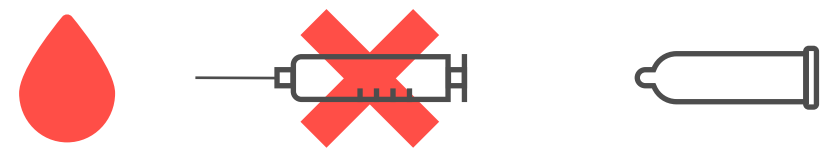
# 01

1. It is transmitted through blood, body fluids.



## PRE-CAUTIONS

- It is advised to not share the same toothbrush, comb or nail cutters as accidental chance of blood transmission is high.
- Do not use the same injection on more than one patient.
- Do not have sex without condoms.



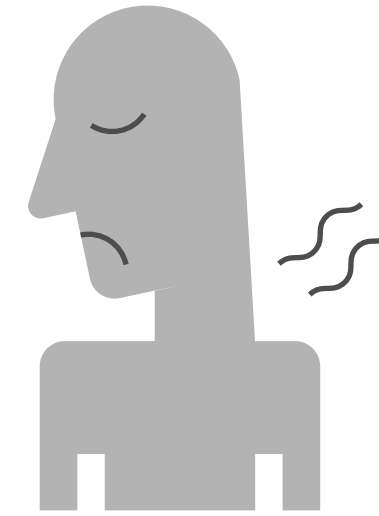
2. There is little chance of it being passed on from the mother to the child.

## SYMPTOMS

### EARLY STAGES

General symptoms such as fever, fatigue and poor appetite. Some people also experience nausea, pain in the stomach and muscle pain.

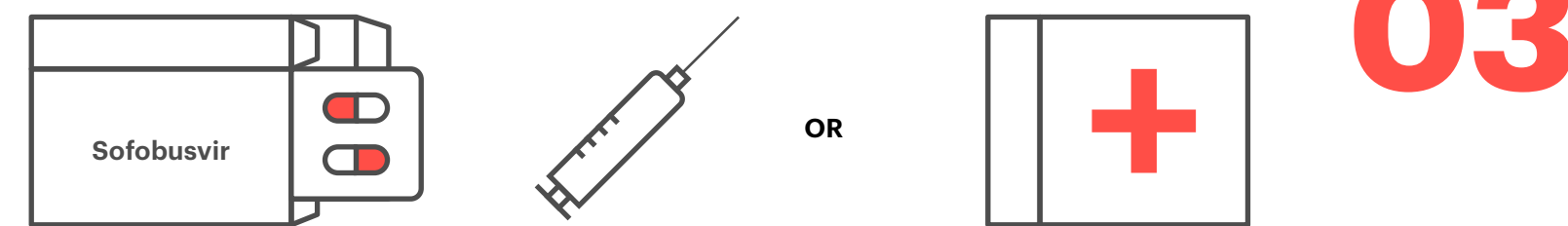
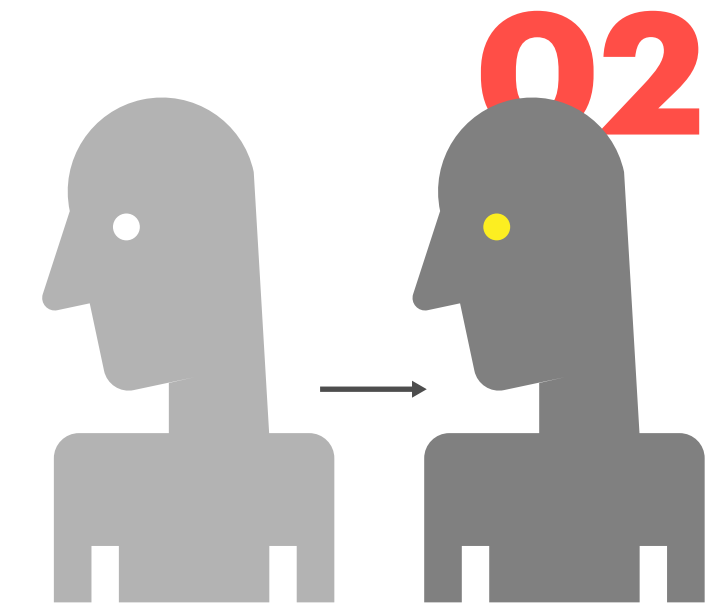
Its is recommended to get a simple blood test done to make sure you do not have Hepatitis C.



### LATER

Once liver starts to deteriorate, the body starts turning black, and the eyes start turning yellow.

This stage is called liver cirrhosis. During this stage, treatment is difficult and therefore a surgery is a must.



## TREATMENT

The treatment for Hepatitis C varies based on the type of virus. You need to undergo a genotype test to understand which type of virus (1-2-3-4-5-6) might be affecting you. In India the most common genotypes are 1 and 3.

The duration and type of treatment depends on various factors such as disease progression, condition of your liver, whether you have taken treatment earlier etc. Typically the treatment lasts from 3 to 6 months



Since the disease acts on the liver, it is advised to keep a healthy diet with less fat intake. A healthy diet will help the liver recover faster.

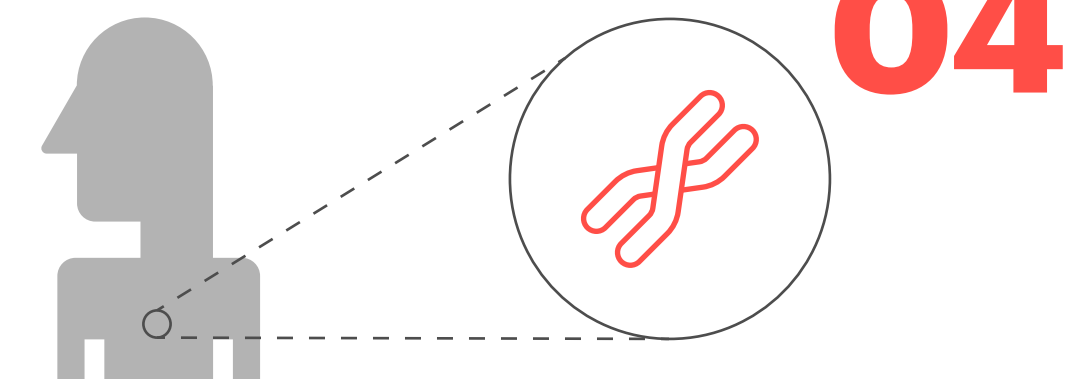
## MEDICATION

For genotype 1, the recommended treatment includes a combination of Sofosbuvir and Ledipasvir. While for genotype 3, the recommended treatment includes a combination of Sofosbuvir and Daclatasvir.

