

Future of hepatitis C care in the Netherlands

**A vision
of care for
HCV**

Think Tank hepatitis C care in the Netherlands
under guidance of The Argumentation Factory

This report was created by:



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How did this report come about?

Over the next few months, new hepatitis C drugs will come onto the market. They will increase the chance of curing the disease to more than 95 percent. The arrival of new drugs requires a critical reassessment of hepatitis C care in the Netherlands. What should the ideal care for hepatitis C look like in 2015? And how are we going to get there?

Under guidance of The Argumentation Factory, a Think Tank of experts has pondered this question. The members of the Think Tank reflected on the issue from their role as expert, keeping their own interests as separate as possible. They spoke in a personal capacity rather than on behalf of their organization. Biopharmacist AbbVie initiated and sponsored the project.

This report is the result of four thinking sessions and two interviews with a total of twelve experts in the field of hepatitis C. The Think Tank convened during the summer and autumn of 2014.

The Think Tank went through three thinking steps. First of all, they drew up an analysis of what hepatitis C care looks like at the moment. This analysis gave them a clear starting point from which the Think Tank looked at the future. Secondly, the Think Tank formulated a vision. The Think Tank then developed this vision in the third and final thinking step: concretization. Concretization is the first step towards the realization and implementation of the vision. The result of these three thinking steps is contained in this report and presented as follows in the form of maps:

1. Analysis

What does the care process for patients with hepatitis C look like at the moment? Which facts about hepatitis C are relevant when considering an action plan? Which developments are there? The results of this thinking are on the Care Map, the Facts Map, and the Trends and Factors Map.

2. Vision

What should care for hepatitis C look like in the near future? The Vision Map shows the Think Tank's vision of hepatitis C care in the Netherlands.

3. Concretization

Based on the first two thinking steps, the Think Tank formulated specific guidelines in order to realize the vision. What needs to happen specifically in order to realize the vision? Who, in the Think Tank's opinion, is best able to implement this? The answers to these questions can be found in the Action Map.

This book of maps will serve as a basis for healthcare providers, policy makers, and others involved with hepatitis C. The results of the Think Tank's work can be used as a starting point for a 'national action plan' in order to jointly improve care for hepatitis C.

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Table of contents

Introduction

How did this report come about?	3
---------------------------------	---

Notes

Notes accompanying the maps	7
-----------------------------	---

The maps

Care Map for Hepatitis C	8
--------------------------	---

Facts Map for Hepatitis C	10
---------------------------	----

Trends and Factors Map for Hepatitis C	12
--	----

Vision Map for Hepatitis C	14
----------------------------	----

Action Map for Hepatitis C	16
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Information lists

Sources and abbreviations	19
---------------------------	----



Notes

accompanying the maps

Map 1. Current care

This map shows what current care for patients with hepatitis C looks like. It forms the starting point for the Think Tank's work. What does the world look like now and what would we like to change?

Map 2. Facts

The Facts Map is a graphic display of key hepatitis C figures.

Map 3. Trends and Factors

The Trends and Factors Map shows the developments and factors that the Think Tank considers significant when reflecting upon hepatitis C care. They concern the structure and cost of care as well as the whole disease and care process; from infection to treatment.

Map 4. Vision

Based on the previous analysis, the Think Tank reached a vision. The vision shows what the future of hepatitis C care in the Netherlands should look like. It is a broad vision which is elaborated upon in the Action Map.

Map 5. Action

The Action Map indicates what should happen for the vision to be realized. Together the actions form a starting point for a national viral hepatitis steering committee whose job it would be to elaborate on the points.

What is hepatitis C?

Hepatitis C is caused by the hepatitis C virus (HCV). This virus can cause infections in the liver. These infections can lead to the formation of scarring in the liver. This, in turn, can lead to a reduction of liver function. Scarring can ultimately lead to liver cirrhosis and liver cancer with possibly fatal consequences. Hepatitis C is a major cause for liver transplantation. There are no exact figures on the prevalence of hepatitis C. There are estimated to be 15,000-60,000 Dutch hepatitis C sufferers. Migrants form the largest risk group.

