

**ATTITUDES ABOUT HEPATITIS C
EDUCATION CAMPAIGN FOR
PEOPLE NEWLY DIAGNOSED WITH HEPATITIS C**

Prepared for:

**Massachusetts Department of Public Health
Boston, Massachusetts**

Prepared by:

**Market Street Research, Inc.
Northampton, Massachusetts**

and

**Policy Studies, Inc.
Cambridge, Massachusetts**

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INTRODUCTION

Hepatitis C, a slow-progressing liver disease, is a disease that affects nearly 2% of the United States population. Discovered in the early 1980s, antibody-detecting blood tests have only been available since 1992. Hepatitis C is a serious health problem; however, the general public is not well-informed about the disease. People who are newly diagnosed with the disease are likely to have many questions about their treatment options and how to avoid spreading the virus.

The Massachusetts Department of Public Health (MDPH) is currently engaged in a hepatitis C education campaign. As part of this campaign, the MDPH plans to develop materials, including videotapes and pamphlets, for people who are newly diagnosed with hepatitis C. These materials would be available through providers' offices and other locations to supply people with information about their disease. The MDPH is working with Policy Studies, Inc. in Cambridge to develop the educational materials, and is interested in understanding the types of questions those who are newly diagnosed with hepatitis C have about their illness. The MDPH has contracted with Market Street Research, Inc. of Northampton, Massachusetts to conduct a qualitative study of people with hepatitis C in order to determine:

- the **amount and quality of information participants received** when first diagnosed with hepatitis C, and their awareness and understanding of the screening tests available;
- participants' **knowledge about the disease**, including modes of transmission, the possibility of re-infection or infection with another strain of hepatitis, and methods for slowing the progression of the virus;
- participants' **knowledge of treatment options**, including the effectiveness of treatment, possible side effects, and, among people in recovery for injection drug use, challenges associated with using needles as part of their treatment;
- the types of questions or concerns people may have about **co-infection with HIV**; and
- participants' **attitudes about educational materials**, including the types of information they feel would be most helpful for others in their position to have about the options available to them, the settings they would prefer for viewing educational videos, interest in additional materials, and attitudes about whether the videos should be specifically targeted toward specific patient groups (i.e., people in recovery vs. people who contracted the virus through a blood transfusion or organ transplant).

This report presents the results of five focus groups conducted by Market Street Research, Inc. among people recently diagnosed with hepatitis C, including people in recovery and those who contracted the virus through a blood transfusion or organ transplant.

METHODOLOGY

Market Street Research, Inc. and Policy Studies began this study by meeting with representatives of the Massachusetts Department of Public Health (MDPH) to discuss the specific research objectives for this study. Following the initial meeting, Market Street Research prepared draft moderator guides for people in recovery and those who contracted the virus through a blood transfusion or organ transplant. Both guides were reviewed by the MDPH and revised, and guides for Spanish-speaking participants were translated into Spanish by the UMass Translation Center. English copies of the guides used for the focus groups appear in Appendices A and B.

This study was designed to include people who have been diagnosed with hepatitis C and:

- **contracted the virus as a result of injection drug use**, and have been in recovery for drug use for at least six months. We conducted groups among both English- and Spanish-speaking people in recovery; or
- **contracted the virus as a result of an organ transplant or blood transfusion** received prior to 1992.

For the English-speaking groups, National Field and Focus in Natick, MA recruited participants using a combination of newspaper advertisements and flyers. For the Spanish-speaking groups, Research Data in Framingham, MA recruited participants using a combination of flyers posted at various substance abuse, recovery, and health care organizations; advertisements in Spanish-language newspapers; and ads on Latino radio programs.

The English-speaking groups were held at Copley Square Focus in Boston on February 13 and 15, 2001. The Spanish-speaking groups were held on February 13, 2001 at Cambridge Cares in Cambridge, and on February 15 at the Greek Cultural Center in Springfield. All participants were given an honorarium of \$125 in appreciation for their time. Table A presents a detailed description of each group.

Professionally trained moderators conducted each focus group, and a bilingual moderator conducted the groups with Spanish-speaking people in recovery. All groups were audio-taped and transcribed to facilitate analysis of the results.

During the process of recruiting participants for the focus groups, it became clear that it is extremely difficult to locate **people who have contracted the virus as a result of a blood transfusion or organ transplant**. In a June 2000 study of hepatitis C conducted by Market Street Research, we estimated that approximately 22,231 people in Massachusetts are infected with hepatitis C as a result of blood transfusions received prior to 1992, a figure that corresponds with estimates from the Massachusetts Department of Public Health.¹ This proportion is fairly similar to the estimated 24,392 Massachusetts residents who have contracted the virus as a result of injection drug use (ibid).

¹ *"Hepatitis C Infection in Massachusetts: A Social Marketing Approach to Increasing Public Understanding and Reducing Risks."* Market Street Research, June, 2000, p. 26.

While these estimates demonstrate that there is a sizable population of people in Massachusetts who have contracted hepatitis C as a result of a blood transfusion or organ transplant, these people differ considerably from people in recovery in terms of their support networks. People in recovery are often involved in addiction recovery programs or other support groups, and often have peer groups facing similar health challenges. People who have contracted the virus as a result of a blood transfusion or organ transplant, however, are much more isolated. In an attempt to locate these people, we contacted a wide variety of sources, including:

- **numerous physicians** from lists provided by the Massachusetts Department of Public Health and other sources of physicians whose patients have hepatitis C as a result of a blood transfusion or organ transplant;
- **the Massachusetts Red Cross**, which screens blood for hepatitis C and notifies people who have received infected blood throughout four New England states;
- **PAACA**, an agency funded by a hepatitis C program in order to find information about area support groups for people who have contracted hepatitis C as a result of a blood transfusion or organ transplant;
- **the American Liver Foundation**, who assisted us by contacting other physicians believed to have sizable hepatitis C patient groups; and
- a source who does **advocacy work with Vietnam veterans** and maintains a large network of related contacts.

There are no systems in place, however, to easily identify and contact people who have contracted hepatitis C as a result of a blood transfusion or organ transplant. In addition, the support groups researched for this population were found not to exist. It is important to understand the difficulty we experienced in locating these people, as it evidences the **isolation of this population and their lack of formal support networks**. In addition, while we have included information about these people based on the three individuals who participated in a focus group, findings for this population should be **interpreted cautiously**, as they may not be representative of all people who have contracted hepatitis C as a result of a blood transfusion or organ transplant.

Throughout this report, several terms are used to identify participants from the interviews and in different focus groups. The term “participants” is used when discussing people who participated in focus groups overall, regardless of their characteristics. The term “people in recovery” is used to identify those people who contracted hepatitis C as a result of injection drug use and are now in recovery. Furthermore, we refer to “English-speaking” and “Spanish-speaking people in recovery” when it is necessary to differentiate these two groups. The term “people who received transfusions” is used to identify those who contracted hepatitis C as a result of a blood transfusion or organ transplant prior to 1992. Any differences among these groups are noted throughout the report.

TABLE A

<i>Date and Time</i>	<i>Location</i>	<i>Number of Participants</i>	<i>Characteristics of Participants</i>
February 13 5:30 p.m.	Copley Square Focus, Boston, MA	3	English-speaking people who contracted hepatitis C as a result of a blood transfusion or organ transplant prior to 1992 (“people who received transfusions”).
February 13 7:30 p.m.	Copley Square Focus, Boston, MA	9	English-speaking people who contracted hepatitis C as a result of injection drug use and are now in recovery (“people in recovery”).
February 13 6:00 p.m.	Cambridge Cares, Cambridge, MA	8	Spanish-speaking people who contracted hepatitis C as a result of injection drug use and are now in recovery (“people in recovery”).
February 15 5:30 p.m.	Copley Square Focus, Boston, MA	9	English-speaking people who contracted hepatitis C as a result of injection drug use and are now in recovery (“people in recovery”).
February 15 6:00 p.m.	Greek Cultural Center, Springfield, MA	8	Spanish-speaking people who contracted hepatitis C as a result of injection drug use and are now in recovery (“people in recovery”).

