

# **Blood-Borne Viruses (BBVs): Prevention, testing and treatment**

A training guide for keyworkers  
in substance misuse services

# Introduction

When you have a client's trust, you can help them change their lives – such as by showing them the benefits of preventing and identifying blood-borne viral illnesses. For those who test positive with a blood-borne virus, you can help them link up to the healthcare system and support them through treatment.

We will cover what you need to know about the blood-borne viruses, focusing on hepatitis C in particular, a highly curable disease commonly transmitted by the sharing of injecting equipment.<sup>1</sup> It can help you encourage clients to get tested, with practical tips on how to support them afterwards.

## Learning objectives

- Understand the specific risks of BBVs in people who inject drugs
- Describe the differences between hep C virus, hep B virus and HIV
- Discuss strategies for reducing risk
- Confidently encourage your clients to test and engage in treatment (if appropriate)
- Understand how testing happens, and what might happen afterwards

# Section 1: About the BBVs

# What is a blood-borne virus?

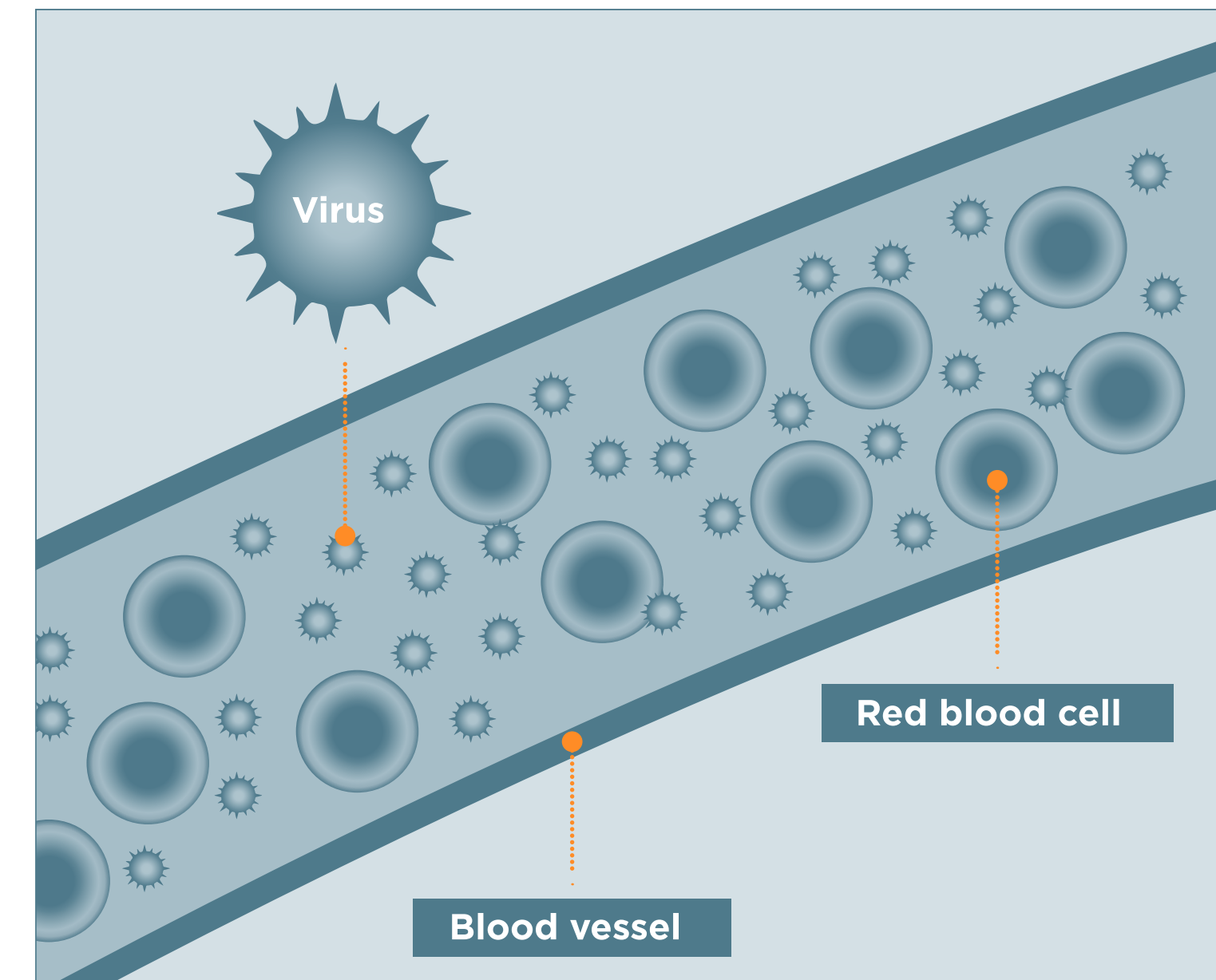
A blood-borne virus (BBV) is a virus that can be passed on when infected blood (or body fluid containing blood) enters the bloodstream of someone else.<sup>2</sup>

Infection with a BBV is most likely when the person punctures the skin with a contaminated item like a needle. There is a lower risk if infected blood comes into contact with skin that is already broken or the eyes/mouth/nose.<sup>2</sup>

## What we mean when we say “virus”

We mean many copies of a virus. Viruses reproduce in the body and there can be thousands of copies in a tiny speck of blood.<sup>3</sup>

All of these viruses can be spread (transmitted) amongst people who inject drugs, through the sharing of contaminated injection equipment.<sup>4</sup>



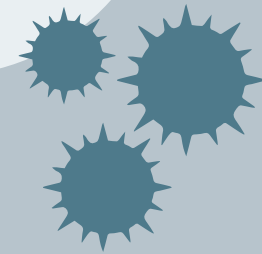
# BBVs in the UK

The most common blood-borne viruses in the UK are:<sup>5</sup>

## Hepatitis C Virus (hep C virus or HCV)

About **50%** of injection drug users in England, Wales and Scotland have the hep C virus, or have had it in the past – about 1 in 2.<sup>10</sup>

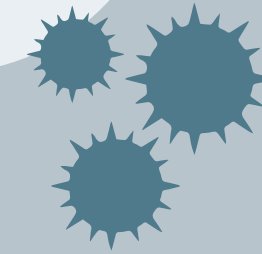
Affects  
**215,000**  
people in  
the UK<sup>6</sup>



## Hepatitis B Virus (hep B virus or HBV)

**18%** of injection drug users in England are infected with HBV – about 1 in 5.<sup>5</sup>

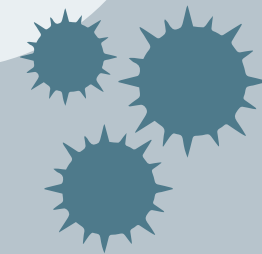
Affects  
**180,000**  
people in  
the UK<sup>7</sup>