## SIDE-EFFECTS

During the treatment you might experience very mild side effects such as weakness, flu and hair loss. Do not be worried though, it just means that the medicines are working. Take adequate rest and eat healthy.

You also have to undergo the HCV RNA test at regular intervals, to check the amount of virus left in your blood. With medication, the viral load will drop. However, please make sure you complete the course of your medication as recommended by the doctor. This ensures that the virus does not re-appear.

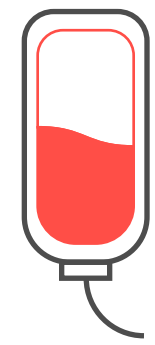


# Patient's Ecosystem

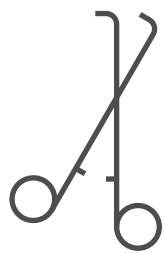
A Hepatitis-C patient has different points of intersection within the community that they engage with throughout their journey. This ecosystem map aided us in understanding the influential intersections. The intervention strategy was designed to direct patient flow from these points to the point of formal treatment.

## DETECTION

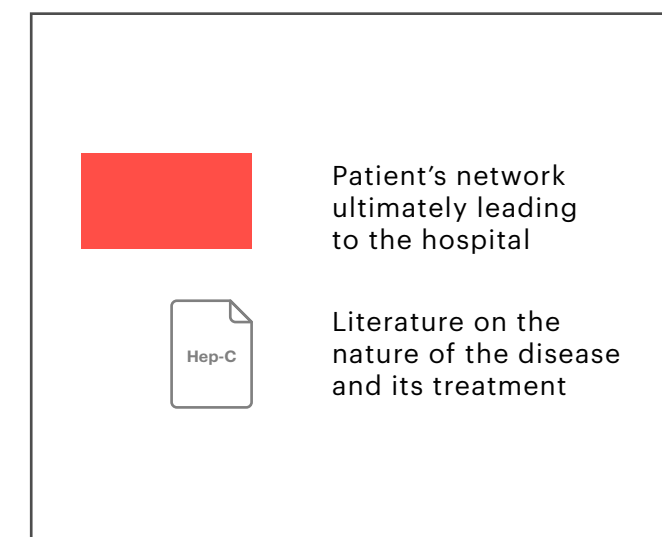
Hep-C Patient



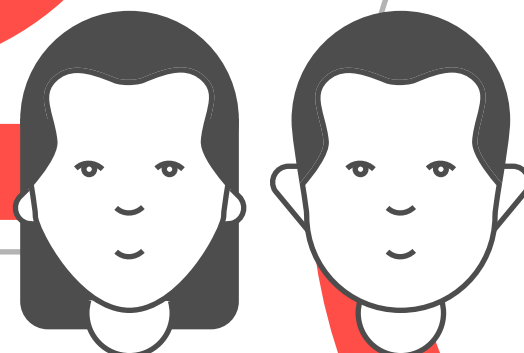
Blood Transfusion



Surgery



## SENSE MAKING



### Heroes

Recovered patients, who are now active helpers and influencers.



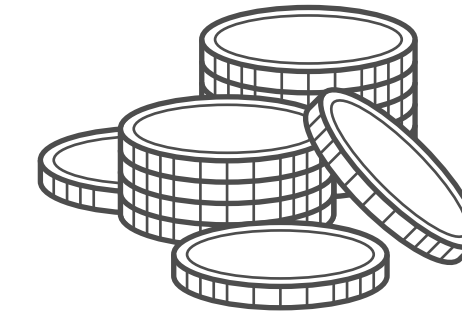
### Pir Mohammed

Trusted local quacks are educated and incentivised to guide patients to a specialist.



### RMP Clinics

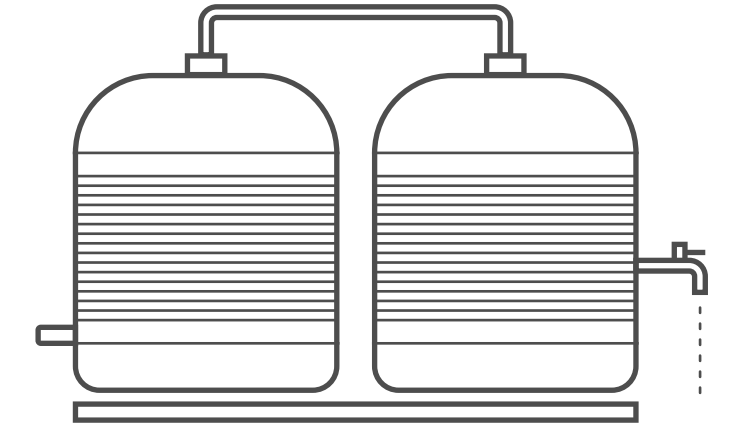
Clinicians guide patients to a specialist depending on the stage of the disease.



### Money Lenders

Authoritarian figures influencing small and big decisions.

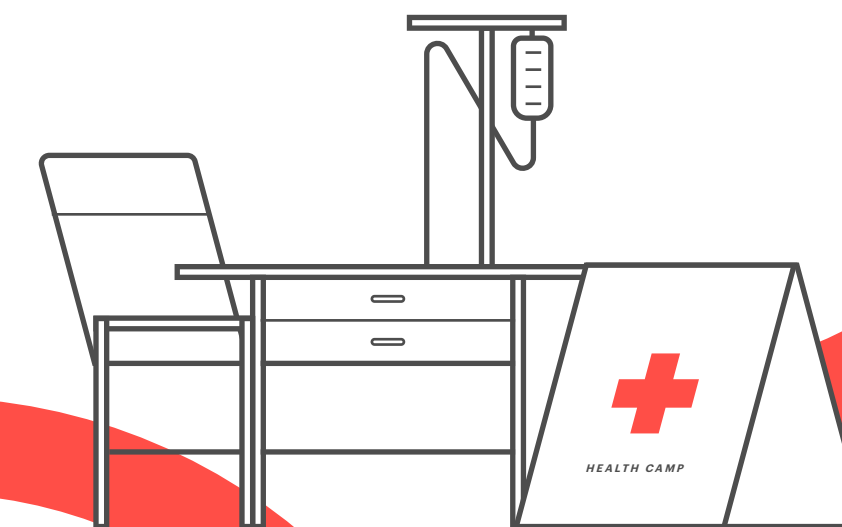
Encourage patients to seek formal treatment.