Limitations of This Study

Focus groups are an appropriate method for determining people’s knowledge about hepatitis C, the questions and concerns they have about the disease and their treatment options, and the types of information they feel should be made available to other people newly diagnosed with hepatitis C. By definition, however, focus groups are qualitative; that is, they involve relatively small numbers of participants, and therefore the results may not be representative of all people with hepatitis C. The results will provide the MDPH with an understanding of the key concerns and questions regarding hepatitis C, and provide them with a base of knowledge to inform the development of the educational materials for people who have been newly diagnosed with hepatitis C. The information presented in this report should be interpreted in general terms only, however, and not in terms of percentages.

EXECUTIVE SUMMARY

In order to assist the Massachusetts Department of Public Health and Policy Studies in understanding the informational needs of people with hepatitis C and to inform the development of educational materials for these people, Market Street Research, Inc. of Northampton, Massachusetts conducted a qualitative study of people with hepatitis C. The study included focus groups with English- and Spanish-speaking people who contracted hepatitis C as a result of injection drug use, and are now in recovery for drug addiction. The study also included one mini group with three people who contracted hepatitis C as a result of a blood transfusion or organ transplant received prior to 1992. This report presents findings from the focus groups conducted by Market Street Research with people with hepatitis C.

Summary of Findings

The findings of this study clearly indicate that people with hepatitis C have **very little information about the virus**. For example, few participants know which strain of hepatitis C they are infected with, or even that different strains of the virus exist. Participants are often unaware that there is more than one screening test for the virus, and the few that are aware of the antigen test either found out about it through their own research, or from a specialist to whom they were referred. Participants are largely uninformed about the risk of re-infection, or the benefits of receiving vaccinations for other genotypes of hepatitis.

Participants are most well-informed about modes of transmission and methods for slowing the progression of the disease, although some also lack specific information or possess inaccurate information. Participants clearly understand that hepatitis C is a blood-borne virus and that it is commonly transmitted through blood transfusions and sharing infected needles. Many have heard that there is a small risk for transmitting the virus sexually, or through blood particles left on instruments like toothbrushes and razors. A few Spanish-speaking people in recovery mentioned other ways they believe the virus is transmitted, such as through drinking water from rusted cups or eating undercooked meat, that indicate a less clear understanding of how the virus is transmitted.

There are several **key barriers** participants face in terms of obtaining information about, understanding, and treating hepatitis C. First, many participants are frustrated by a **lack of available information**, or are concerned that the information they do receive is not easily understandable. To some extent, this is unavoidable due to the fact that hepatitis C is a relatively newly-discovered virus, and further research must be conducted before the medical industry itself understands the virus thoroughly. There are many ways, however, for the MDPH to provide easily understandable, complete information about what is known about the virus. Many participants say they did not receive detailed information about the virus when they were diagnosed. A few were given a pamphlet by their physician, and others were told about the virus in an offhand manner. Others say they have received inconsistent or unconvincing information about the virus from various sources. A few mention a desire to use the Internet to obtain information, although there is some concern about the credibility of online information. Some complain about physicians who do not take the time to explain the virus using

terminology they can understand. In many cases, Spanish-speaking people in recovery have the added challenge of a language barrier.

Secondly, many participants are facing **stressful life circumstances** that can impede their ability to seek information or treatment. Some participants, particularly those in recovery from drug addiction, have multiple, serious health issues such as diabetes and HIV. Some are dealing with depression, living in halfway houses, or have recently been released from prison. This accumulation of circumstances can lead to a feeling of hopelessness and being overwhelmed which reduces their motivation to take care of their health.

Finally, participants clearly feel that there is a **stigma** associated with having hepatitis C, which is similar to the stigma associated with HIV-infection. People in recovery often feel that their physicians treat them poorly because they are viewed as drug addicts. A few people who received transfusions also feel that they are unfairly judged, feeling that physicians will perceive them as having had multiple sexual partners or engaging in other unsafe behaviors. Participants feel a sense of shame related to having hepatitis C and the unhealthy behaviors that may have led to infection, and this shame can often inhibit them from discussing the virus with loved ones or sexual partners. It is also important to note that participants often expressed a general feeling that they did not feel they had to consider treatment because they feel relatively healthy currently. This is an important finding, as people with hepatitis C who wait until they feel ill to undergo treatment may already have an advanced stage of liver disease.

In order to obtain adequate information, participants must be **strong advocates** for themselves with their physicians. Most of the participants in this study feel that they have been required to advocate for themselves in a variety of ways, such as to have their physician explain the virus in terms they can understand, or to receive approval for the antigen test. Advocacy skills are critical for people in recovery who fear discrimination from their providers, and are especially important for Spanish-speaking people in recovery who face the added challenge of a language barrier.

Many people with hepatitis C turn to formal systems, such as support groups, and informal systems, such as friends and family, both to obtain information about the virus and receive emotional support. It is **critical that people with hepatitis C have adequate support systems** in place to help them cope with this illness. People not only learn a great deal about the virus from others who are infected and have lived with it for a longer period of time, but relationships with other infected people provide them with a sense of optimism and community: a feeling that they are not facing the illness alone, and there is hope for them to enjoy a high quality of life with this illness. This sense of optimism and community poses a great health benefit to people with hepatitis C, in that it will assist these people in dealing with the potential adverse mental and emotional effects, such as depression, that often occur when they begin taking medication to treat the virus.

English-speaking people in recovery generally have adequate support systems, with most of these participants involved in some kind of support group for their recovery process. Spanish-speaking people in recovery express a very strong need for support, with some of these participants resisting treatment out of fear that they will not be able to handle the depression they have been told will result from the medications without proper support. Spanish-speaking people in recovery also appear to have less support

than those who speak English; in general, these participants are less likely to mention being involved in a support group or having friends and family they can turn to in crisis.

The **people who are most critically in need of support systems**, however, are those who contracted the virus as a result of a blood transfusion or organ transplant. These participants tend not to be involved in any kind of support group. The extent to which people who received transfusions are facing their illness without connections to any support organizations is evidenced by the extreme degree of difficulty we had in trying to identify and locate these people to participate in a discussion. It is important for the MDPH to understand the lack of support structure for these people. Physicians can play a key role in linking these individuals with support organizations, as often personal physicians are a main contact point for questions and concerns relating to hepatitis C.

With regard to the educational materials the MDPH and Policy Studies are developing, participants are enthusiastic about having materials in the form of a videotape that they could watch either in a doctor's office or at home, and in the form of brochures or pamphlets. Many participants, especially Spanish-speaking people in recovery, feel it is important to educate the community about the risk of contracting hepatitis C, and would like to see a statewide educational campaign about the illness.

People in recovery were very positive about viewing a videotape that provided information both for those who contracted the illness through intravenous drug use, and those who contracted it through a blood transfusion or organ transplant. The three people who received transfusions who participated in a discussion group are also generally positive about this idea, provided people delivering testimonials on the videotape look as if they are no longer active drug users.

Participants had a wide variety of specific questions they would like addressed in the educational materials, and these are outlined in detail in the body of the report. Overall, however, it is important for participants that the educational materials **convey an optimistic message**, and focus on living with hepatitis C and enjoying the highest quality of life possible. Again, this is an important issue, as it relates to stressful life circumstances these participants are already facing, the negative effect stress can have on their health, and the importance of keeping themselves emotionally healthy in order to cope with the adverse emotional effects of hepatitis C medications. In addition, participants would like to see the information **delivered by a credible spokesperson**, such as someone who is infected with hepatitis C themselves. Participants also want to see the educational materials provide information in **plain, easily understandable, non-medical language**.

From the perspective of people with hepatitis C, the type of videotape that is likely to be most effective is one in which information is delivered by another person with hepatitis C, someone they can identify with and to whom they can relate. It would be advantageous to use visual aids or graphics when presenting information about strains of hepatitis C and other specific information. Finally, it is very important that the videotape leave people feeling that they have options in dealing with this illness, and that there are a variety of ways to care for themselves, slow progression of the disease, and enjoy a high quality of life.