## Human Immunodeficiency Virus (HIV)

**1%** of injection drug users in England are infected with HIV – about 1 in 100.<sup>5</sup>

Affects  
**101,600**  
people in  
the UK<sup>8,9</sup>



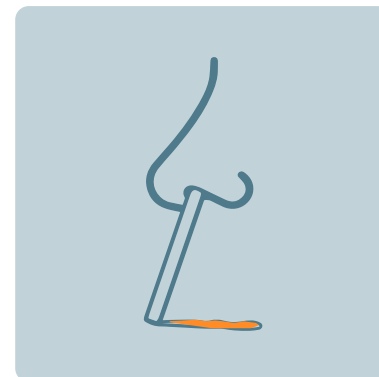
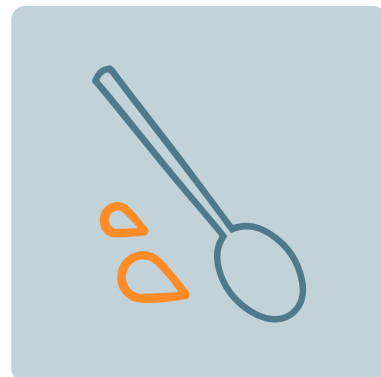
# BBVs and routes of transmission

## How are blood-borne viruses spread?

### Sharing or reusing infected needles and syringes<sup>6,11-14</sup>

Other high risk behaviours:

- Sharing cookers, waters, filters and spoons<sup>6,11</sup>
- Sharing crack pipes or straws for snorting drugs<sup>3,11</sup>



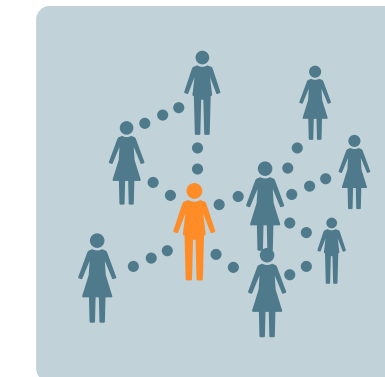
### Contaminated sharps or personal care items<sup>6,11,12,14</sup>

- Sharing toothbrushes and razors<sup>6,11,12,14</sup>
- Tattoos and piercings with reused, unsterilised equipment<sup>6,11,12</sup>
- Medical or dental procedures under unhygienic conditions<sup>12,14</sup>

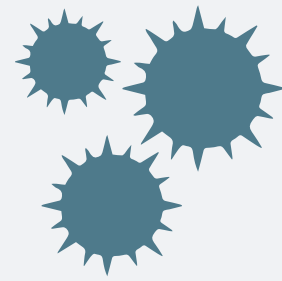


### Other routes of transmission

- Unprotected sex, particularly for HIV and HBV<sup>4</sup>
- Mother to baby transmission, particularly for HBV<sup>14</sup>



# About HCV



## What is it?

Hepatitis C Virus (HCV) is the most common blood-borne virus affecting injection drug users in the UK.<sup>5,6,12</sup> Almost every case of hepatitis C infection in the UK occurs as a result of injection drug use (90%) – mostly due to needle sharing.<sup>5,6,10</sup> Many people do not know they are living with the hep C virus,<sup>10</sup> and up to 2017, only around **4%** of people with the virus received treatment each year in England.<sup>15</sup>

## HCV: the risk for injection drug users

- About half of injection drugs users in the UK have antibodies to the virus, which means they have been exposed to hep C virus at some point.<sup>5,10</sup>
- The hep C virus is up to 20 times more likely to be caught from an infected needle than HIV.<sup>16</sup>
- HCV can survive for 63 days inside a syringe and up to several weeks on a spoon, toothbrush or razor.<sup>6,16,17</sup>



## C for cure: hep C virus can be cleared by treatment<sup>1</sup>

If left untreated, hepatitis C virus can cause chronic hepatitis C, a form of viral hepatitis that can cause serious damage to the liver over time. But unlike hepatitis B, drug treatment for hep C is curative. Today's drugs can eliminate the virus from the body in over **95%** of people.

# About HBV

Hepatitis B Virus (HBV) is a very infectious blood-borne virus that is less common in the UK than hepatitis C.<sup>5,7,12</sup> Untreated HBV can cause chronic hepatitis B which is an inflammatory liver disease that can have serious health consequences.<sup>12</sup>

There is currently no cure for HBV, but lifelong treatment with medication can help suppress the virus and protect the liver.<sup>7,12,14</sup>

## **B for block: there is a vaccine available against hepatitis B<sup>14</sup>**

A full course of the hep B vaccine can provide protective antibody levels in 95% of patients over a 20 year period and potentially over a lifetime.<sup>14</sup>

All users of drug and alcohol services should be offered vaccination.<sup>19</sup>

The partners and children of injection drug users should also be vaccinated.<sup>19</sup>

## **HBV: the risk for injection drug users**

- In England and Wales, injecting drugs is the most common cause of HBV infection.<sup>18</sup>
- HBV can survive for a week outside the body.<sup>7,14</sup>
- It's easy to catch hep B, but the body usually gets rid of the virus by itself and the person becomes immune to it.<sup>7</sup>
- In a few people the infection becomes **chronic** and they require ongoing treatment.<sup>7,14</sup>

**HBV vaccination schedule: 2 to 4 doses (jabs) given over 2 months to 1 year.**



# About HIV

Human Immunodeficiency Virus (HIV) is a virus transmitted in blood and body fluids.<sup>13</sup> If untreated, it weakens the immune system and can ultimately lead to the development of **AIDS**.<sup>13</sup>

Early detection is important. There is no cure for HIV, but lifelong treatment with HIV antiretrovirals enables most people infected to live a long and healthy life.<sup>13</sup>

## HIV: the risk for injection drug users

Amongst people who inject drugs, the risk of having HIV is greatest in younger people, those who trade sex, need help injecting, inject cocaine, or have unsafe sex with an HIV-positive partner.<sup>5</sup>

HIV can survive for at least a week in dried blood or up to 4 weeks inside syringes.<sup>20</sup>

## Transmission and prevention<sup>13</sup>

HIV is most often spread through unprotected sex, but sharing injecting equipment is also a risk. Safe sex and safe injecting are key to avoiding infection.

Emergency medication can also help prevent infection if started shortly after possible exposure to HIV. This is called **post-exposure prophylaxis**.

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All website links checked and active as of September 2019.