### RO Stations

Educating children about the disease through RO stations.

Breaking misconceptions around water.



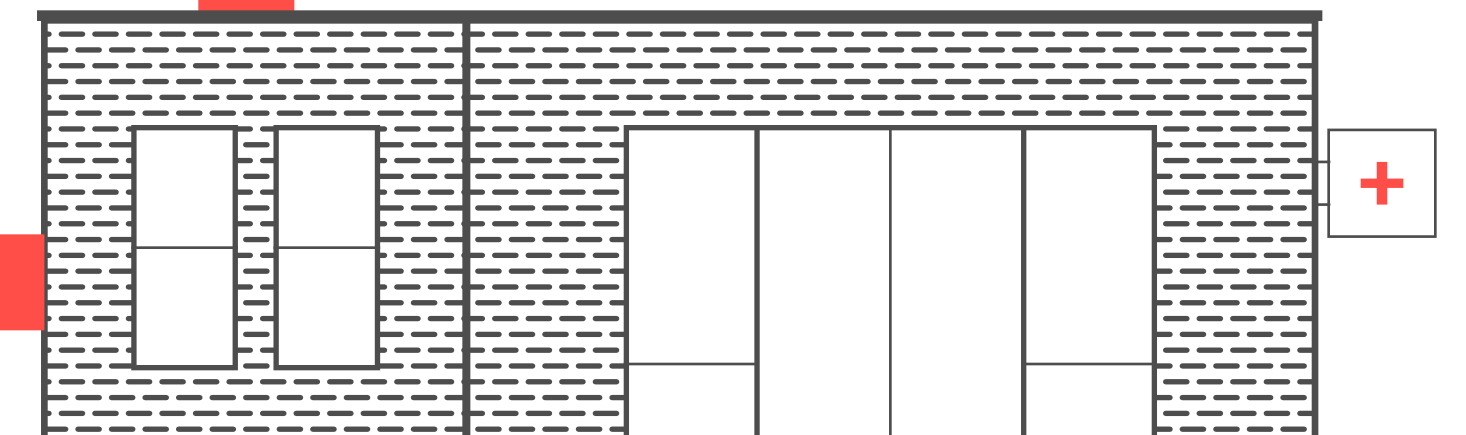
### Health Camps

Camps provide an easier access

Hep-C camps re-positioned as 'general health' camps saw a higher influx of people.

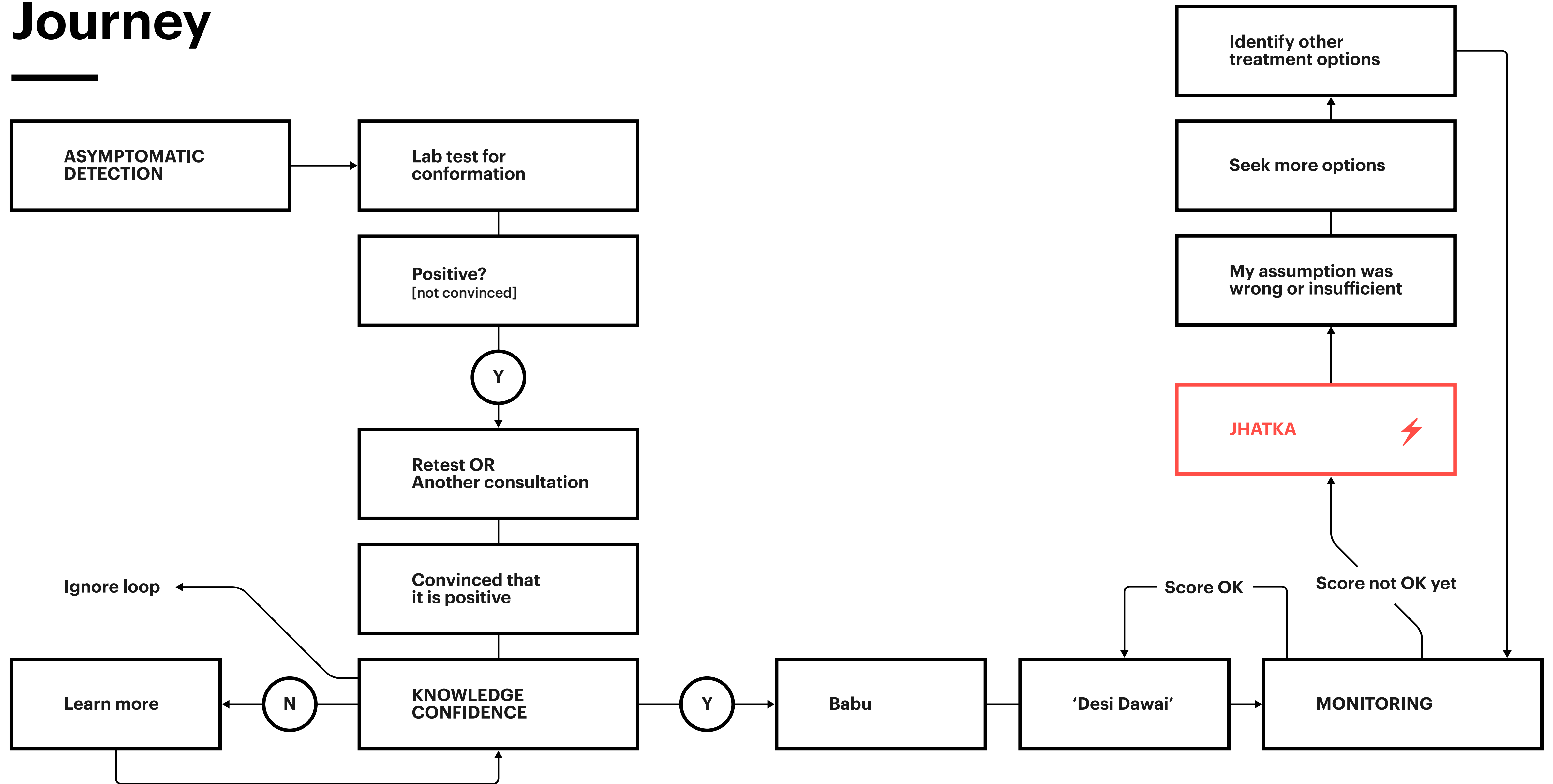
*Ultimately, we'd want the patients to visit the nearest hospital to get a proper treatment necessary for Hep-C.*