Recommendations

People with hepatitis C must be provided with information about **support structures** within their community. We highly recommend that the MDPH work with physicians to enable them to understand the issues facing people with hepatitis C, including their fear of discrimination by health professionals. Some physicians may benefit from sensitivity training in order to communicate more effectively with people who are in recovery from drug addiction. In addition, physicians are key contacts to link people with hepatitis C with support organizations in their communities. We recommend that the MDPH develop lists of statewide support organizations and distribute these to physicians, who can then provide this information to people who are newly diagnosed with hepatitis C.

The MDPH may want to explore ways of **streamlining the process of obtaining information** for people newly diagnosed with hepatitis C. For example, participants mentioned books that are available about hepatitis C and collections of information they have received from online organizations. It would be extremely helpful if, at the time of their diagnosis, people were able to receive a list of contacts, such as a pamphlet providing contact names and phone numbers of statewide support groups; addresses of reputable state- and nationwide hepatitis C organizations online; and information about other books and packages of information that might be helpful to them.

We recommend that the MDPH and Policy Studies take a **two-stage approach** to disseminating information about hepatitis C to those newly diagnosed with the virus. The first stage would involve an educational videotape as described earlier. Some would like to view the videotape in their provider's office so that they can ask questions after viewing, and others would like to bring the videotape home so that they can view it with their partner or loved ones. This videotape would provide specific information about what is known about the virus and could outline the basic options that are available for treatment, but would not give detailed information about current treatment methods. In addition, it would be useful for people to receive a brochure or pamphlet outlining the key issues that were discussed in the videotape, so that they will have this information for later reference.

As more and more is known about the virus, treatment options will expand and change. Therefore, we recommend that the second stage in this approach involve a brochure or handout detailing current, up-to-date information about treatment options. The advantage to this approach is that the brochures regarding treatment can be updated as needed on a more cost-effective basis than updating the educational videotape.

DETAILED FINDINGS

KNOWLEDGE ABOUT HEPATITIS C

In order to understand the extent to which people with hepatitis C are informed about the disease and their treatment options, we asked people who participated in the focus groups about their knowledge of hepatitis C, including their awareness of the different strains of the virus and the availability of screening tests; modes of transmission and the possibility of re-infection; and ways that they can slow progression of the disease.

Overall, **people with hepatitis C are not well-educated about the disease.** Some lack an understanding of the virus or possess inaccurate information, and most express frustration about the lack of information available to them. Few are actively involved in treating their disease, often as a result of concern about the serious physical and emotional side effects of available medications. The following sections present detailed information about the extent to which people understand specific information about their illness and treatment options. Later in this report, we will present findings regarding the reasons that people lack specific information about these issues.

Awareness of Strains of Hepatitis C

There are three common strains of hepatitis C in the U.S.: Type 1, which is the most prevalent, accounting for over 70% of hepatitis C cases, and the least responsive to treatment; and Types II and III, which are typically more responsive to treatment and less likely to progress. During the focus groups, we asked participants if they are aware that there are different strains of the virus, and if they knew what strain they have.

Overall, there are **very low levels of awareness** of the different strains of hepatitis C. While participants are aware of the genotypes of viral hepatitis (hepatitis A, B, C, etc.), they are generally unaware of the strains of hepatitis C specifically. A few of the English-speaking people in recovery, who tend to be more well-informed than Spanish-speaking people in recovery or people who received transfusions, are aware of the different strains of the virus and know which strain they have. The few individuals who have this information generally learned it as a result of a referral to a specialist, and still feel they did not get convincing or adequate information about the disease. As one woman said, *“I have strain 1 and two genotypes, A and B. Or 1 and 2, whatever. And I wanted to know if treatment was less successful if I had two types [rather] than just one. [My specialist] said ‘no, no,’ but I didn’t really believe him. It didn’t sound like an educated answer.”* Spanish-speaking people in recovery and people who received transfusions tended not to know that there are different strains of the virus, and a few expressed frustration that their physician had not provided them with this information.

Awareness of Diagnostic and Prognostic Tests for Hepatitis C

There are two major screening tests for hepatitis C: an anti-body test, such as an EIA or an ELISA, which is usually the first test people are given; and an antigen test, such as PCR for viral RNA, which is usually performed to confirm a diagnosis of hepatitis C. In addition, once a patient receives a positive diagnosis for hepatitis C, they can elect to undergo a liver biopsy in order to assess the extent of damage to the liver and determine their prognosis. During the focus groups, we asked participants if they were aware of these methods for diagnosing the virus and determining their prognosis.

Most of the participants were **not aware that there are two screening tests** for the virus. Many received a diagnosis in the course of a standard physical exam, or in the course of testing for or monitoring an unrelated health problem. Participants generally did not question their physician about the types of tests that were being ordered. As a person who received a transfusion said, *"My doctor just sends me to the lab, and he sends me with a piece of paper, and on that is the write-up of the blood work. I never knew enough to ask. They just do a blood test."* A person in recovery described a similar situation: *"I had a physical, he took blood, and then he told me, 'Oh, by the way, you have hep C.' [And I said], 'What's that?'"*

Several English-speaking people in recovery are aware of the antibody and antigen tests. Of these participants, individuals said they found out about the two tests through their own research, or because the specialist to whom they were referred explained the tests to them. A few said that they had to advocate for themselves in order to get the antigen tests, which they say insurance companies are reluctant to approve due to its expense. One person in recovery said, *"I advocated for myself. I asked for it, and [my physician] said, 'Well, we don't normally do that for people with hepatitis C. We only do that for HIV.' And I said, 'Well, I'd like to get it, because I'd like to know for sure.' So she said, 'Well, we'll do this strange thing for you that we haven't for anyone else.'" Another person in recovery said, "You have to really yell and scream, too, to really get that test, 'cause a lot of insurance [plans] don't even want you to get that test that often."* Spanish-speaking people in recovery and people who received transfusions tend to be less aware of the screening tests than are English-speaking people in recovery.

In general, participants are **more aware of the option of having a liver biopsy** than they are of the two types of screening tests. Most have heard about this option, and a few have had the procedure performed. Those who have heard about the biopsy or had it performed generally found out about it from their physician or specialist. A few have heard that the test has risks associated with it, with some mentioning the risk of damage to the pulmonary artery and internal bleeding. Some say their physician or specialist informed them of the potential risks, while others found out about the risks through talking with other people with hepatitis C. A few also mentioned that they have heard that the test is painful and invasive; for example, a Spanish-speaking person in recovery said, *"If by chance, during the biopsy, the instrument goes in . . . and touches the lungs, you think you're going to die, like the air in your lungs is coming out, the world is coming apart."*

Awareness of Modes of Transmission and Re-Infection

Participants clearly understand that the hepatitis C virus is transmitted via infected blood, and understand that blood transfusions and sharing infected needles are primary modes of transmission. People who received transfusions also mentioned the possibility of infection following an organ transplant.

Participants are less certain about the risk of transmission through sexual contact, with the general consensus being that it is possible, although rare, for the virus to be sexually transmitted. As one person in recovery said, *"I've heard it [can happen], but then they said, 'Well, there's been like one in a million cases where it has come up.'" Several believe hepatitis C is transmitted through the same means as HIV.*

In addition, participants mentioned that there may be a risk of transmitting the virus through blood particles left on toothbrushes or razors. As a person in recovery said, *“The thing that concerns me most is in some of the literature that I’ve read, it said that there are concerns about toothbrushes, razors, those types of instruments.”* Some believe it is quite possible to transmit the virus through traces of blood left on these instruments, while others have heard that the virus will not survive exposure to the air, thereby reducing the risk of infection through these means.