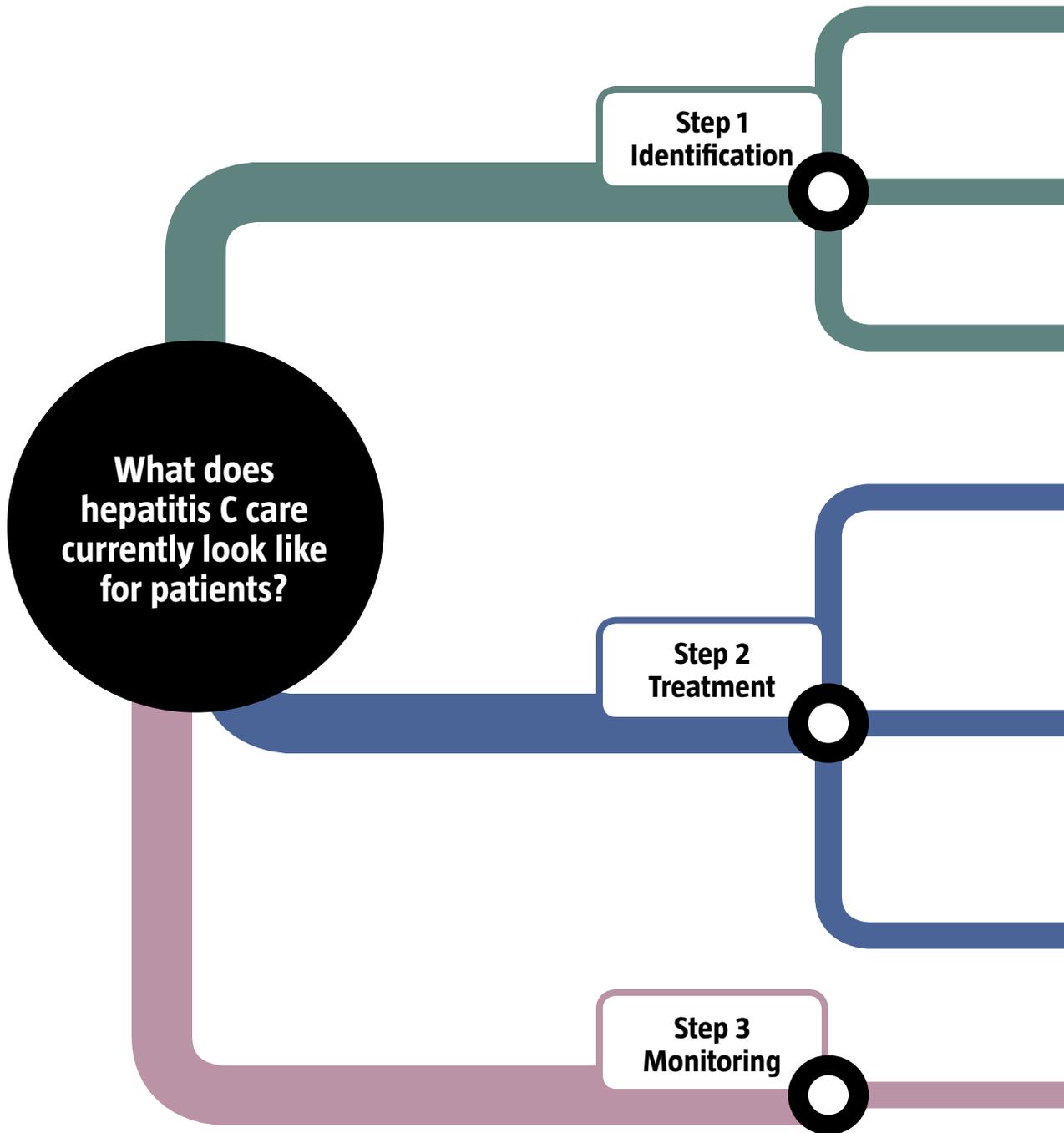
How do you get hepatitis C?

HCV can be transmitted via blood. The incubation period for acute hepatitis C is approximately seven weeks to three months. In the case of an acute HCV infection, the immune system itself is able to

remove the virus from the body of 20 to 25 percent of the infected individuals.

A patient with chronic hepatitis C (an HCV infection which has existed for more than six months) does not necessarily feel ill; it can take up to forty years before the patient is troubled by hepatitis C. The current treatment methods for hepatitis C are long-lasting and tough. The medicines contain the substance Peginterferon which has to be administered subcutaneously, and there are a lot of side effects. Many patients have difficulty completing the treatment.