**Hospital**



# Patient's Journey

A patient goes through various stages during the course of Hep-C. Here is a map illustrating the same.



# Kinds of patients.

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There are 4 types of patients you might encounter:

## a

### First-timer

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**A patient who's been detected with Hep-C for the first time**

First-timers are patients who don't know anything about the disease, or may have very little idea about it through someone who might be undergoing treatment currently.

The information they'd be looking for would be—

*What is Hep-C? How did it happen to me?*

*What are my options for getting better?*

*What are other people around me doing?*

## b

### Lurker

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**A patient who already knows he has Hep-C and is on no treatment**

Lurkers are the ones actively seeking information on Hep-C. They may/may not be monitoring the progress of the disease through the point test.

The information they'd be looking for would be—

*What are my options for getting better?*

## c

### Seeker

---

**A patient who knows he has Hep-C and is on some treatment from a baba**

Seekers have patchy bits of information on Hep-C from different sources. They are looking for and weighing their options for the most feasible and failure-proof method of treatment.

The information they'd be looking for would be—

*Do English medication guarantee a full recovery? Does it have any side-effects?*

*What are my financing options?*

## d

### Convinced

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**A patient who has Hep-C and is on an english treatment**

These are patients who are currently undergoing formal treatment but need constant reassurance about their decision they have taken.

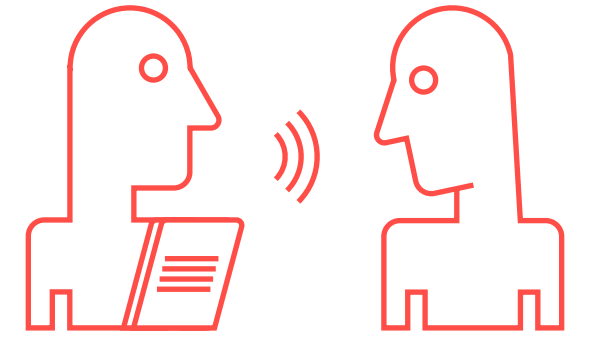
The information they'd be looking for would be—

*Do English medication guarantee a full recovery? Does it have any side-effects?*

*What is the guarantee that my disease won't reappear?*

**Communication Strategy  
for counsellors dealing with  
Hepatitis-C patients.**

# Delivery of information & Pointers for conversations



**a**

## FIRST-TIMER

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### Assurance

Thank you for coming here. It's not an incurable disease, thank you for showing the strength to come. I'm sorry to tell you this, but your test is positive. I can only imagine the strength it would've taken to come here. I'm very glad you came.

### Facts

The disease is curable. Today there are a lot of treatments out there which assure you to get rid of Hep-C. It's not a cause of worry.

#### ***What do you think of Hep-C, what have you heard till now?***

There is a lot of research going on and now there are medicines that lead to no side effects; you might experience slight discomfort but it does vary patient to patient.

Would you like to speak to someone? We have patients here who are fully cured. Would you like to meet them?

### Important

1. *Try to listen what they already know about it. Let them talk.*
2. *Ask them if they have any fear/concern.*
3. *Tell them about the precautions they have to take such that it does not happen to anyone else in the family. Discuss with them if they have any doubts about the precautions.*
4. *Tell them what food-items to avoid. "Parhej is necessary"*
5. *Inform that there is an RNA test which needs to be done to determine how much the virus is (and which type of virus it is).*



## LURKER

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Ask them since when do they know about the disease.

If anyone in their family has the disease. Are they taking precautions such that it does not spread to others? Tell them about the precautions. Tell them that "Parhej" is necessary in the disease.

Ask if they know about the treatment of HEP-C? Is it curable? What have they heard about it?

### Important

1. *Let them talk and see what they have to say.*
2. *Narrow down the reason. Some of it can be:*
  - *Do not know about cure/Think it is not curable: Tell them that it is curable. Give reference of a local hero (treated patient) to give them proof. Later tell them to interact with him/her.*
  - *Afraid of the treatment: Tell them about the pills. No side-effects. Can carry their day to day work with no problems. Need to go for buying the pills only once a month.*
  - *Is indifferent/Says feeling fine: Tell them that it works slowly and has no symptoms until it is at later stage. "It works like a dimak". Say that foolproof treatment is available in English medicine. It is their decision whether they want to take the treatment today or later.*
3. *Lastly, tell them about the RNA test.*



## SEEKER

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How long have they been taking other medicine?

Do they feel they are getting any better?

### Important

1. *Let them talk and get a sense of why they are taking the medicine. Check if it is any of the following reasons mentioned below:*
  - *Because it is natural OR Because they are afraid of side-effects of English drugs.*
  - *Because the local doctor recommended them*
  - *Because of financial reasons (Either they thinks it is very expensive e.g. in Lakhs or if they cannot afford 45-50k for treatment)*
  - *OR for any other reason.*
2. *Once you narrow down the reason why they are taking Desi Treatment, you can counsel them accordingly:*
  - *Tell them that the pills have no side-effects. They can carry their day to day work with no problem. And also that they need to buy them every month.*
  - *Ask them if they have seen anyone who has been totally treated by the doctor.*
  - *If they took point test to judge, tell them about what point test is and that it does not give a true picture of HEP-C.*
  - *Tell them about the RNA test. Counsel them to take the RNA test which will tell them the virus load as well as the type of virus.*
  - *Tell them about the Umeed scheme in which they have to pay only 2000-2500 for 18 months with ZERO INTEREST. Correlate the expenses of current medication with the Umeed scheme.*





## CONVINCED

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How are you feeling about the medication?