It should be noted that **Spanish-speaking people in recovery often have a less clear understanding of how the virus is transmitted**, and that some participants indicate confusion about prevention methods. These participants tend to believe that there is a much broader variety of ways that the virus can be transmitted, compared with other people with hepatitis C. Spanish-speaking people in recovery tend to feel it is much more possible to transmit the virus through instruments like razors, toothbrushes, nail clippers, and straws, or from handling currency, than do other people with hepatitis C. One individual professed a belief that drinking from rusted tin cups could result in hepatitis infection: *“You have to be very careful of that,”* this person said, *“because when you drink that, the rust immediately gives you hepatitis C. Because when I was drinking coffee in prison, I got hepatitis C . . . drinking coffee, the bottle was rusty, the rust gave me hepatitis.”* Others believe that the infection may be transmitted through improperly prepared food, such as undercooked meat or seafood that is not thoroughly cleaned. One was momentarily confused upon hearing from other people in recovery that needles should be cleaned with bleach to kill the virus: *“If I knew something like that, or thought about how [bleach] can kill HIV and hepatitis, I probably would have injected myself with a dose of bleach.”*

In terms of **re-infection**, current research indicates that once a person recovers completely from a particular genotype of viral hepatitis, they can be re-infected with that genotype of hepatitis as well as with another genotype of hepatitis; for example, someone who recovers from hepatitis C will get hepatitis C again in the future, and also could become infected with hepatitis A. In general, participants have low levels of awareness of the possibility of re-infection. Several participants do not believe it is possible to truly cure the virus or recover completely from hepatitis C; they believe the virus might lay dormant for a period and then resurface. Individuals believe it is possible to be re-infected with the virus, such as by sexual contact with someone with a more advanced case of hepatitis.

We also asked participants if they had heard anything about the possibility of becoming infected with another strain of hepatitis C; for example, if it were possible to become infected with Type I hepatitis C if they have already been diagnosed with Type II hepatitis C. Due to the general lack of awareness of the different strains of hepatitis C, participants did not know the extent to which this was a possibility, although one English-speaking person in recovery believes it is possible.

Awareness of Methods to Slow Disease Progression

In general, participants mentioned a variety of ways to slow the progression of hepatitis C. They stressed the importance of **taking care of themselves**, such as getting enough sleep, exercising, and maintaining a healthy diet. Some take vitamins or dietary supplements. Others actively work to reduce the amount of stress in their lives,

and feel that a healthy attitude is as important as any other method for slowing progression of the disease.

Most mentioned **abstaining from alcohol**, although more commonly participants discussed reducing their alcohol intake rather than abstaining from consumption altogether. Some also mentioned reducing their caffeine or nicotine intake. A few people in recovery said that the fact that they are already in recovery for drug addiction has eased the process of abstaining from alcohol. As one person in recovery said, *“I knew, basically, that alcohol was bad for the liver. I mean, it wasn’t in the forefront of my mind when I was drinking, but I feel very lucky that I was already in early [drug] recovery when I found out I had hep C, because even though I understand that alcohol affects the liver . . . and that you should stop drinking, I don’t know that I could have stopped drinking just because I knew I had hepatitis C if I wasn’t already in recovery, so I feel grateful for that.”*

Most are aware that they should be cautious when taking **prescription and over-the-counter drugs** such as Tylenol that could cause liver damage, with many saying they avoid taking these medications. Several mentioned using **homeopathic or alternative methods for detoxifying the liver**, including acupuncture and herbal remedies such as milk thistle.

No one mentioned **vaccinations for hepatitis A or B** as way to slow the progression of the disease, although individuals have been vaccinated for other types of hepatitis. An English-speaking person in recovery said, *“I got recently vaccinated for A and B, but the reason my doctor did it was because if I got hepatitis A, it’s just like putting a cherry on top of the sundae. So they said, you might as well get vaccinated for it. . . . If you have C and then you get A, you’re screwed.”* Another English-speaking person in recovery, however, reported hearing from her physician that vaccinations would speed progression of the illness.

As previously discussed, a few Spanish-speaking people in recovery discussed taking care with food preparation. For example, one said, *“You have to take care, the way that you eat, and the meat that you buy, and the time [the meat has] spent in the market. Sometimes they are outdated, and any little thing—like when you go and buy a hamburger and the meat’s bad, it poisons your stomach and the hepatitis develops because it gives you more virus inside, and it takes advantage of that and grows more.”* One mentioned washing dishes and utensils in cold water to sterilize them.

Most participants report that they have **changed many of their behaviors**, and have healthier lifestyles as a result. Many are optimistic about their prognosis. Some feel that as long as they continue to have healthy lifestyles, getting adequate sleep and exercise and maintaining a healthy diet, they do not have reason to be concerned about their hepatitis C prognosis. A Spanish-speaking person in recovery said, *“[I don’t think] too much about it. Live a normal life. . . . The issue is to get good nutrition, and the hepatitis won’t bother you at all. . . . I’m not taking any kind of pills, I’ve got them in the drawer, forgotten. . . . While you don’t drink or don’t have bad vices, you can last a thousand years.”*

AVAILABILITY OF INFORMATION ABOUT HEPATITIS C

Hepatitis C was identified in 1989, and antibody tests to screen for the disease were developed in 1992. The disease is relatively new both to the health industry and those afflicted with the illness. Most people have not heard of the illness, although it affects an estimated five million people in the United States.² Those who have contracted it must face the prospect of living with a disease that researchers are still working to understand. They may receive little or contradictory information about the illness from their physicians, and must make difficult choices about their treatment options.

We spoke with participants about the resources they use to obtain information about their disease, the support systems available to them, and their ability to advocate for themselves with their physicians. The results indicate that there are several key challenges people face in understanding and seeking treatment for the virus, and that people often do not have adequate sources of information about the disease. The following sections present detailed findings about the challenges people face in understanding the disease, the sources of information they turn to, and their ability to advocate for themselves in learning about the disease and their treatment options.

Barriers to Understanding and Treating Hepatitis C

The results of this study indicate that people face three major challenges in terms of understanding their disease well enough to take appropriate steps to care for themselves and treat the illness. These include:

- **a lack of available or comprehensible information**, including language barriers among Spanish-speaking participants;
- **stressful life circumstances**, including multiple health issues; and
- **stigma, prejudice, and feelings of shame.**

Most participants feel that they **do not have access to accurate, comprehensive, or clear information** about hepatitis C. This is due in part to the fact that hepatitis C has been identified relatively recently, and existing research cannot yet answer all questions about the virus. Health care professionals often have only a modicum of information about the virus themselves. People who received transfusions generally lack any kind of formal support system and have very little information about the illness. English-speaking people in recovery are in the best position to access information, as these people tend to have the widest support networks. They are often involved in support groups and many have friends or family with hepatitis C. A few are living in halfway houses where they participate in educational workshops about health issues. These participants still have concerns, however, about the way in which information is presented to them, with some feeling that their providers do not explain their health issues to them in a language they can understand, such as relying on medical jargon when discussing their illness.

² "Hepatitis C Infection in Massachusetts: A Social Marketing Approach to Increasing Public Understanding and Reducing Risks." *Market Street Research*, June, 2000, p. 26.