## Section 2: Practicalities of BBV testing

# How does BBV testing work?

**Your service will have its own policy and pathway for BBV screening, but in general:**

- All substance misuse service users are eligible for BBV testing.<sup>1</sup>
- NICE (the UK's main health authority) recommends annual HIV and HCV testing for people who continue to inject drugs or practice other risky behaviours.<sup>2,3</sup>
- NICE recommends that substance misuse services also offer and promote hepatitis B testing and vaccination.<sup>2</sup>
- BBV testing can be considered part of treatment, as it can reduce harm and improve well being.<sup>1</sup>

**There are different ways that substance misuse service keyworkers can test for BBVs, starting with a small amount of blood obtained by a finger prick:**

- The dried blood spot test (DBST), where spots of blood are carefully placed onto a card and allowed to dry, then sent to a laboratory for testing. This is probably still the most widely practiced method of testing in drug treatment services, which is why we provide relevant information in this guide.
- A “point of care” test, where results can be generated at the same time and place as the test itself. This usually involves a cartridge or capillary test – blood drops are placed on a strip or in a tube that is inserted into a small, portable device. The result can be read shortly afterwards.

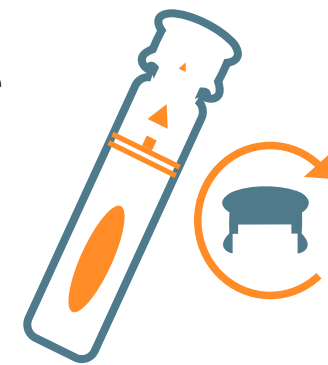
# Performing DBST

## Preparing to test

Ask client to rub their hands together for 10 seconds and/or massage finger, and allow the hand to hang at their side for 30 seconds. Place the chosen hand with the palm side up on the sterile field.

### Remove safety cap from lancet

- Release the protective cap from the lancet by turning gently, **DO NOT** snap off, but gently twist and remove.
- Discard the lancet cap.



### Position the lancet

- Avoid index finger.
- Minimise discomfort to the client by using the side of finger.
- Press lancet firmly against finger.
- Press the trigger.
- Lancet will pierce the skin.



### Gently 'milk' blood from the finger

- Hold hand downwards.
- Gently milk towards the fingertip to obtain a good sample.
- Do not just squeeze the finger as this blocks blood flow.



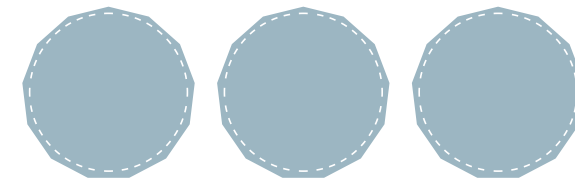
**Note:** The different types and brands of DBST may have slightly different instructions. This guidance is an overview to the general steps, but always pay attention to the instructions of DBST that you are using.

# Performing DBST

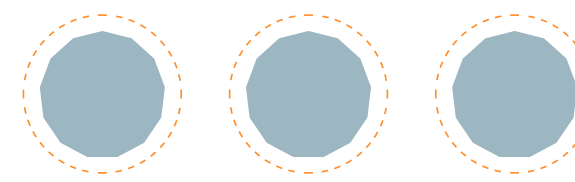
## Full circles on the card

- Wait until drop of blood is large and hanging.
- Use 1-2 drops to fill each circle.
- Fill minimum of 5 circles.
- Ensure circles are completely filled, but avoid over-saturating the cards.

## Valid specimen



## Invalid specimen



## Let spots air dry

- Allow blood spots to dry for 10-15 minutes.
- Ensure client details are completed on front of card (full name and DOB).
- Place sample card in clear, self-sealing plastic bag.
- Place plastic bag and a copy of the test request form in an envelope and send to the Specialist Virology Laboratory.

10-15 minutes



**Note:** Some DBST kits come with a desiccant. Be sure to keep the desiccant in the bag when you send the sample.

# Talking about results

## Clients who test positive

You can help the client come to terms with the result by reframing it as positive news. Knowing means less anxiety about the unknown and the chance to take control of their health.<sup>4</sup>

The client may require further tests to confirm the infection, or may be waiting for their first appointment with a healthcare worker. You can play an important role in helping them engage with their care.<sup>4</sup>

## Be positive about a positive

Treatment halts disease progression and risk of transmission.



Test | Results | Healthcare team

Positive

## Clients who test negative

The focus is on helping clients stay negative by managing future risks. That means working with them to maintain safe practices. Offer a re-test for HIV and hep C every year if risky behaviours continue.<sup>2,4</sup>

## Be negative about a negative

Risk reduction advice and link to harm reduction services.



Negative

# Your service:

## What you need to know

If you are new to BBV testing, there will be people in your network who can support you in getting things done. Here are some of the kinds of questions you might have: some of this information will be useful to your clients too.

- How do I access formal training on BBV testing?
- Which BBVs do we test for?
- Who is the lead clinician named on the form and what is their role?
- How do I clarify on the form who is sending the request and who needs the report?

- How long does our lab take to get results for each BBV?
- How are patients notified if they need to give a venous blood sample at some point? Who performs this?
- Are results given in the service (keyworkers or BBV nurse) or elsewhere (lead clinician)?
- How do we encourage clients to come back for their results?
- When/how/by whom is the referral made to the relevant service for clients testing positive?

- How do we encourage clients to engage with their healthcare?
- Where will their appointments take place?
- What support groups can I recommend?
- How will my client receive their medication supply?
- Is treatment provision able to be integrated into addiction treatment provision?
- What can I do to help them get through treatment?



# References:

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All website links checked and active as of September 2019.

# Section 3: Focus on hepatitis C

# The drive to eliminate hepatitis C virus

The NHS in England is highly focused on hepatitis C prevention, testing and treatment.

## This means a commitment to:<sup>1</sup>

1. All people at risk of hepatitis C infection having easy access to testing.
2. All people at risk knowing how to reduce the risk of catching or transmitting the virus.
3. People who test positive for chronic hepatitis C being treated effectively.

Hep C testing rates are going up. 80% of people in England who have ever injected drugs report having been offered hep C testing at some point.<sup>1</sup>

However, even though chronic hepatitis C is a curable disease, having a positive test doesn't always result in treatment. In those people who had ever injected drugs and tested positive, one third said they had never seen a doctor after diagnosis, and of those who did see a doctor, one third said they declined treatment.<sup>1</sup>

You can make a difference by helping clients understand the ins and outs of hep C, so that they are likely to accept testing and, if testing positive, remain on treatment for the recommended duration.

# Hepatitis C prevention advice

## Advice on preventing hep C infection (applies to all BBVs)

- Remind clients that blood is not always visible when engaging in risky behaviours. Tiny specks of dried or fresh blood can contain infectious virus.<sup>2-5</sup>
- Ensure they are accessing sterile equipment via pharmacies and needle exchange centres.<sup>4</sup> Advise them to take more than they think they need.<sup>4</sup>
- Using new equipment also makes injecting easier, reducing discomfort and infection at the injection site.<sup>4</sup>
- Remind them that all equipment carries a risk, even if they use a new needle.<sup>5</sup>
- Make sure they know how to clean injection works if no access to a new syringe and needle:<sup>5</sup>
  - Draw bleach into the syringe via the needle and flush it. Repeat several times.
  - Repeat the flushing process with hot water to clean out the bleach.