The new treatment methods do not last as long, the medicines are easier to take, and there are fewer side effects. Moreover, the chance of recovery increases to more than 95 percent. These new medicines will become available in the Netherlands from the end of 2014.



hepatitis C

The patient develops symptoms

- The patient presents (vague) health problems to their general practitioner, for example fatigue and abdominal pain.
- The general practitioner has the patient tested for HCV.
- The general practitioner reports acute hepatitis C to the RIVM's virology laboratory.

The patient does not develop any (clear) symptoms

- The patient is tested for HCV by the Public Health Service (GGD), blood bank, or Custodial Institutions Agency (DJI).
- The patient undergoes blood tests for HCV in the hospital or at the blood bank.
- The patient presents (vague) health problems to their general practitioner, and liver tests show HCV infection.

Risk groups are actively approached for screening

- Some GGDs and addiction clinics run screening projects for risk groups.

The patient has acute hepatitis C

- The general practitioner immediately sends the patient to hospital.
- Treatment does not always start immediately; sometimes the disease is allowed to follow its natural course for three to six months.

The patient has chronic hepatitis C

- The patient is examined by a gastroenterologist or an infectious disease specialist in a hepatitis treatment centre.
- The physician assesses whether treatment is required.
- The physician adapts the treatment to the genotype of the virus, the symptoms, and other individual factors.
- Drug users sometimes receive support from addiction care specialists during treatment.
- The patient receives treatment with injections and/or pills.
- The treatment lasts six months to a year.
- The treatment is paid for via the Healthcare Insurance Act.
- The physician monitors the adherence to and effects of the therapy.

In addition to chronic hepatitis C, the patient has cirrhosis of the liver

- Where there is serious cirrhosis, the patient needs to be given a liver transplant.

- Six months after treatment, the patient is tested for the presence of the virus in the blood.
- If the virus is no longer present in the blood, the patient is no longer monitored.
- If the virus is still present in the blood, the patient continues to be monitored.
- If the patient has cirrhosis of the liver, they continue to be monitored.
- If the patient still runs the risk of HCV infection, they are monitored for reinfection.

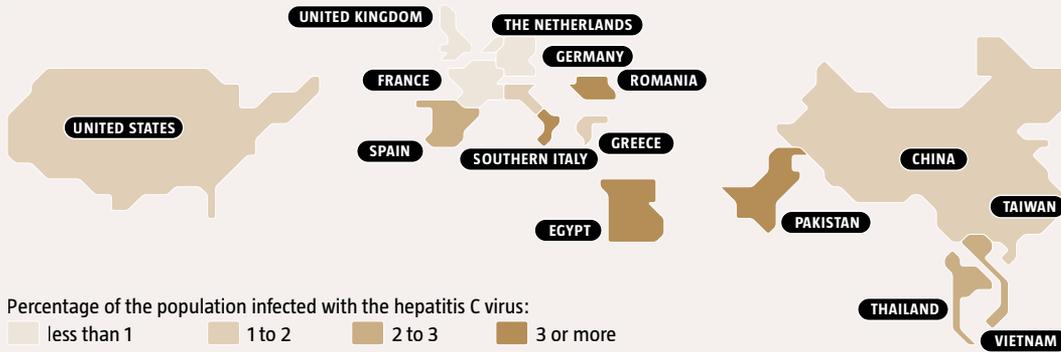
Worldwide, around 2 percent of the population is infected; in the Netherlands around 0.2 percent.

World population 2.0

Dutch population 0.2

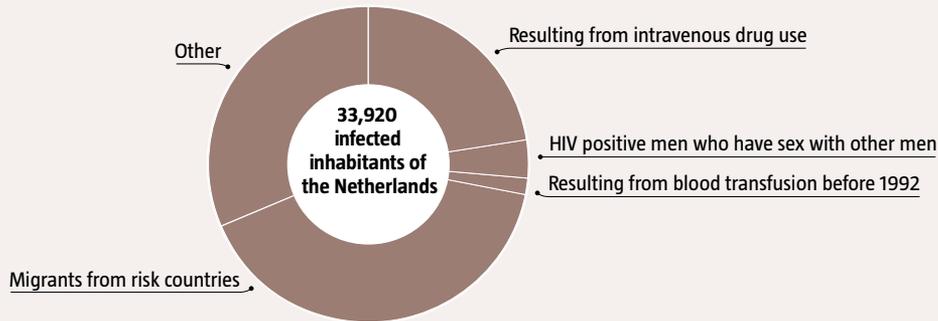
Source: 1a 1b

Concentrations of HCV are found around the Mediterranean and in Asia.