Spanish-speaking people in recovery appear to have fewer formal support structures available to them, compared with English-speaking people in recovery. In addition, Spanish-speaking people in recovery have the added challenge of **language barriers**, requiring that they not only advocate for information and fair treatment but also for information in a language they can understand. A few have had to work with their doctors to get them to speak in a language they can understand, either because they use technical medical jargon, or because their providers are not fluent in Spanish. Existing strong relationships with trusted physicians help to ease this process. One Spanish-speaking person in recovery said, *“In the beginning I was lost, but I trust [my doctor]. . . . When I don’t understand something, when she tells me the titles or tells me numbers, I tell her, ‘Speak to me in English so that I’ll understand you, speak to me so that I’ll understand you.’”* Another said, *“My doctor, to me is like a godfather—look at the trust that I have in my doctor. . . . I tell him, ‘Doctor, I don’t understand this. Put it in black and white, because I don’t understand.’ He sits down there and looks for a pencil or whatever he’s got to find, and he takes the time to deal with me . . . he sits down and explains to me what’s going on, and if I don’t understand, he says it again, and if not, he looks for someone that can explain it to me.”* One Spanish-speaking person in recovery believed it would be easier to seek treatment for hepatitis C if physicians received sensitivity training: *“I think that the Department of Health should grab the doctors by their necks to tell them that they have to be more sensitive to deal with this type of person, because many of us go there . . . who don’t say anything, because we see the doctor as up here, and ourselves [as] down here, and because we see it that way, we’re going to be scared.”*

Many participants, particularly people in recovery, have a variety of **stressful life circumstances** in addition to their hepatitis C diagnosis that can effectively prevent them from following up on treatment or taking steps to care for themselves. All people in recovery are overcoming drug addictions, with many describing long histories of multiple, serious substance abuse. Some of the people in recovery who participated in the focus groups have other serious health problems, such as HIV, diabetes, and STDs. Several people in recovery have been incarcerated and have criminal records. Others are living in poverty or suffering from depression. This combination of factors can often leave people in recovery feeling overwhelmed and hopeless. The situation is further complicated by the fact that they run the risk of liver toxicity if they take medications to combat other health concerns, and as a result, some participants are opting not to seek treatment for any of their serious or life-threatening illnesses. Some of these participants describe a feeling of apathy resulting from the number of health challenges with which they are faced. For example, a Spanish-speaking person in recovery said, *“I was hepatitis B positive for ten years, so they did a test for hepatitis C and I came out positive, according to the doctor. When I found out, I thought, ‘Another disease, who cares?’ . . . I’ve also been HIV positive for the last sixteen years.”*

Finally, many people with hepatitis C suffer from **feelings of shame** and **worry about stigmas and prejudices** relating to their behaviors. Participants feel a similar stigma as might people diagnosed with HIV (several of the people in recovery who participated in the study are co-infected with HIV), with most expressing shame over adverse behaviors such as drug abuse or having multiple sexual partners. Others, particularly people who received transfusions, express anxiety that health care providers and others will assume they have a history of such behaviors as a result of their diagnosis. For example, a person who received a transfusion discussed her lack of a support network, saying that people who have contracted hepatitis C as a result of a

blood transfusion or organ transplant *“won’t talk about it. A lot of people won’t—they are not going to tell you [they have the illness]. . . . [Doctors] used to say [people contracted the disease because they had] too many sexual partners.”* This feeling of shame can also inhibit people from discussing their health issues with loved ones or with sexual partners; for example, one person in recovery was diagnosed with hepatitis C as she was beginning a new relationship and was afraid her partner might leave her if he knew about her condition: *“This is a new relationship, and I’m like, ‘Oh my God, I hope I didn’t give it to him,’”* she said. *“When I left the [doctor’s office], he picked me up and he was like, ‘What’s wrong?’ I didn’t want to tell him—I was like, he might leave me.”* This is important to note, as these feelings of shame may inhibit people from taking proper precautions to prevent transmission of the virus to their partners and loved ones.

People in recovery often feel as if their physicians discriminate against them because they are recovering addicts. One person in recovery said, *“We’re second-class citizens in a lot of their minds. If it’s on your record, you’re an addict.”* Another person in recovery described being refused treatment as a result of his history of addiction: *“My primary care doctor knew about my drug history, up and down, and everything else. When he sent me for a liver biopsy . . . he sent my records over, and he wrote a brief thing that I was a recovering drug addict, and he wrote that I was clean for nine months and everything. I went in for the first visit to be examined. The doctors came in, opened up my record. Point blank refused even to examine me, because of my drug history.”* English-speaking people in recovery had the following exchange during a focus group:

“You go to the doctor and tell him you got hep C, it’s like you’re a dope fiend.”

“Automatically, you’re a dope fiend.”

“I feel you don’t get the same care.”

“No. No, you don’t.”

“They look at you like you’re a piece of shit.”

Similarly, a few participants discussed having developed poor relationships with their providers as a result of their complex medical histories and resistance to treatment in the past. This is important to note, given the difficult position people with hepatitis C find themselves in with regard to treatment and the fact that many medications carry a risk of liver toxicity. Physicians must be sensitive to the difficult choices these people must make with regard to their treatment. For example, a Spanish-speaking person in recovery expressed concern that he might be denied treatment for hepatitis C because he has a history of non-compliance with other health issues: *“The doctor said to me, ‘How do you expect me to give you medication for hepatitis C when you don’t even try to care for your diabetes?’ For me, I thought it was a breach of medical ethics.”*

Information Provided During Initial Diagnosis

Most participants were diagnosed with hepatitis C by their primary care physician, often in the course of a standard physical exam. A few people in recovery were diagnosed with hepatitis C while in prison, and one individual was diagnosed at a walk-in health clinic. A few Spanish-speaking people in recovery said they were diagnosed with hepatitis C by a psychiatrist. Most **did not receive much information at the time of their diagnosis**, with a few saying they were given a pamphlet on the disease. One person in recovery said, *“When I was told, the only thing I got was a pamphlet. It wasn’t sat down and gone over with me. It was just a pamphlet.”* People are frustrated by the lack of information they receive from physicians who often seem as

uninformed about the details of the illness as they are themselves. Several feel that they were told about the virus in an offhand or indifferent manner, with the virus often showing up in blood work taken to test for other illnesses; for example, one person in recovery said, *“I thought I had diabetes, because I had such a strong history of it in my family. They just told me, ‘By the way, you tested positive for hep C.’”*

Several participants voiced the concern that at the time of their diagnosis, they were not given a **realistic or accurate sense of the severity of their condition**. Some feel their physicians downplayed the severity of the virus, giving them a false sense of security and leading them to believe they had nothing to worry about. For example, a person in recovery said, *“When I got diagnosed, I was like, well, what should I do about this? [My doctor said,] ‘It’s not really a big deal. You know, a lot of people have it.’ So I’m playing it, like, you know—then, when I did the research, it’s like you find out that it can kill you.”* Others feel that their physicians overstated the severity of the virus, leading them to believe that they might not have long to live. One person in recovery said, *“[The doctor who diagnosed me] gave me a paper saying ‘You’re positive for hepatitis C,’ and like it’s a crucial disease—like making me feel like I was going to die from it soon. Like a severe disease, like cancer, like you’re going to die immediately.”* One person in recovery summarized the situation: *“Now you basically have doctors who are misinformed in two different directions, some doctors telling patients that they are definitely going to get cirrhosis, they are definitely going to die; and other doctors saying, ‘Don’t worry about it. Don’t [even] change your diet.’”*

Sources of Information About Hepatitis C

People generally do not feel they are receiving adequate information from their physicians when they are diagnosed, and therefore turn to a variety of other **sources for information**, including:

- **formal support structures.** This is the source of information most often used by people in recovery, most of whom are often involved in support groups;
- **friends and family with hepatitis C.** People in recovery also tend to have a wide informal support structure. In some cases, the friends they used to share needles with are also in recovery and have been diagnosed with hepatitis C, and these friends are now a source of information and support. As a person in recovery said, *“I got sober in 1990, and the friends that I had then . . . we’ve all been diagnosed with [hepatitis C], and we all shared [needles]. We all pretty much have the same thing, so just talking with them and talking to other people in recovery now, about their history with it as well.”*;
- **the Internet and hepatitis C organizations online.** The Internet is used more often by English-speaking people in recovery than by Spanish-speaking people in recovery, with some mentioning specific hepatitis C web sites or pharmaceutical company web sites. The Internet appears to be the main way that people discover hepatitis C organizations. One mentioned that the company that manufactures Interferon, a leading hepatitis C medication, sent him a package of information on the illness that was very helpful. There is some concern among participants, however, about the quality and accuracy of information on the Internet. As a person who received a transfusion said, *“I never did really go to the Internet. [My doctor] said he didn’t even have a*

computer at home. He said anyone could put anything they want on the computer.”; and

- **the library.** It should be noted that people who were diagnosed with hepatitis C several years ago indicated that the library did not contain much information at the time of their diagnosis, as a result of how little was known about the virus. For example, a person who received a transfusion said, “*I did a lot of reading. I went to the library, and at that time, in 1998, they didn’t have much on it, compared to what they have now.*” It should be noted that people who received transfusions, who tend not to be involved in support groups or have friends with the illness, often mentioned turning to the Internet and the library in order to find information about their illness.