Do you have any doubts or questions?

Is anything else about the disease bothering you?

### Important

1. *Let them talk about how they are feeling. They might want to voice their concerns and doubts around the effectiveness of the treatment.*
2. *Answer each query with patience and empathy. You need to assure them that they have taken the right decision.*

*Check if their query matches with any of the following:*

- *I am not sure this is working. I am spending so much money, what if I don't get okay?*
- *People around me think I am a fool for adopting this expensive treatment.*
- *What if I die? The loan will become an added burden for my family.*
- *How much longer will it take for me to get ok?*

*Here are some ways to counsel them.*

*Depending on the patient's stage, tell them their chance of getting cured. Unless the patient has developed cirrhosis or cancer, the disease is 100% curable. Reinforce the importance of following a healthy diet and lifestyle.*

*Tell them that this is the only form of treatment with assured results and that you understand how difficult it must be to be under scrutiny for your treatment choice. Once they get cured, everyone will praise them for their decision.*

*Reinforce the importance of treating this disease on time to make sure it doesn't become fatal. Praise them for their courage. Ask them to focus on getting well, as that would automatically ensure that they are able to pay off the loan.*

*Propagate the idea of getting the right tests done. Ask for their reports and give them an honest and sensitive status of their disease. Assure them of getting well soon.*

# **Supportive Tools for Communication Strategy**

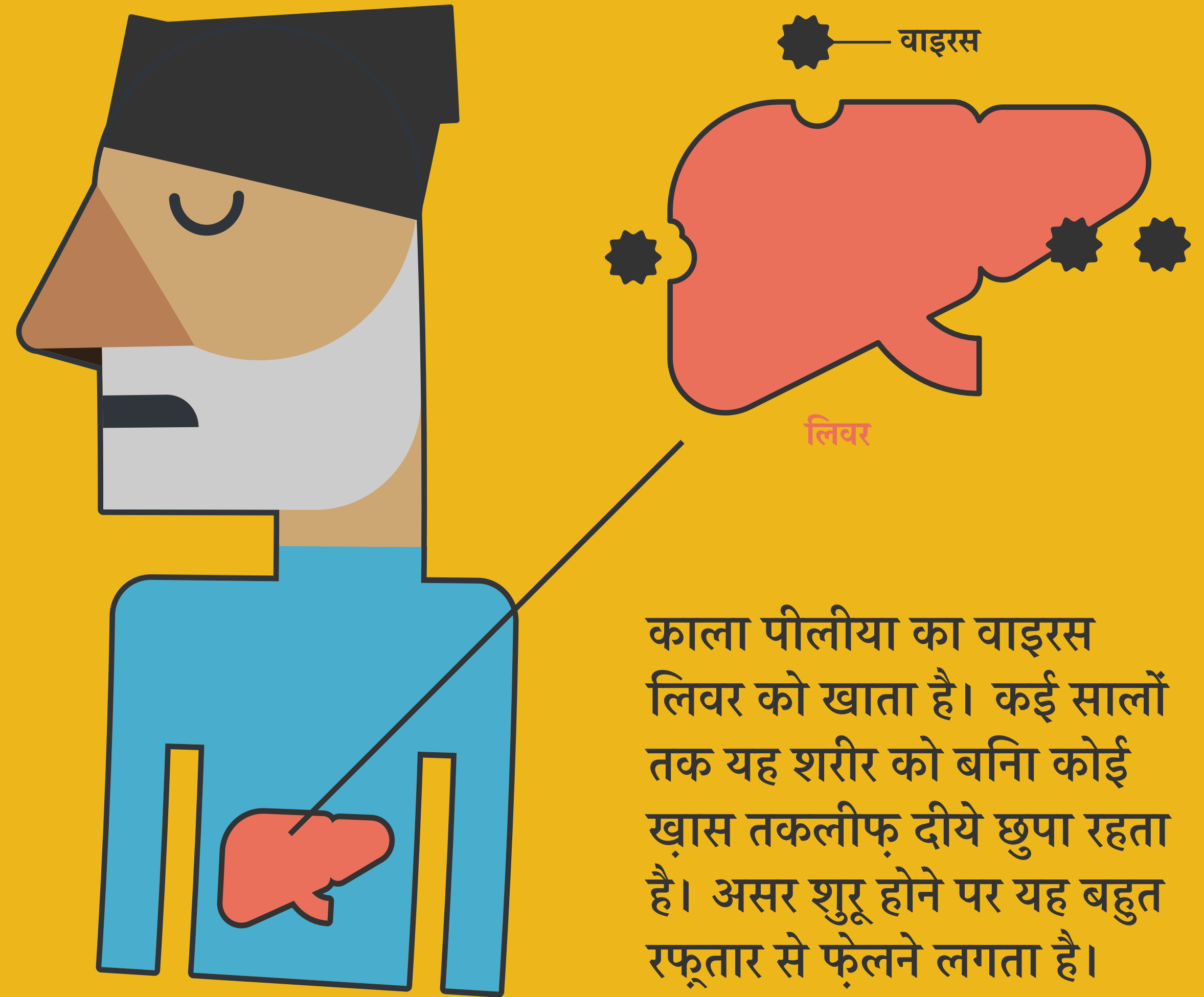
# Hepatitis-C handbook [in vernacular]