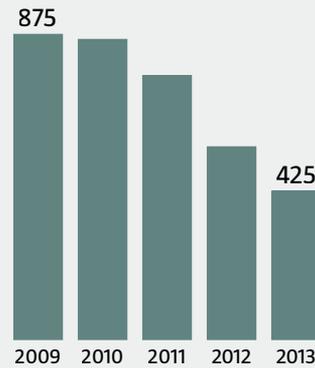
Source: 2

Dutch infections are largely contracted abroad.



Source: 3

The number of reports of hepatitis C are in decline.



Source: 4

Infection

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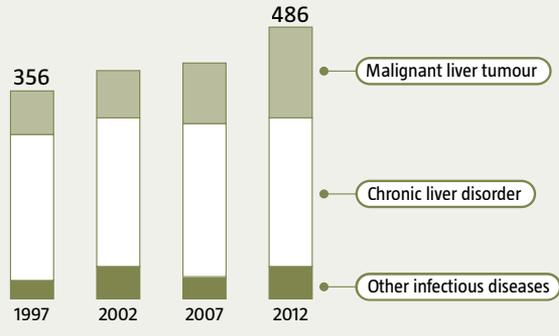
Identification

hepatitis C

What are the facts in about the care for hepatitis C in the Netherlands?

Disease progression

In the Netherlands, it is estimated that around 500 people a year die from hepatitis C and B.

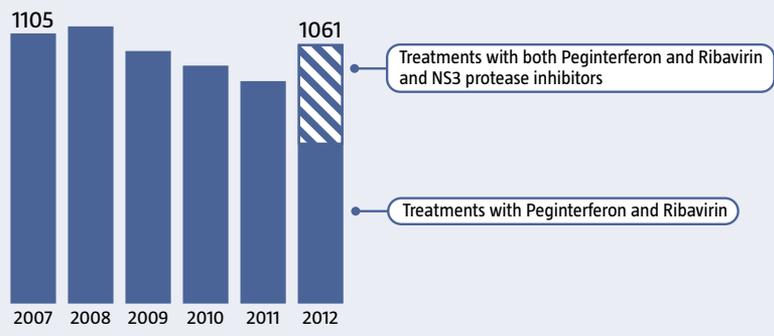


Statline: Causes of Death, Hepatitis, Primary liver, malignancy*0,26, cirrhosis*0,35

Source: 5

Treatment

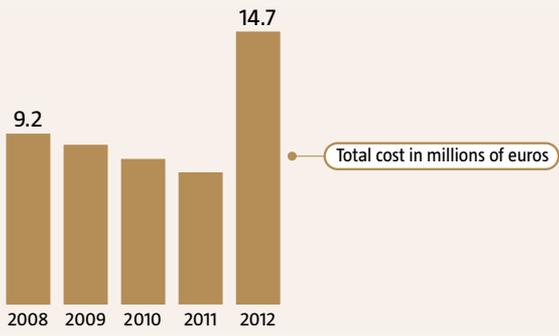
There are around a thousand treatments per year.



Source: 6

Cost

The cost of hepatitis C medicines has increased by more than 50 percent over recent years.



Source: 7

Structure

The organization of care and support has improved but is not yet optimal

- Since 2012, the Netherlands has around 48 specialist treatment centres for HCV.
- Hospitals do not have a standard treatment plan or priorities for treatment per target group.
- Patients who have dropped out of or refused treatment have no access to programmes to get them to start (again).
- Healthcare providers and policy makers place more focus on curing HCV than on quality of life.
- Many healthcare providers do not know how HCV support or treatment is funded.

The Dutch approach toward HCV can be improved by learning from abroad

- In the Netherlands, the introduction of new HCV drugs takes longer than in other European countries.
- At a European level, there is an exchange of knowledge but no joint policy for HCV.
- Unlike Scotland and France, for example, the Netherlands has no national hepatitis plan.