A few individuals mentioned other sources of information, such as Matthew Dolan’s *The Hepatitis C Handbook*; national and state organizations for disease control; and newsletters from organizations such as the American Liver Foundation. A few expressed concern that some of the information they receive through one source contradicts information from another source, such as obtaining contradictory information from the National Center for Disease Control and a state organization.

With regard to **support structures**, it should be noted that Spanish-speaking people in recovery expressed a strong need for support structures throughout the discussions, and these people appear to have greater difficulty finding adequate support. Compared with English-speaking people in recovery, stress and depression and the need for strong familial or spiritual support seem to play an even stronger role in their lives. Spanish-speaking people in recovery are highly oriented to the adverse mental and emotional effects of treatment, such as the risk of depression. They believe that individuals with strong support systems will be in the best position to deal with these mental and emotional side effects. A few individuals have resisted treatment out of fear that the emotional risks of undergoing treatment without appropriate support in place are too great, and they would be at risk for suicide.

Advocacy Issues Among People with Hepatitis C

Hepatitis C is a relatively new and poorly understood virus, and many people—particularly those in recovery—fear discrimination on the basis of their past behaviors. People with hepatitis C must therefore be strong advocates for themselves in order to obtain information and ensure that they are equipped to make the best decisions about their own health care. In general, the people who participated in this study tended to feel that they are **strong advocates** for themselves. Participants are fairly confident about their advocacy skills, and several described situations in which they demanded and received specific tests or types of treatment initially denied them.

Some Spanish-speaking people in recovery reported that they initially had difficulty advocating for themselves. The issue of advocacy and support seems to be of **particularly critical importance** for Spanish-speaking people in recovery as a result of the language barriers discussed earlier in this report.

People who received transfusions feel that they do not ask their physicians enough questions and that it would help them if they were to write down their questions prior to their office visit, as well as the information their physician gives them during the visit.

ATTITUDES ABOUT TREATMENT OPTIONS

People with hepatitis C face unique challenges in deciding whether or not to seek treatment for their illness. These people may not have symptoms or feel ill when they begin treatment, and current conventional treatment methods may make them feel worse in the short-term. For many individuals, the medications can have serious physical, mental, and emotional side effects, and people may be unable to work during treatment. In addition, people in recovery must consider the fact that one of the conventional methods for treating the disease involves medicinal injections, which for some may be counter-productive to their recovery program. Some people with hepatitis C may also be infected with HIV. HIV medications pose the threat of liver toxicity, and the process of treating HIV may speed progression of hepatitis C; some people may therefore find themselves in the position of determining which health issue to treat. The following sections discuss participants' attitudes about the various treatment options and the challenges they face in determining whether or not to seek treatment for hepatitis C.

Awareness of and Attitudes Toward Conventional and Alternative Treatment Options

In general, most people who participated in this study are aware of **conventional treatment options**, such as Interferon medication therapy. At the time of the focus groups, most were not taking any conventional medications to treat the virus. A few indicated that they were planning to begin treatment soon, and a few have received treatment in the past but stopped as a result of adverse side effects. Many expressed resistance toward treating the virus, often due to concern about the possible physical and emotional side effects of conventional treatment. A few also expressed concern about how little seems to be known about the virus, and feel as if medications are prescribed more as experiments than as proven treatments. As one Spanish-speaking person in recovery said, *"Some patients are almost used like experiments. A new medication comes out, and it gets used without really knowing what the effects or results will be."*

Many reported that their providers explained the possible side effects of treatment to them, and clearly, awareness of the adverse effects of conventional treatment methods discourages many people from seeking treatment. Among the **adverse physical side effects** of treatment mentioned by participants are weight loss or gain, hair loss, dizzy spells, pain or tingling in extremities, stomach aches, diarrhea, vomiting, memory lapse, and general bodily aches and pains. One Spanish-speaking person in recovery had heard that people could contract diabetes as a result of treatment. Participants clearly are concerned about these possible physical effects, and many know that the side effects can become serious enough to prevent people from working. A Spanish-speaking person in recovery said, *"When I was taking Interferon, they talked to me about that, about how you're going to feel, that you're going to get headaches, feel dizzy, that you have to drink a lot of water. That when you walk, you're going to feel like an old man of ninety years, falling apart with your bones and everything, really bad."*

The major **adverse mental and emotional side effect** mentioned is depression, with some feeling that the emotional side effects can range in severity from feeling irritable to suicidal, depending on the patient. Few participants reported that their

physician asked them about whether or not they had a history of depression. The mental and emotional side effects of treatment seem to be of even greater concern for Spanish-speaking people in recovery than for other participants. These people often have other stressful life circumstances, such as multiple health problems, poverty, and in some cases, criminal records; many feel that they currently suffer from depression, and fear exacerbating this condition if they pursue a course of treatment for hepatitis C. One Spanish-speaking person in recovery said, *“You have to be careful with treatment, because if you are depressed, or if you have a lot of stress, the medication can do more harm than good.”* Another described avoiding treatment because he lacked the necessary support structure to cope with the adverse emotional effects: *“My daughter’s mother . . . she got it, and she told me, ‘I wanted to kill myself,’”* he said. *“You want to close yourself off, you don’t want anybody to bother you . . . she told me that if you have people who support you, people who listen, people who give you encouragement, it gets a little easier. That’s why I won’t dare take it, because I’ll get bad quickly.”* One individual reported that he left his physician’s office when the physician began explaining the adverse effects of treatment.

The **people who received transfusions** who participated in a focus group seem to have less detailed information about the adverse effects of treatment, although they understand that there are risks associated with the treatment. As one said, *“A cure might make you sicker than the [virus].”* These participants indicated that they mainly rely on lifestyle changes to keep them healthy, and some feel that they are not actively concerned about their health because they are currently asymptomatic. As one said, *“I’m putting it all on a back burner. [I’m] going to try to maintain [my health] through exercise.”* Another said, *“I’ve had [hepatitis C] since I was eighteen. So I’m not dead yet, then. Then after my twenties I drank a lot and I didn’t take care of my health. If I’m still alive now without any pain, then nothing is going to happen to me.”* People who received transfusions feel that they would like to have a better sense of their treatment options in order to be prepared later in life when they may need treatment. As one patient said, *“I want to maintain it the way I’m doing right now, but certainly down the road, four, five, ten years down the road, I may need that treatment. So I always like to be prepared, and to know which [way] I’m going to go. I want to know the side effects.”*

There are mixed opinions about **alternative treatment methods**. A few do not trust alternative methods, or expressed skepticism about their effectiveness. Others, particularly English-speaking people in recovery, are currently using alternative treatment methods such as acupuncture, homeopathic medicines, and herbal remedies to decrease their liver toxicity.

Attitudes About Using Needles as Part of Treatment Among People in Recovery

One of the primary methods for treatment of hepatitis C is the injection of Interferon. During focus groups with people in recovery, we asked about the extent to which this is perceived as a barrier to seeking treatment.

Overall, most of the people in recovery who participated in a focus group are **very concerned about the risk of relapse** as a result of having to receive treatment via injection. Most perceive the needle as a strong trigger for the urge to use injection drugs.

A few have heard of **alternatives**, such as the use of a “pen” instrument that delivers the medication, or the option of visiting the hospital several times a week for injections rather than administering the injections themselves. Those who have heard about the “pen” option are relatively positive about this option and prefer it to injection.