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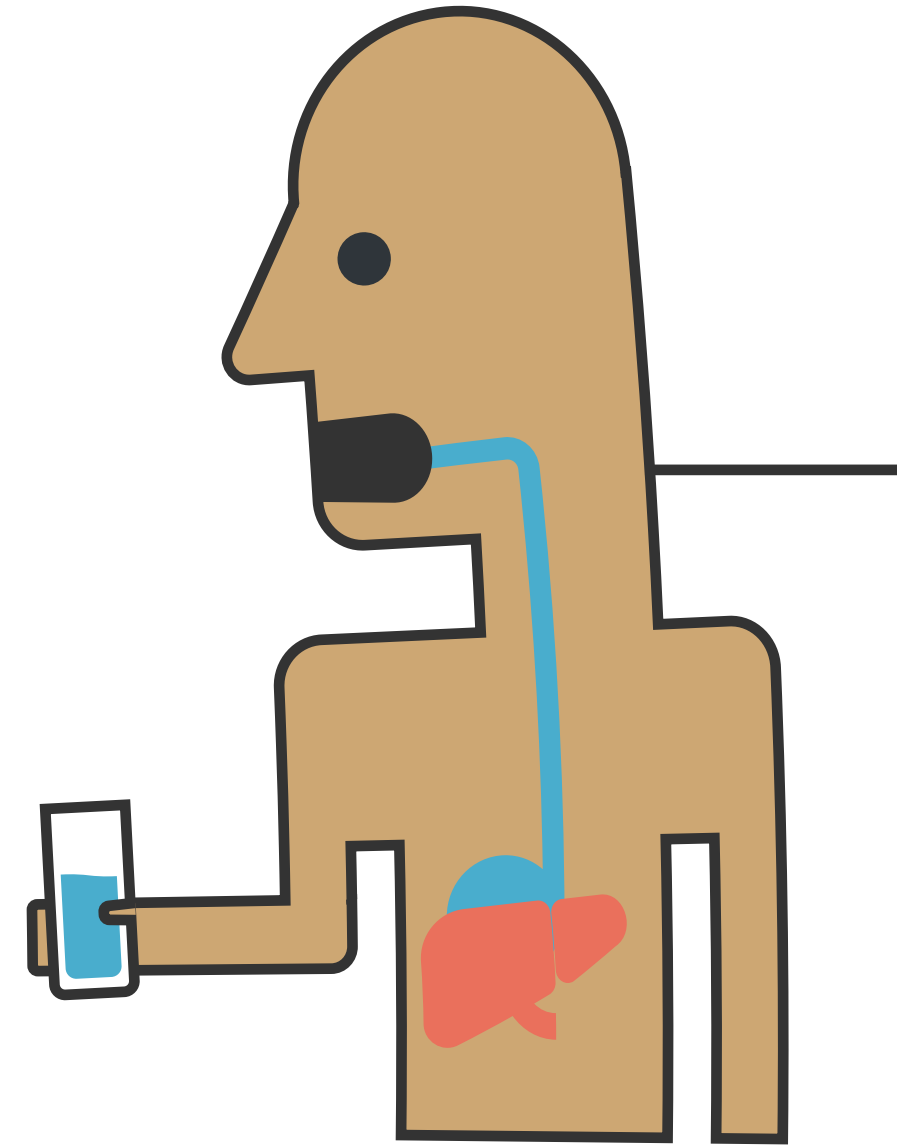
# काला पीलीया क्या है?

काला पीलीया आप बचा सकते हैं।

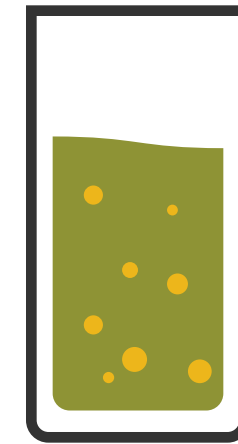


काला पीलीया का वाइरस लिवर को खाता है। कई सालों तक यह शरीर को बना कोई खास तकलीफ़ दीये छुपा रहता है। असर शुरू होने पर यह बहुत रफ़्तार से फ़ेलने लगता है।

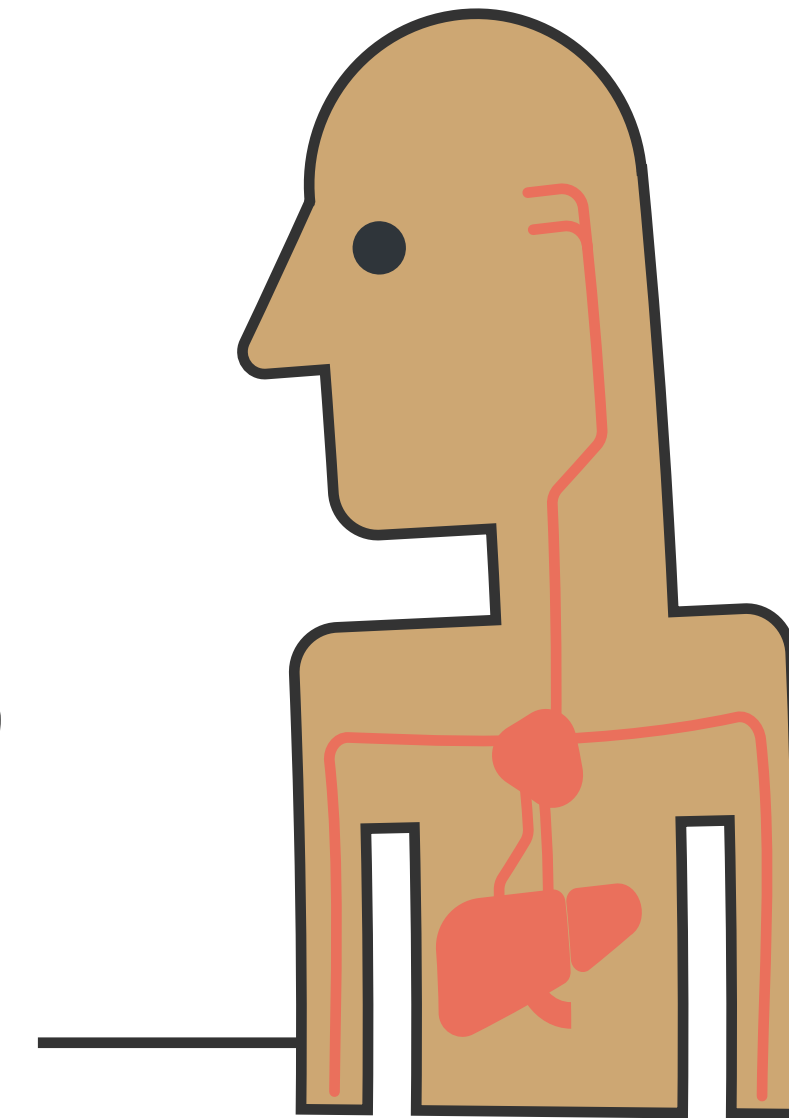
# काला पीलीया और पीलीया एक समान नहीं हैं।