Infection

HCV occurs relatively infrequently in the Netherlands

- Exact prevalence rates are lacking; it is estimated that 0.22 percent of Dutch citizens are infected with HCV.
- The use of intravenous drugs hardly ever occurs in the Netherlands.
- The transmission of HCV by blood transfusion has decreased due to improved hygiene.

Migrants, drug users, and men who have sex with other men are risk groups for HCV

- Half of current HCV infections occurred in non-western countries.
- A quarter of current infections occurred through intravenous drug use.
- At the moment, acute hepatitis C mainly occurs among men who have unprotected sex with other men.
- Some people who belong to a risk group are unaware of this.
- HCV infections are more common in lower socio-economic classes.

HCV is given little attention by healthcare providers and is poorly recognized

- The symptoms that belong to HCV, like fatigue, could also indicate other disorders.
- General practitioners have insufficient knowledge about the risk groups, nor do they actively look for HCV.
- Most healthcare providers do not automatically test for HCV infection in cases of impaired liver function.
- Healthcare providers must report acute HCV to the RIVM; the number of reports has decreased between 2008 and 2013.
- Fewer people are getting tested because they have to pay for the tests themselves.
- More than 80 percent of HCV infections run their course without symptoms and go unnoticed.

There is no systematic screening for HCV infections in the Netherlands

- Despite great efforts, the detection of HCV infections through screening projects is often low.
- Where there is a positive HCV test, the patient's social environment is not tested as a standard procedure.
- Screening can have negative side effects, including psychological ones, such as fear, anxiety, and stigmatization.

Not everyone who tested positive for HCV in the past is still being monitored

- Addiction care has a clear picture of current drug users, but not of former users.
- Patients with HCV infection are not always monitored after diagnosis, nor are they placed on a national register.

Identification

What relevant trends and factors influence the future of hepatitis C in the Netherlands?

Map for hepatitis C

What are the trends and thinking on the future of care for hepatitis C in the Netherlands?

Disease progression

The course of the HCV disease depends on various factors

- Age, sex, lifestyle, such as alcohol use or being overweight, determine the course of the disease.
- Other diseases, such as HIV, determine the course of the disease.

HCV is a disease with a low mortality rate but potentially serious effects

- Most patients with HCV die with the disease, but not as a result of it.
- Despite effective medication, the number of fatalities from HCV and HBV has increased slightly since 1996.
- Since 1996, the number of fatalities from the direct or indirect effects of HCV or HBV has increased from 450 to 500.
- Since 1996, the number of fatalities from the direct or indirect effects of HIV has decreased from 327 to 44.

HCV does not always need to be treated

- Whether or not treatment is provided depends on the medical prognoses and the patient's risk behaviour.
- Some patients are physically, financially, and/or socially unprepared to complete the treatment successfully.
- A lack of a proper consultation structure between healthcare providers means patients are not always referred to a specialist.
- Addiction care specialists pay little attention to HCV in treatment programmes and make few arrangements with hospitals.
- Prison inmates with HCV are only treated if it is medically necessary.

Treatment of HCV is not optimal

- As new therapies are expected, the Netherlands has currently called a 'treatment stop'.
- Until now, treatments for HCV can be accompanied by Peginterferon.
- Treatments last six months to a year and are associated with side effects such as psychological symptoms.
- The chances of recovery are around 50-80 percent and lower if patients also have HIV.
- Around 20 percent of patients stop treatment prematurely because of the side effects.
- In the case of serious cirrhosis of the liver, a liver transplant is the only course of treatment.
- The minister has named three groups whose treatment is to be reimbursed.

New medicines make HCV more treatable

- New medication has increased the chances of cure from HCV to 96 percent.
- The new treatments last 12-24 weeks and have few side effects.

Treatment

The current methods of treatment are reimbursed; new treatments as of 1 November 2014

- Health insurance companies pay the cost of current HCV treatments.
- Health insurance companies will reimburse the new treatments for patients in an advanced stage.
- The cost of current treatments comes to 25,000-60,000 euro per treatment per patient.
- The current cost of the new treatments comes to 96,000 euro per treatment per patient.
- The Ministry of Security and Justice pays the cost of treating detained patients.