In addition, many believe that people in recovery have to be strong advocates for themselves, and for the option of using alternative administrative devices such as the pen, because their **physicians do not fully understand the difficulty they face in having to use needles** as part of their treatment. As one English-speaking person in recovery said, *“My doctor, he’s a liver specialist. Everybody else was old people—you know, I was the one junkie.”*

Attitudes About Co-Infection Issues

Among people in recovery, several related during the discussion that they are HIV positive. About one-half indicated that their physician asked them about their HIV status when they were diagnosed with hepatitis C, and most understand that HIV medications carry a risk of liver toxicity. In fact, several people in recovery say they have **discontinued their HIV treatments** out of concern about the effect the medications will have on their liver. Many express frustration that treating one condition necessarily aggravates the other. As an English-speaking person in recovery said, *“You’re taking all of a dozen pills a day, [they have] to be toxic, you know? Like I said before, it’s like between a rock and a hard place. What disease should I treat, you know?”*

The three people who received transfusions who participated in the focus group had little awareness of co-infection issues. Individuals believe that hepatitis C can progress to the point that people develop HIV, or that their immune systems can break down as a result of having hepatitis C. One believes the treatment methods for HIV and hepatitis C are the same.

ATTITUDES ABOUT EDUCATIONAL MATERIALS

The Massachusetts Department of Public Health is developing educational materials to increase awareness about hepatitis C and provide newly diagnosed people with accurate, clear information about their illness. The following sections provide a detailed analysis of the types of educational materials people would like to see available and the settings they feel are appropriate for such materials; their attitudes about viewing educational materials developed both for people who contracted the virus as a result of a blood transfusion, organ transplant, and those who contracted it from infected needles; and the specific questions they would like to have answered in the educational materials.

Attitudes About Types of and Settings for Educational Materials

There are three main ways that people would like to receive information about hepatitis C: (1) a statewide or national **educational media campaign**; (2) an **educational videotape** when they are diagnosed with the virus; and (3) **brochures or pamphlets**.

Participants feel it is important for others to receive information about hepatitis C through an **educational media campaign**. Spanish-speaking people in recovery, especially, focused on the need to make information about the disease, the risk of contracting it, and methods for prevention available to others. They would like this information to be made available to school children, to the people in their communities, to prison inmates, and to people in recovery support groups. They would like to see information made available about hepatitis C through the same means as they have seen information about other health issues, such as television advertisements and posters on buses and other public transportation.

The nature of this study is to assist in designing educational materials for those already infected with hepatitis C, and it is beyond the scope of this research to determine the information that the general public should have about the virus. It should be noted, however, that during one of the focus groups with Spanish-speaking people in recovery, a few participants discussed the potential **limitations of educating active drug users about the dangers of infected needles**. Several of the people in recovery agreed that at the time they were using, knowing about viral transmission through infected needles did not affect their behavior. As one person in recovery said, *"My friends would say, 'Don't use my syringe, because I have HIV and I have hepatitis C' or this or that, and I'd say, 'Look, just give me the needle and never mind that.' I didn't want to think about anything else."* It may be that educational media campaigns are less likely to be effective among IV drug users, a population that is at serious risk for contracting hepatitis C and other blood-borne viruses. The Massachusetts Department of Public Health may want to conduct further research among this population in order to determine the most effective means of communicating the health risks of these behaviors to this population.

Participants are highly positive about the concept of people viewing an **educational videotape** when first diagnosed with the disease. They believe there are a variety of appropriate settings for such a videotape. Several would like to view the videotape in their provider's office. They believe this might lend the video credibility, and

that after viewing the videotape, they could then ask their provider any questions they may have.

It should be noted that a few individuals, however, expressed concern about viewing the videotape in their provider's office, which they perceive as a cold or "sterile" environment. Due to the emotionally trying nature of learning about the disease for the first time, these participants prefer a setting in which they feel more comfortable. Several expressed a desire to be able to watch an educational videotape in their home, both to be in a more comfortable setting and so that their partner could watch the videotape with them.

Some mentioned other settings in which they felt it would be appropriate to show an educational videotape, such as at treatment clinics for drug users or at the local library. A few would like to view the videotape in a support group setting along with others who are infected with the virus.

Many participants expressed a desire for **pamphlets and brochures** about hepatitis C. Literature offers people the advantage of looking up specific information about the virus after they have had a chance to absorb the reality of their diagnosis. There are several types of pamphlets and brochures participants would like to see made available to them. Some would like to see literature specifically geared toward methods for maintaining liver health; for example, brochures recommending behavior changes such as abstaining from alcohol, diet recommendations, and warnings about taking Tylenol and other over-the-counter medications that carry a risk of liver toxicity. Others would like to have literature about their rights as patients, including such issues as their right to confidentiality and legal options related to maintaining employment through a chronic illness.

Attitudes About Videotape for Both People in Recovery and Those Who Have Received Transfusions

One of the ways the Massachusetts Department of Public Health is considering making information about hepatitis C available to people newly diagnosed with the virus is through an educational videotape. One option is to develop a videotape that presents information relevant to both people in recovery and those who received transfusions, and add a separate component at the end geared toward people in recovery. Another option would be to develop an integrated videotape that presents information to both audiences with hepatitis C. During the focus group, we asked participants if they had a preference for how the videotape was designed.

In general, **participants are comfortable viewing an integrated videotape.** These results should be interpreted very cautiously, however, due to the small number of people who received transfusions who participated in a focus group (N=3). People who received transfusions expressed a sense of community among people with hepatitis C regardless of how they contracted the virus. As one person who received a transfusion said, *"We are all in the same boat, regardless of how we got it."* Another said, *"It's not up to us to say how they got it, you know, and if they got it by using drugs, we all make mistakes. So let's give us all a chance to cure [the disease]."* It should be noted that one person who received a transfusion said that if the videotape included testimonials of people with the virus, it was important to her that they not look like current

drug addicts. This person said, “[I wouldn’t mind seeing] the people that do the drugs, as long as they look like they really recovered.” This may indicate underlying reservations about an integrated videotape, or possible prejudices people who received transfusions did not feel comfortable voicing during the discussion.

People in recovery had no concerns about an integrated videotape, with some commenting that a videotape presenting information for both types of people may help to relieve some of the stigma surrounding blood-borne illnesses like hepatitis C.

Information Participants Would Like to Have About Hepatitis C

Throughout the focus groups, participants discussed the information they would have liked to have had when they were first diagnosed with hepatitis C, and the ways in which they would prefer the information be presented. There are a few key issues that will assist the Massachusetts Department of Public Health in designing the most effective educational materials for people newly diagnosed with hepatitis C. Specifically, people with hepatitis C believe that:

- **educational materials should have an optimistic message.** Participants want the educational materials to focus on living with hepatitis C, both in terms of the possibility of living a long life with the illness, and their ability to enjoy a high quality of life. As an English-speaking person in recovery said, *“I would just let somebody know that it’s not a death sentence . . . don’t let anybody scare you.”* This is an important issue, considering the stressful life circumstances many people with hepatitis C are already struggling with at the time of their diagnosis, and the possibility that medication for the illness will cause or exacerbate depression. Information should be presented in an accurate but reassuring manner. A Spanish-speaking person in recovery said, *“If you start telling them, with pity, a video of pity—then the person falls apart. You should talk to them positively about the recovery of hepatitis C. Everything positive, everything positive, and they’ll maintain themselves. They’ll live a more normal life, more positive.”*
- **information should be delivered by a credible spokesperson.** A few participants voiced a desire either for the spokesperson to be a recovering hepatitis C patient, or for the educational materials to include the experiences and insights of others with the virus. As a Spanish-speaking person in recovery said, *“People who have hepatitis C should be the ones to give the information, because I think those are the best people that could speak.”* Many people with hepatitis C, specifically those in recovery for drug addiction, often have strained relationships with their physicians, who they feel do not understand their particular challenges or are unsympathetic to their condition. Some people distrust their physicians or are resistant to hearing about their illness from this source; instead, many turn to friends who have also been diagnosed or to support groups for information about the illness. Having people who are afflicted with hepatitis C delivering information about the illness and testimonials about their own experiences will lend the materials credibility while sending the message that those newly diagnosed with hepatitis C are not alone; and
- **information should be delivered in plain, easily understandable, non-medical language.** Many people are confused by the terminology they hear

with regard to hepatitis C. Few have any awareness of the strains of hepatitis C, and say their providers do not take the time to explain issues like testing to them. People also express frustration over hearing vague or contradictory information from different sources, with a few saying they would like to see the educational materials discuss or “admit” that there is still much to learn about hepatitis C. People will be most receptive to educational materials that present factual details about what is known about the virus in language that they can easily understand.