## Help the client think about safe strategies for different scenarios:

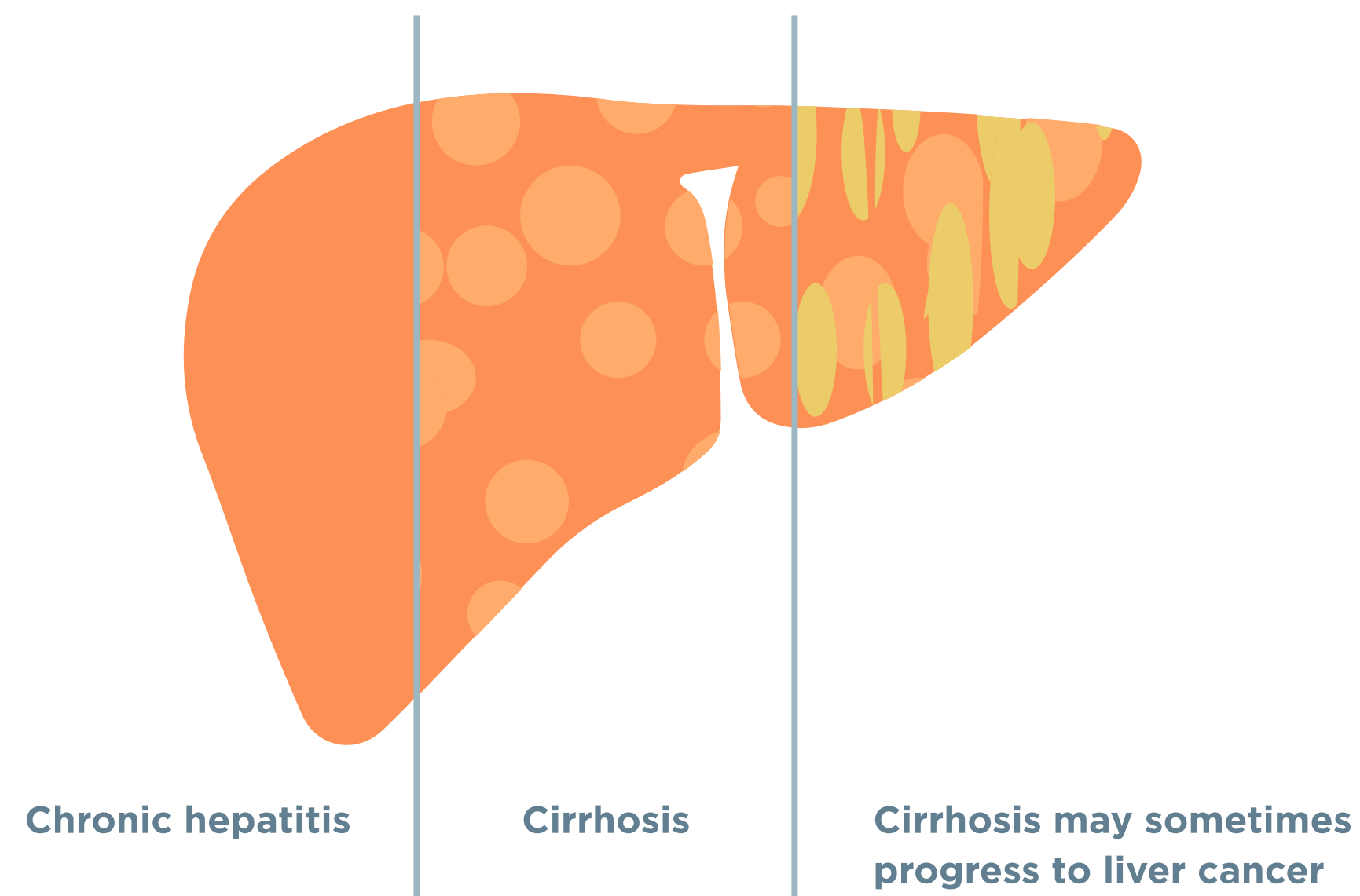
- If you need help injecting, who is helping and what are they using?
- How do you clean your equipment? How would you clean equipment that wasn't your own?
- How would you dispose of needles at home, in public, at a friend's place?

## You can't catch hep C virus from:<sup>3-5</sup>

- Kissing
- Hugging
- Sharing cutlery and crockery
- Toilet seats
- Sharing food or water

# Hepatitis C and the liver

Whereas most cases of hepatitis B clear up by themselves, hepatitis C is usually chronic – meaning the infection stays in the body until it’s detected and treated.<sup>6</sup> Ongoing (untreated) hepatitis C can cause serious damage to the liver.<sup>6,7</sup>



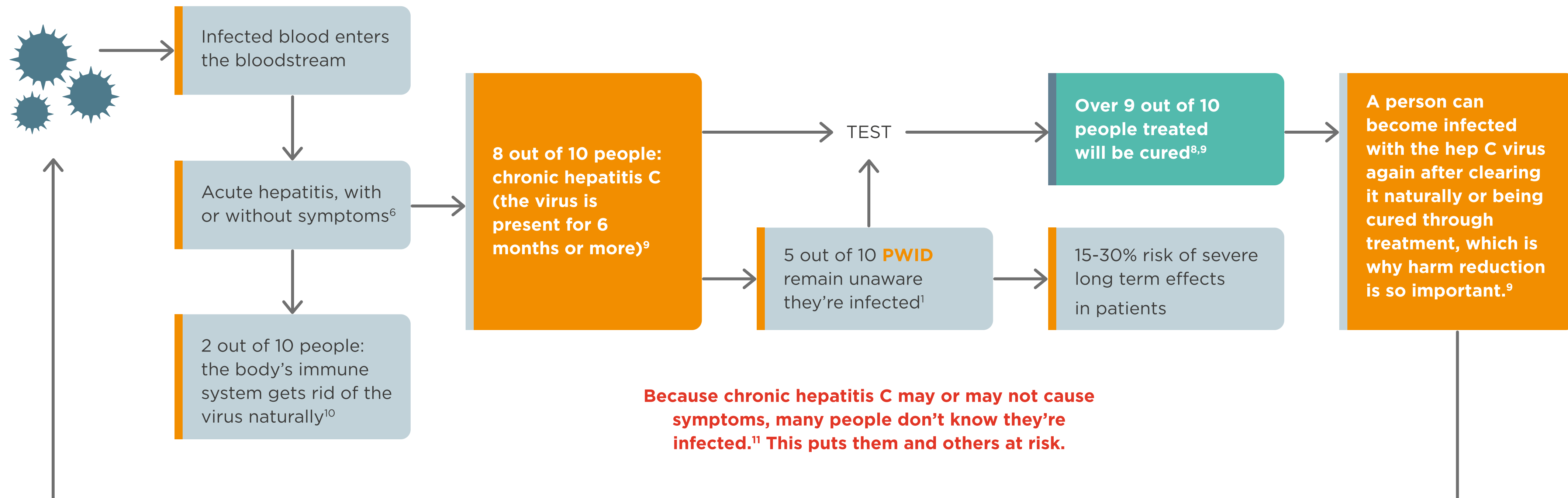
Chronic hepatitis C causes **fibrosis** (scarring) in the liver which can progress to **cirrhosis**.<sup>6,7</sup>