पीलीया के कई ज़रयि हो सकते हैं। सबसे आम ज़रयिा है दूषति पानी।



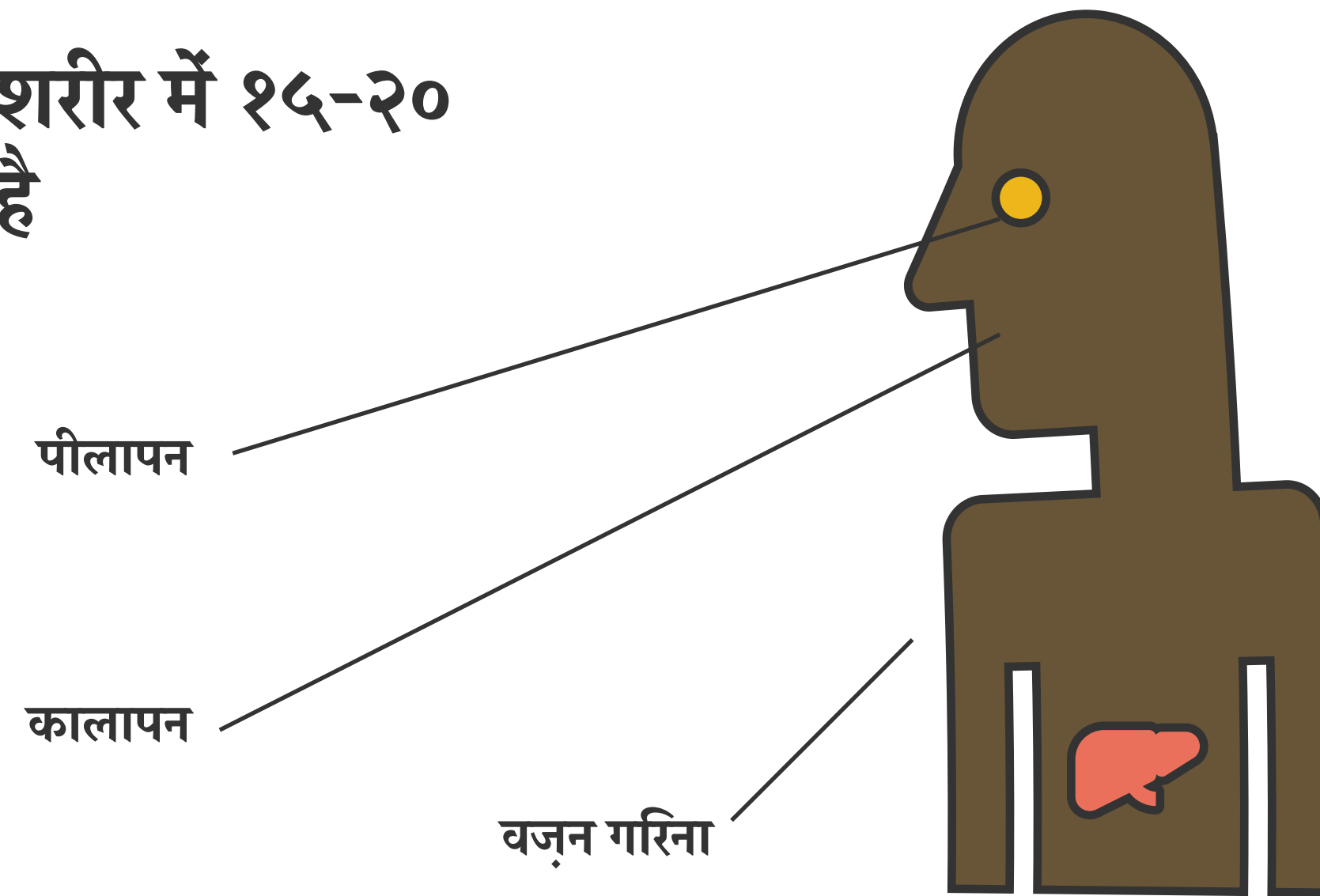
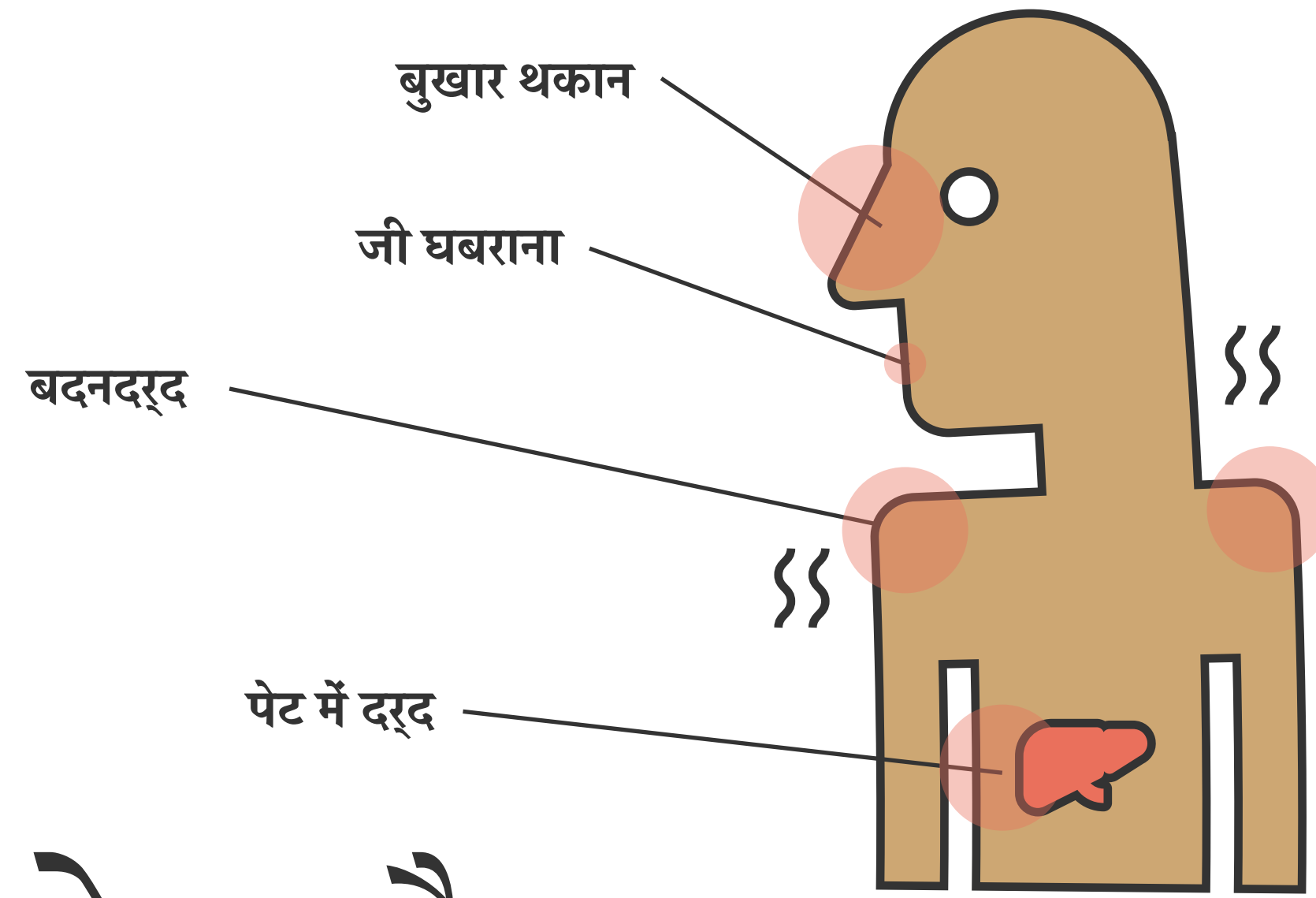
लेकनि काला पीलीया फ़ेलने का प्रमुख ज़रयिा है लहू।