Cost

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Structure

HCV care is coordinated and focused

- Healthcare providers make regional arrangements about referrals, treatment, and support.
- Treatment for HCV only takes place in centres that meet quality criteria of the relevant medical specialists.
- Healthcare providers take account of the aftercare of HCV patients, such as reintegration.

Knowledge and data about HCV are stored and shared nationally

- Healthcare providers register patients in a national data bank.
- Laboratories add data about existing HCV infections to the national register.
- Policy makers use the national register for policy purposes.

More people, especially those in risk groups, are informed about hepatitis C

- The Dutch population knows what hepatitis C is and how it can be prevented and treated.
- Risk groups know why it is wise to get screened for HCV.
- People belonging to risk groups are informed by GGDs, RIVM, DJI, and addiction care.

Raising awareness

Healthcare providers are alert to potential HCV infections

- Healthcare providers are capable of identifying HCV infections.
- Healthcare providers know that an HCV infection is an easily treatable condition.

HCV is routinely and nationally detected

- High-risk groups are routinely screened and informed about what it is, how it happens and why this is so.
- Where possible, screening for HCV is combined with screening for other (infectious) diseases.
- Anyone who has ever been diagnosed with HCV but has gotten out of sight is localised and given a care plan.
- Every adult is tested for HCV, HBV, and HIV at least once in their lifetime.

Identification

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Disease progression

In the Netherlands, nobody dies of HCV any more

- Patients with HCV are treated before they get cirrhosis of the liver.
- An HCV infection is less likely to lead to liver damage.

Treatment

Treatment is carefully considered

- Patients with cirrhosis of the liver and severe fibrosis are given priority for treatment of HCV.
- The greater the chances patients have of passing the virus on, the sooner they are treated.
- The greater the chances patients have of completing the therapy, the sooner they are treated.
- Prisoners with HCV are treated, especially if they will still be imprisoned after the treatment has ended.

After diagnosis, all patients are given a care plan and continue to be monitored, even if they are not undergoing treatment

- Healthcare providers draw up a care plan in consultation with patients.
- Healthcare providers and patients monitor progress and adapt the care plan if necessary.
- Healthcare providers make the care plan understandable for patients, using plain language and clear agreements.
- Prisoners diagnosed with HCV are given a care plan that continues after their release.

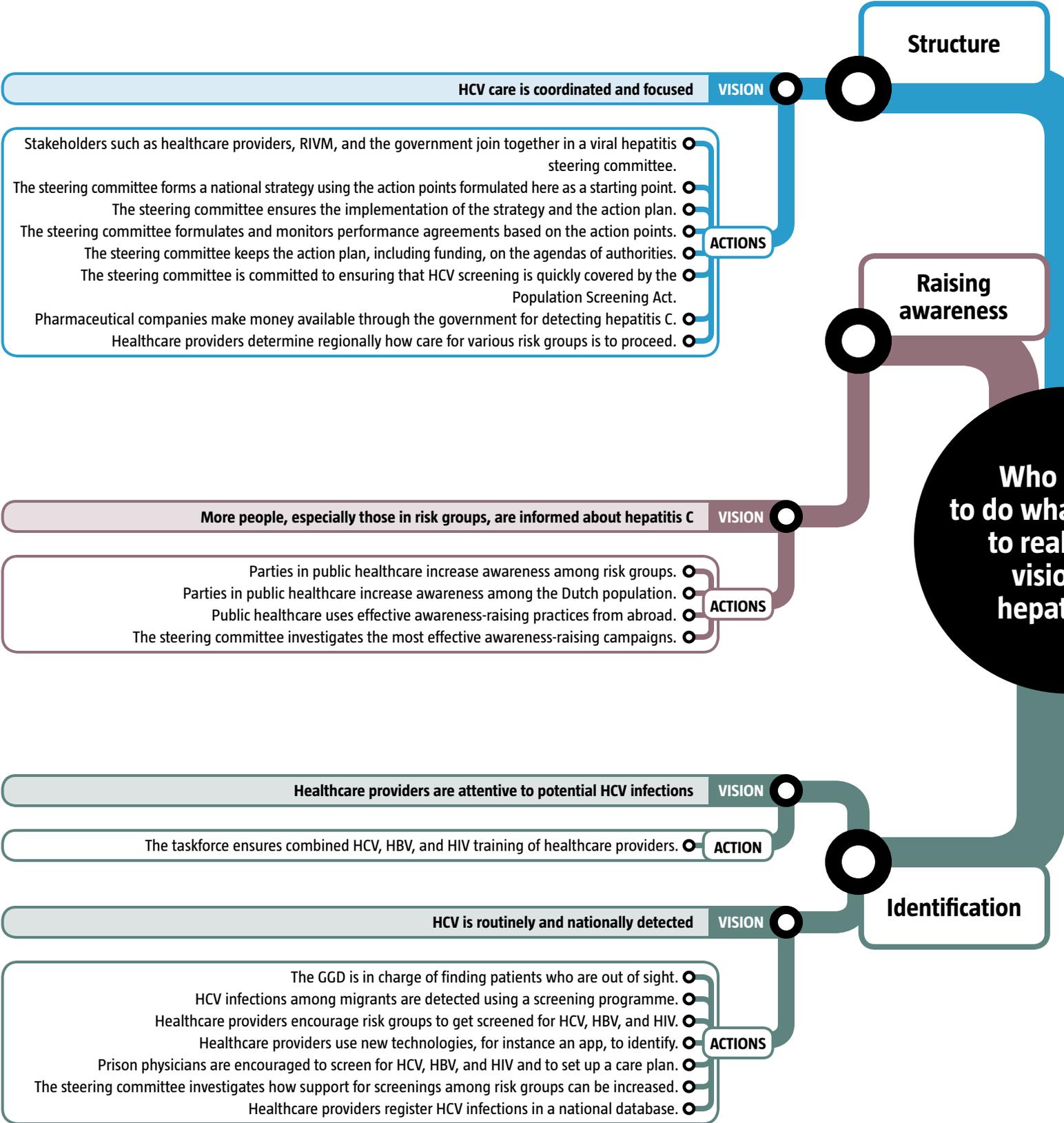
Healthcare providers are familiar with the latest developments