- Of people with chronic hepatitis C, the risk of developing liver cirrhosis is 15-30% within 20 years.<sup>7</sup>
- People with cirrhosis are at risk of liver failure and liver cancer.<sup>7</sup>
- Regular or heavy alcohol use, being male and over 40 when hep C was contracted, and the presence of other illnesses like hepatitis B, HIV or diabetes can all increase the chances of liver disease in chronic hepatitis C.<sup>7,8</sup>

Fibrosis: Scar tissue in the liver.<sup>7</sup>

Cirrhosis: Severe fibrosis of the liver that stops it functioning properly.<sup>7</sup>

# The hepatitis C disease pathway



# Symptoms of hepatitis C

Many people with hepatitis C (acute or chronic) don't have symptoms. Some may have vague symptoms like feeling tired or foggy-headed, and symptoms can come and go. They may worsen as the liver gets more and more scarred, but even advanced liver disease can go unnoticed for a long time.<sup>7,11</sup>

## TIME

### Symptoms of acute hepatitis C (recent infection)<sup>7</sup>

- High temperature (feeling hot and cold)
- Tiredness
- Loss of appetite
- Stomach pains
- Feeling sick
- Being sick

### Symptoms of chronic hepatitis C (long-term infection)

- Feeling tired all the time<sup>7,11</sup>
- Joint and muscle aches<sup>7,11</sup>
- Stomach pains<sup>7</sup>
- Feeling sick<sup>7,11</sup>
- "Brain fog"/difficulty concentrating or short term memory loss<sup>7,11</sup>
- Feeling depressed, anxious or moody<sup>7,11</sup>
- Indigestion-like symptoms<sup>11</sup>
- Bloating<sup>11</sup>
- Itchy skin<sup>7,11</sup>

### Potential signs of severe liver damage<sup>5,11</sup>

- Clients should seek medical help urgently if they have:
- Jaundice (yellow skin and/or eyes)
- Blood in their vomit
- Dark faeces
- Build-up of fluid in legs or belly
- Confusion, disorientation or personality change

### Reminders:<sup>7,11</sup>

Often there are no clear signs or symptoms of acute or chronic hepatitis C, or vague symptoms might be attributed to other things. It usually takes years for the hepatitis C virus to cause severe liver damage. With testing and treatment so easily available, no-one should risk it.

# Testing for antibodies: Step 1

First the lab looks for **antibodies** in the dried blood. Antibodies tell us whether a person has been exposed to the hep C virus.<sup>12,13</sup>

- A non-reactive or negative result means antibodies are not present
- A reactive or positive test means antibodies are present.<sup>12-14</sup>

**If the step 1 test is  
negative/non-reactive**

The laboratory will report a negative antibody result, which could mean:

- a) The client has never been exposed to the virus at all.
- b) They are in the hep C window period. If they were recently at risk, or have potential symptoms, you can suggest they wait 3-6 months and test again. This is because they may have the virus, but the body hasn't yet had time to make hep C antibodies.<sup>12,15</sup>

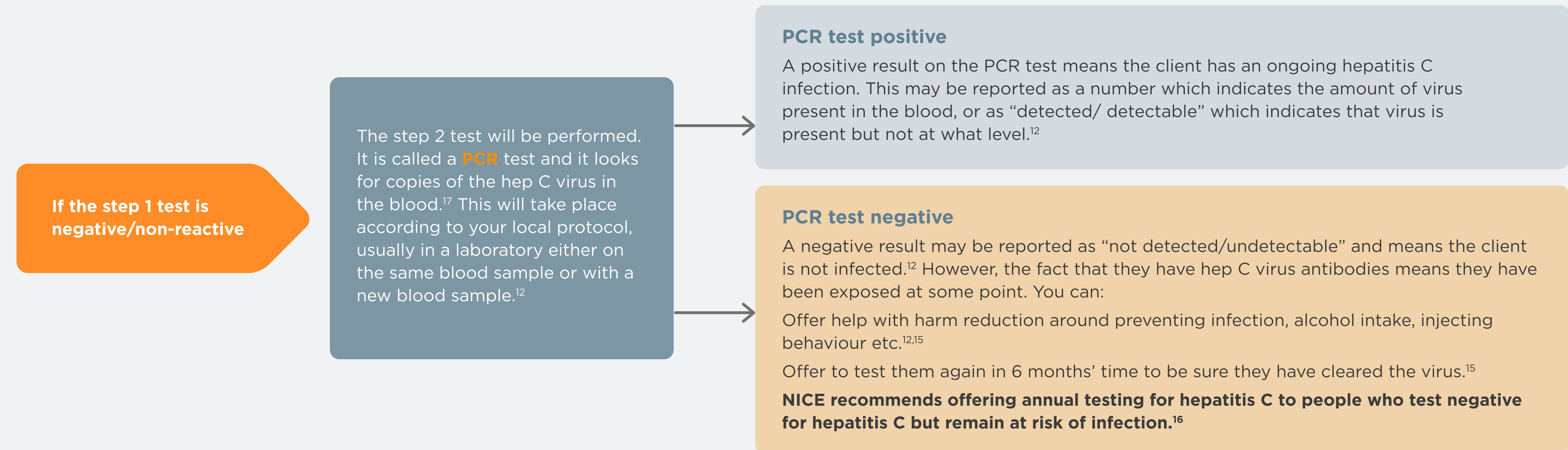
If the client has been at risk, think about re-testing in a few months.

NICE recommends annual testing for hepatitis C to people who test negative for hepatitis C but remain at risk of infection.<sup>16</sup>



# Testing for current infection: Step 2

If the sample is positive for antibodies, it doesn't necessarily mean the person has an active hepatitis C infection. Some people may have had a past infection that cleared naturally but are still carrying hep C antibodies. The only way to tell is a step 2 test.<sup>12,13,17,18</sup>



# Referral after a positive result

Once a patient has been diagnosed with chronic hepatitis C, they need to be referred into specialist care.<sup>12,17,18</sup> This may take place in the community via a specialist nurse. Your clients might need a lot of support to get them to their first appointment and beyond. Start by busting some of the myths:<sup>19</sup>

## You can be treated if you're still injecting drugs

Everyone with chronic hepatitis C should be offered treatment if it is suitable for them. This includes people who currently use illicit drugs, alcohol, opioid substitution therapy such as methadone or buprenorphine, and people who have been treated for hepatitis C in the past.<sup>\*7,8,20</sup>

- The drugs for hepatitis C can be just as effective in these people, and
- They can carry on taking their methadone or buprenorphine.<sup>\*7</sup>

## Treatment is better than it used to be

Up until a few years ago, treatment for chronic hepatitis C was very different. It lasted for up to 48 weeks, involved unpleasant and serious side effects, and offered lower cure rates even in people able to complete the course.