गंदे पानी से बचना अनविर्य है, पर वह हमें काला पीलीया से नहीं बचा पाता

# क्या महसूस होता है

काला पीलीया का वाइरस शरीर में १५-२० सालों तक शांत रह सकता है



१

जब वाइरस शांत हो -

बुखार थकान भूख कम लगना, जी घबराना, पेट में दर्द, बदनदर्द, कमजोरी

०३

२

जब रोग फ़ेलने लगता है -

आँखों में पीलापन, शरीर में कालापन, वजन गरिना

## Reference cards [for counsellors]

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# निर्देश पत्ते

REFERENCE CARDS

यह  
छुपा  
हमल

क्यूँकि यह लविर  
पेरेज़ रखना महत्व  
ताली चीज़ें, दारू ल  
कमज़ोर करता है

इन दवाइयों के साइड इफ़ेक्ट  
नहीं होते - दनि में कुछ बदलाव  
नहीं आएगा

# Community Awareness Posters



Dr.Reddy's

ਪਾਣੀ ਦਵਾਰਾ ਕਈ ਹੋਰ  
ਬੀਮਾਰੀਆਂ ਫੈਲਦੀਆਂ ਹਨ।  
ਕਾਲਾ ਪੀਲਿਆ ਨਹੀਂ !

ਕਾਲਾ ਪੀਲਿਆ ਕਿਸ ਤਰ੍ਹਾਂ ਫੈਲਦਾ ਹੈ

- × ਦੂਸ਼ਿਤ ਨੀਡਲਾਂ ਦੀ ਸਾਂਝ
- × ਡਾਇਲਿਸਿਸ ਦਰਮਿਆਨ
- × ਅਸੁਰੱਖਿਅਤ ਸੰਭੋਗ ਦਵਾਰਾ
- × ਅਮਲੀ ਲੋਕਾਂ ਦੇ ਦਰਮਿਆਨ ਅਮਲੀ ਦਵਾਈਆਂ
- × ਲੈਣ ਨਾਲਖੂਨ ਚੜ੍ਹਾਉਣ ਦਰਮਿਆਨ

**ਕਾਲਾ ਪੀਲਿਆ**  
ਸੱਚ ਦਾ ਸਾਹਮਣਾ  
ਸੂਚਨਾ ਕੇਂਦਰ

ਕਾਲਾ ਪੀਲਿਆ ਦੇ ਕਾਰਣ, ਨਿਦਾਨਕਾਰੀ ਜਾਂ ਇਲਾਜ ਦੀ ਸੱਚਾਈ ਦਾ ਪਤਾ ਲਾਉਣ ਲਈ ਮਿਹਬਾਨੀ ਕਰਕੇ ਕਾਲ ਕਰੋ



ਫੋਨ:

ਬਿਨਾਂ ਇਲਾਜ ਕਾਲਾ ਪੀਲਿਆ ਜਾਨਲੇਵਾ ਹੋ ਸਕਦਾ ਹੈ



Dr.Reddy's

ਜੀਵਨ ਦੇ ਸਫ਼ਰ ਨੂੰ  
ਕਾਲਾ ਪੀਲਿਆ ਦਾ ਹਾਦਸਾ  
ਬਣਨ ਨਾਂ ਦਓ !  
ਅੰਗਰੇਜ਼ੀ ਦਵਾ ਨਾਲ ਇਸ ਦਾ  
ਪੂਰਾ ਇਲਾਜ ਹੋ ਸਕਦਾ ਹੈ  
ਬਿਨਾਂ ਸਾਈਡ ਇਫੈਕਟਸ ਦੇ !

**ਕਾਲਾ ਪੀਲਿਆ**  
ਸੱਚ ਦਾ ਸਾਹਮਣਾ  
ਕੈਂਪ

ਸੱਚਾਈ ਜਾਨਣ ਲਈ ਆਪਣੇ ਪਿੰਡ ਵਿਚ ਕਾਲਾ ਪੀਲਿਆ ਅਵੇਅਰਨੈਸ ਨਿਦਾਨਕਾਰੀ ਕੈਂਪ ਵਿਚ ਜਾਓ

ਸਥਾਨ:  
ਤਾਰੀਖ:

ਬਿਨਾਂ ਇਲਾਜ ਕਾਲਾ ਪੀਲਿਆ ਜਾਨਲੇਵਾ ਹੋ ਸਕਦਾ ਹੈ