- Healthcare providers know how the new drugs work and how effective they are among various patient groups.

Cost

HCV care remains affordable

- The cost of treating HCV with new drugs needs to come down in the next few years.
- The care and detection of HCV are cost effective.
- Like general practitioner care, the HCV test does not fall within personal liability.
- Funding does not stand in the way of treating prisoners with HCV.



for hepatitis C

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in order
to
optimize the
investment
for
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Treatment

VISION Treatment is carefully considered

ACTION Relevant medical specialists adapt the guidelines for HCV.

VISION After diagnosis, all patients are given a care plan and continue to be monitored, even if they are not undergoing treatment

ACTIONS

- The Ministries of Justice, VWS, and health insurance companies make agreements about the treatment of prisoners who are released.
- The Ministries of Justice, VWS, and health insurance companies make agreements about the treatment of migrants.

Cost

VISION The cost of HCV care continues to be affordable for the Netherlands and patients

ACTIONS

- The steering committee carries out a study into the most cost-effective method of care and detection.
- The Ministry of VWS arranges for the HCV test to be outside personal liability.
- The Ministry of Justice funds treatment of prisoners who meet treatment criteria.
- The Ministry of VWS negotiates with pharmaceutical companies on the cost of new medicines.



Information lists

List of sources

- 1a WHO, Factsheet Hepatitis C, 2014
- 1b Vriend et al., 'Hepatitis C virus seroprevalence in The Netherlands', *European Journal of Public Health*, 2012
- 2 Centers for Disease Control and Prevention, *Yellow Book*, Chapter 3, 2014
- 3 Vriend et. al, 'Hepatitis C virus prevalence in The Netherlands: *migrants account for most infections*', *Epidemiology and Infection*, 2013
- 4 RIVM, *Infectious Diseases Bulletin*, January 2014
- 5 CBS Statline 2014
- 6 National Healthcare Institute GIP data base Netherlands, 2014
- 7 National Healthcare Institute GIP data base Netherlands, 2014

List of abbreviations

- DJI Custodial Institutions Agency
- GGD Public Health Service
- HBV Hepatitis B Virus
- HCV Hepatitis C Virus
- HIV Human Immunodeficiency Virus
- RIVM Netherlands National Institute for Public Health and the Environment
- VWS Netherlands Ministry of Public Health, Welfare and Sport