The modern direct acting antivirals (DAAs) are much more effective and better tolerated. Treatment is typically 8-16 weeks but sometimes up to 24 weeks. **Over 95% of people are cured with the modern DAAs.**<sup>8,19</sup>

### You may not need to be under a GP to get treated

Not all Trusts require testing and referral to take place via a GP.<sup>19</sup> If your pathway does require it, you can help the client access this.

# What to expect from healthcare

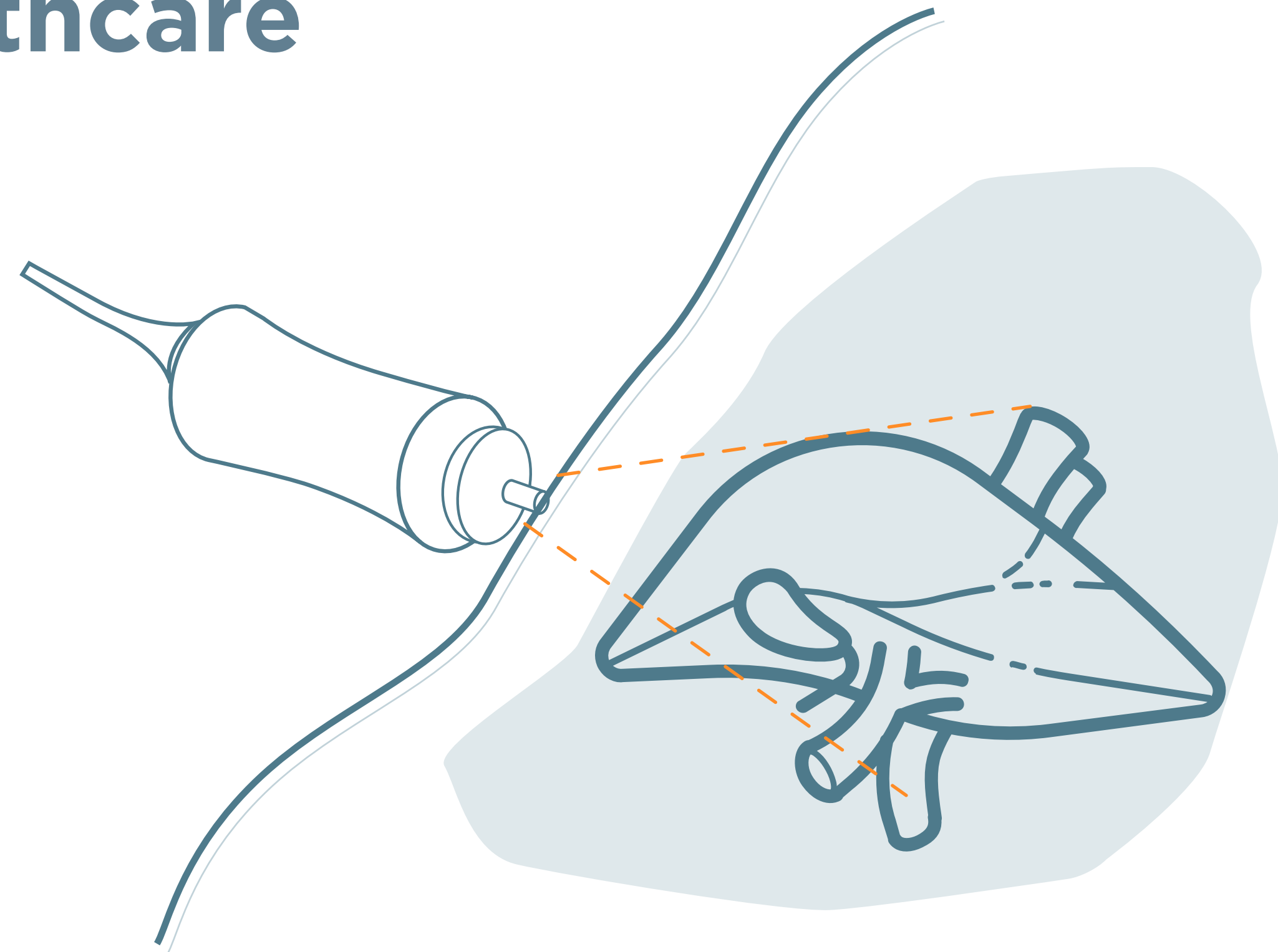
The healthcare team will look at the health of the liver. They may want to know if there are any complicating factors which may also have affected the liver, such as alcohol abuse or other diseases.<sup>8</sup> They will ask questions and do a few investigations.

## FibroScan

A FibroScan is a painless procedure to check how healthy the liver is. An ultrasound probe is held against the skin over the liver area to assess liver damage (**fibrosis**).<sup>13,21</sup>

## Does your client know...

Liver biopsies are no longer performed in the majority of people diagnosed with hepatitis C<sup>7</sup>



# Blood tests



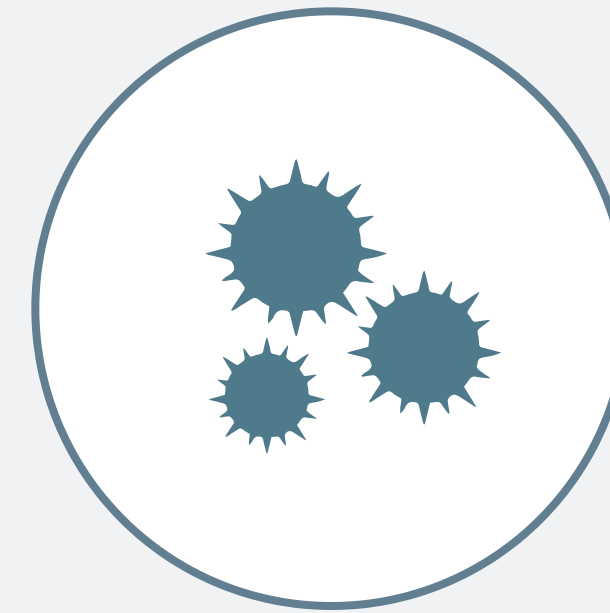
## 1. Liver function

Blood tests look for signs of how well the liver is functioning.<sup>7,13,15</sup>



## 2. Viral load

A venous blood test may be required to detect the number of viral copies in the blood.<sup>7,15</sup>



## 3. Hep C virus genotype

Blood tests can confirm the hep C virus **genotype**, which sometimes guides the choice of treatment.<sup>15,22</sup>

# Treatment goals

Treatment for chronic hepatitis C aims to completely clear the virus from the body, known as sustained virological response (SVR), or more simply, “cure”.<sup>8</sup>



Getting rid of the virus can help stop the progression of disease in the liver.<sup>8</sup>

After you have been cured of the hep C virus (or cleared it naturally yourself), it's possible to catch it again – and you can be treated again.<sup>8</sup>

Cure is a positive message, but it's only one of the many other benefits to getting tested and treated. Find out what matters to your client and what could motivate them... to get tested, to get onto the care pathway and to see their treatment through. Tell them about the ways in which getting tested and treated for hep C has helped other people, such as:<sup>23,24</sup>

- Freedom from worrying about infecting others
- Freedom from shame and the stress of being infected
- Feeling well, less exhausted, happier and more productive
- A chance to break from the past and make a fresh start
- Enjoying personal relationships more, e.g. parenting with less guilt
- A chance to move on and create new social connections
- Becoming more motivated to inject safely and prevent reinfection.

# Deciding to access treatment

Declining treatment is common amongst people who inject drugs.<sup>1</sup> They have many conflicting priorities<sup>14</sup> and it can be difficult for them to commit to their care.<sup>14,19</sup>

Peer support is important for those who are unsure about whether or not to access treatment for hepatitis C. They can speak to people like you, to their social workers, to their healthcare team or to someone who's been through it all already.<sup>7</sup>

You can ask your client to consider the pros and cons of treatment, starting with the benefits others have gained from treatment as shown on the previous page.<sup>7</sup>

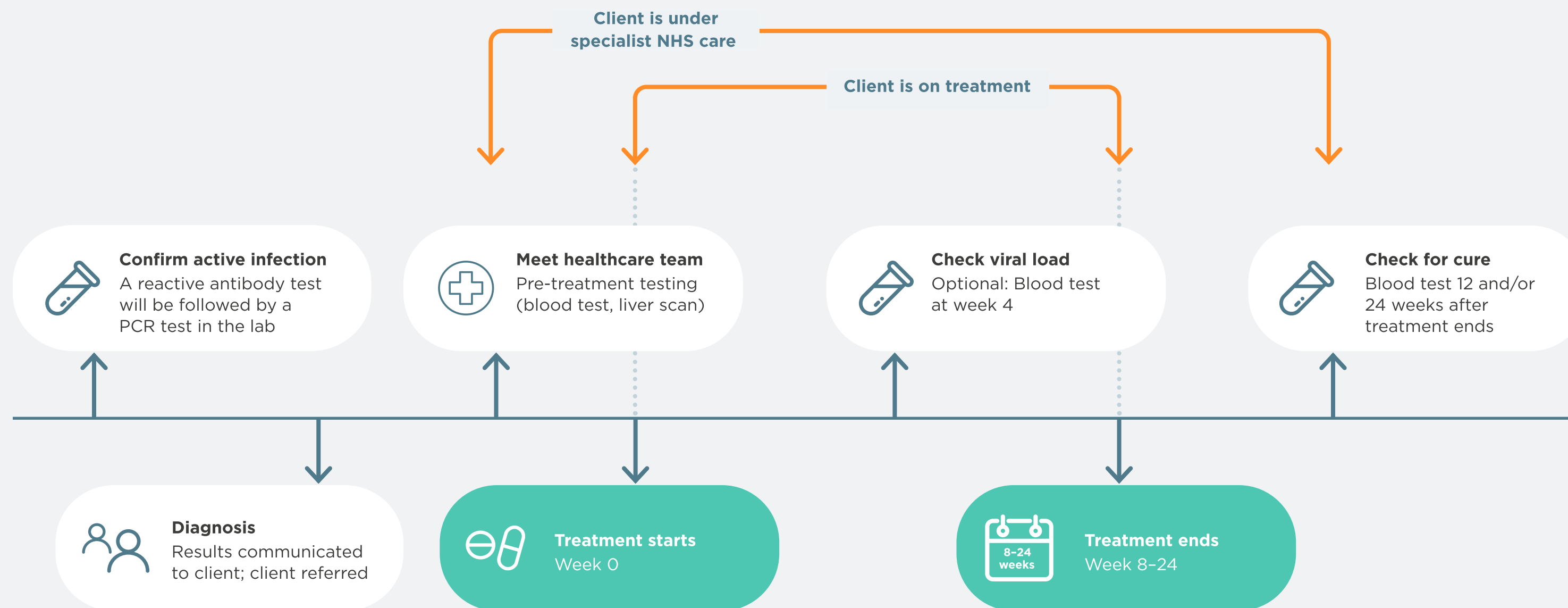
Reasons to defer treatment that the client may want to discuss with the healthcare team are:<sup>7</sup>

- Being pregnant or trying for a baby
- Being in the middle of particularly difficult life or medical situations<sup>15</sup>

## Does your client know...

The Hepatitis C Trust has a well established peer support programme that carries positive experiences forward to benefit other service users. Peers (who may have been through treatment themselves) may be able to help you generate awareness in your centre and drive not only testing, but uptake of treatment. Peers may also be able to help clients come to terms with diagnosis and engage with their healthcare.<sup>14</sup>

# Timeline of treatment



## Setting expectations

- Following clinical investigations, the healthcare team will make decisions about the client's care. They will set up an appointment or communicate with the client via a phone call.
- In addition to choosing the right treatment for the client, the healthcare team will also want to understand the barriers he or she may face in completing the treatment course. They will ask questions about their lifestyle and may link them into other support services.<sup>8</sup>
- The healthcare team may offer diet and lifestyle advice, such as reducing alcohol consumption, in order to reduce stress on the liver.<sup>7,8</sup>

## Giving support

- You can encourage and support your clients to attend all follow-ups and help them commit to seeing the treatment course through.<sup>19</sup>
- Find out who is working with them in the specialist service and what support is on offer to help them cope with feelings of isolation, stigma, or practical things like medication side effects.<sup>8,19</sup>

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# Section 4: Practical case study

# Imagine a client like Emily...

*Emily has been collecting methadone scripts from your service for 2 years. She's tried tapering the dose, but ends up using and back at square one every time. Part of the problem is her boyfriend John, a dealer who is often abusive. When John isn't around, Emily is scared to stay in the flat alone. She stays with friends or in shelters.*

## Things weren't always this way.

When Emily was younger she got a degree in fashion design and had a bright future ahead.

But when she had a baby at 23, Emily became unwell mentally. She had repeated admissions to a secure unit, started sleeping rough and developed an injecting habit. When Chloe was 4, her grandparents applied to the courts for custody and won.

In good times, Emily is able to make a bit of money selling jewellery at markets and festivals. She dreams of being clean, having a regular income, and being worthy of a place in her daughter's life. If she didn't feel so tired and depressed all the time, maybe she'd be strong enough to change.



# Emily's barriers to testing

**Emily has been offered BBV testing before, but always has an excuse:**

"My veins are terrible"<sup>1</sup>

"I only ever share needles with John, so I'm not at risk"<sup>1</sup>

"I hate hospitals - doctors judge me"<sup>1,2</sup>

"I might lose access to my daughter completely"<sup>2</sup>

## Think about it...

- What would you say to these objections?
- Why would testing be in Emily's best interests and how would you articulate this?
- How would you support Emily to become more engaged in her healthcare overall?

**What other concerns could a client have in terms of testing and treatment? You have probably heard all of them!**

# Moving through the barriers

## Speak confidently about the benefits

- Even if the result is positive, it can be a weight off a person's mind<sup>3</sup>
- Testing provides access to treatment for all BBVs and a cure for hepatitis C<sup>3</sup>
- Going through testing can motivate a fresh start in many areas of life<sup>3</sup>

## Remind them of the risks

- Are there times she has shared equipment that she may not recall?
- Might John be regularly sharing needles and therefore putting Emily at risk?
- Does she ever share personal care items with others?

## Make it personal

- You don't need to be an expert in BBVs: rely on your knowledge of the client
- Show Emily that you care about her as a person, not a "service user" or "addict". Show her you are thinking about her future, not just her needs today
- Mention that her fatigue and low mood may be related to a blood-borne virus<sup>2,3</sup>

Ensure the client knows that whatever happens, support is available, and they will be treated with respect

Explain your service's policy on confidentiality and consent. When you have the client's **informed consent**, you are ready to test<sup>1,3</sup>

# Informed consent: **The pre-test discussion**

*An in-depth discussion before testing means Emily is able to give informed consent to test. You can be confident she understands the process and is equipped to deal with what follows.*

## Why you are recommending a test<sup>5</sup>

- Explain your policy of testing people who may be at risk of a BBV because of past or continuing use of injection drugs.
- Explain that testing can lead to health-improving treatment.
- Ask about the last time the client may have been exposed to the virus, as testing too soon could result in a falsely reassuring negative antibody test in the case of hep C.

## How testing works<sup>3</sup>

- Explain how results are generated according to how testing takes place in your service for each BBV.
- Explain that if the hep C test is negative, the client may be in a window period and, depending on a risk assessment, could benefit from testing again in a few months.

## How results are handled and what happens next<sup>5,6</sup>

- Discuss the process for receiving results (ideally in a face to face appointment when all results are available). Explain the support available in case of a positive result, and referral to specialist services.
- Explain that if she tests negative, you will work with the client to reduce her risk of infection and may offer repeat testing if she remains at risk.

**The pre-test discussion ensures the client understands...**

# Confidentiality and data protection

## “What happens to my blood sample?”

Ensure you understand your NHS Trust’s storage policy for virological samples so that you can describe it to clients.

Explain that blood samples and computerised results are stored securely by law and are only accessible to NHS staff, who work under strict confidentiality rules.<sup>7,8</sup>

## “Who has access to my results?”

- Your consent policy should clarify whether the results (anonymised) will be entered into the public health database.<sup>9</sup>
- NHS specialists and/or GPs are bound by a Code of Ethics and certain laws surrounding confidentiality. The only people they can notify about a client’s status, without the client’s permission, are other healthcare workers involved in the client’s care.<sup>8</sup>
- Describe your NHS Trust’s confidentiality policy – have a copy of it in the waiting room.<sup>10</sup>
- Remind Emily that disclosure to friends, family and employer is her choice, and something that you can support her with.<sup>8</sup>

## Remember: In every case, support with harm reduction<sup>11,12</sup>

If the client keeps refusing to test, offer prevention advice especially if specific risks are identified.

- Advise on safer injecting and local needle exchange services.
- Offer printed information on testing to take away.

# Giving results: The post-test discussion

Emily's results are in and you have been asked to give them to her. Her results are...



## Remember: “Be positive about a positive”

Focus on the benefits of knowing their status (access to treatment and in the case of hepatitis C, a likely cure).

## Reminder of what this means

Emily had a reactive antibody test that was followed up with a positive PCR test (detectable amounts of the hep C virus in the blood). She therefore has chronic hepatitis C.<sup>3,6</sup>

### Things to cover:

- Check that she understands all the information you provided before testing
- Tell her who she will be referred to and where appointments will take place
- Reassure her that she is in the hands of experts
- Tell her how you will support her during the care pathway
- Encourage her to bring up concerns/questions about the process.

# Linking patients into the care pathway

## You've come so far – don't lose her now

Many drug service clients test positive for the hep C virus, but fail to turn up to their appointments.<sup>11,13</sup> This results in the label “DNA” (did not attend) which you may hear about.<sup>13</sup> There are many ways that you can support your clients to keep them engaged in their care.

- Describe the treatment timeline, telling her what appointments to expect and when.
- Ensure she is receiving phone, text or email reminders (as appropriate) for her appointments.<sup>12</sup>
- If her appointments are happening in the service, try to co-ordinate them so that they coincide with her visits to collect methadone.
- Tell her about the support offered by groups like the Hepatitis C Trust. You can arrange for a phone call from a support worker if needed.
- Help prepare her for her appointments – explain the importance of being open about her lifestyle and anything which might affect the choice of treatment.
- Keep reminding her of the benefits to getting treated in terms of what matters to her personally.

## You can also...

- Ask the healthcare team to see your client as soon as possible at a time that suits her (ask them to be flexible to client need).<sup>1</sup>
- Be a great communicator: get to know the clinic staff and tell them about Emily in advance of the appointment.<sup>12</sup>
- Find someone (a “buddy”) who has been through treatment and link them up with Emily.<sup>12</sup> You can also ask Hepatitis C Trust if they have a peer service in your area who can do this.<sup>1</sup>



# Life after cure

*It's six months later and things are looking up for Emily. She's been treated for hepatitis C, cured, and she's never looked back. She's living in a hostel, having split up with John for good. Feeling confident and well, she's started tapering off methadone and is managing the process with your help. She's got a few job leads and is spending more time with Chloe.*

## Think about it...

- Who are the clients you would prioritise for BBV testing, in addition to people like Emily?
- Do you know any ex-users who have never been tested?
- Do you have hep C-positive clients who are still refusing treatment?
- Do you have any clients who have been cured of hepatitis C in the past and may be in need of another test?

## So, what have you learned? What can you put into practice today?

- Be comfortable and confident. You are the expert on the client.  
Be negative about a negative result (give advice on reducing risks).
- Be positive about a positive result (focus on the opportunity to cure the disease).  
Get your referral in as quickly as possible, working to ensure the client is on board all the way through.<sup>12</sup>  
Always provide ongoing harm reduction support to avoid infection or reinfection.<sup>11</sup>  
Remember to offer further testing in future if the client declines a test, or undertakes testing/treatment and continues with risky behaviours.<sup>3,12</sup>

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