There are a wide variety of questions people in recovery and people who received transfusions would like to have had answered when they were initially diagnosed with the disease. Many participants have **questions related to the detection, transmission, and prognosis of the disease**. These questions include:

- *How did I contract the disease?*
- *Why is it showing up now, if I have been visiting my doctor for annual physicals?*
- *What are the symptoms of hepatitis C?*
- *What are the different strains of hepatitis C? What do these different numbers and tests mean? What does it mean when my physician says my “function levels are fluctuating?”*
- *When should I consider having a liver biopsy?*
- *Will having hepatitis C permanently alter my lifestyle?*
- *Is hepatitis C sexually transmitted? Can I give the virus to my sexual partner? What steps should I take to prevent transmission?*
- *What is my life expectancy? How might my life expectancy change depending on whether or not I quit drinking, and whether or not I decide to receive treatment?*
- *Where can I find out more about the virus? Where can I find out about support groups?*

Many of their questions, however, revolve around **treatment of the virus**. As discussed earlier in this report, the issues surrounding hepatitis C treatment are challenging, and many people have to make the decision about whether it is worthwhile to seek treatment at all. In addition, the virus is still being studied and researched, and it is therefore likely that educational materials will quickly become outdated if too much detail is given about their treatment options.

The Massachusetts Department of Public Health may want to consider a **two-stage process** for providing people with information about hepatitis C treatment. The videotape could be developed in such a way that it presents people with clear information about issues surrounding treatment that are unlikely to change in the near future as advancements continue to be made in hepatitis C therapies. The spokesperson in the educational video could explain that medical researchers are still in the process of studying the disease and coming up with new, improved treatment options. Then, physicians could present people with a brochure or handout with detailed information about the most current treatment options. Developing brochures or

handouts is a more cost-effective method for providing people with up-to-date information about their treatment options, as they can be more easily created, produced and distributed as needed.

The questions participants would like to have answered for the **first stage in the process**—that is, information that could be presented on an educational videotape and is unlikely to change in the near future—include:

- ***What are the pros and cons of getting treatment for hepatitis C?***
- ***Do I have a choice about whether or not to seek treatment?***
- ***What can I do to live a normal life if I decide to live without medication?***
- ***What can I do to slow progression of the disease? How can I alter my behaviors to improve the quality of my life as a person with hepatitis C?***
- ***If I do not have any symptoms currently, should I seek treatment anyway? Will this help me to be in better health in the future?***
- ***Is the treatment worthwhile? Will it lengthen my life expectancy?***
- ***Are there alternative therapies available, if I opt not to use conventional medications? What are some of the alternatives, and how effective are they?***
- ***If I have another serious health problem, how should I determine whether or not to continue treatment for that health problem if the necessary medications carry a risk of liver toxicity? Which illness should I treat first?***

The questions participants would like to have answered for the **second stage**—information that could be provided in a brochure or handout about the most up-to-date treatment methods being used—include:

- ***What form does the treatment take? Would I take pills, or would I have to have injections?***
- ***Is the treatment painful?***
- ***What are the side effects of treatment? How will treatment affect the quality of my life?***
- ***Do I have a choice about how long I take the medications? If the side effects are too severe and I have to discontinue treatment, is the treatment less effective?***
- ***How long will I have to receive treatment before I notice an improvement in my health?***
- ***Is the treatment more or less effective depending on the particular strain of hepatitis C I have? Is the treatment more or less effective if I have two genotypes of hepatitis?***

In summary, the educational videotape is likely to be most effective if information is delivered in an optimistic manner by a credible spokesperson in plain language. The

educational videotape should provide newly diagnosed people with specific information about the virus, modes of transmission, diagnostic and prognostic tests, and ways to maintain their health and slow progression of the illness. Supplementary materials can then be developed to provide the most updated information on treatment options.

APPENDIX A: MODERATOR GUIDE PEOPLE IN RECOVERY

Purpose

You have all been asked to participate in this discussion because you have been diagnosed with Hepatitis C, and you are all in recovery for injection drug use.

The reason we are having this discussion today is that the Department of Public Health is in the process of creating some educational materials for people who have been diagnosed with Hepatitis C. The purpose of this group is to get input from you that will help the Department of Public Health develop these educational materials.

Ground Rules

- Audio taping/Mirror
- Candid point of view is essential/No “right” answers/Okay to disagree
- No side bar discussions/Speak one at a time
- Role of Moderator—unbiased and not an expert

Introductions (5 minutes)

- Name, where lives, how long since diagnosed with Hepatitis C, and how long been in recovery.

Questions, Concerns When First Diagnosed (25 minutes)

First, I would like you all to think back to when first met with your health care provider and found out that you had Hepatitis C.

1. What type of physician originally diagnosed your Hepatitis C (e.g. primary care physician vs. specialist)? What information did your health care provider give you at that first visit that was particularly helpful? What questions or concerns did you have when you were first diagnosed that were not answered during that visit? What kinds of issues were most confusing or unclear for you during that first meeting with your provider? Who gave you information at that first visit—was it your physician, a nurse, or both?
2. From what you know or have heard, what kinds of tests are there for screening for Hepatitis C?
3. [IF NEEDED: There are two major screening tests for Hepatitis C: an **antibody test** such as an EIA or an ELISA, which is usually the first test patients are given; and an **antigen test** such as PCR for viral RNA, which is usually performed to confirm a diagnosis of Hepatitis C]. Were you aware that there were two separate screening tests for Hepatitis C when you were first diagnosed?

4. Did your physician explain the two types of screening to you when you were being tested for the illness? Did you have any questions about the tests at that point that you would have liked your provider to answer? Did you get both tests?
5. Some people with Hepatitis C are given a liver biopsy—how many of you heard of that? What information can you get from a liver biopsy? Do you know whether or not getting a liver biopsy is a dangerous procedure?
6. Are you aware that there are different strains of Hepatitis C? How many different major strains are there? What do you know about the differences between them in terms of progression and effectiveness of treatment?
7. When you were first diagnosed with Hepatitis C, did you know what strain of the virus you had? Did you have any questions about the three major strains of the virus that you would have liked your provider to answer? [IF NEEDED: There are three most common strains in the US: Type I, Type II, and Type III. Type I is the most prevalent (over 70% of cases of Hepatitis C are Type I), and is the least responsive to treatment. Types II and III are typically more responsive to treatment and less likely to progress.]

Prevention (10 minutes)

8. What are the **main** ways that Hepatitis C is transmitted? From what you know or have heard, how can people protect themselves from getting the Hepatitis C virus? [FOCUS ON MAJOR BEHAVIORS]
9. From what you know or have heard, after you have been successfully treated for Hepatitis C, is it possible to get re-infected with the virus? [IF NEEDED: or do you think you're immune to it after that, like the measles?]
10. From what you know or have heard, if you have one strain of Hepatitis C, is it possible for you to become infected with another strain of Hepatitis C? For example, if you've been diagnosed with Type II Hepatitis C, is it possible for you to become infected with Type I Hepatitis C?
11. What did your physician tell you about passing the virus onto others through sexual transmission? Do you have a sense of whether Hepatitis C is easily transmitted through sexual activity?
12. I'd also like to talk about slowing down the progression of Hepatitis C. As you may know, physicians have some suggestions for people with the virus about ways that they can slow the illness down. From what you know or have heard, what kinds of things can you do to slow down the progression of this virus?

PROBE FOR:

- abstaining from alcohol
- having a healthy lifestyle, including eating well and getting enough sleep
- getting vaccinations for Hepatitis A and B
- taking care with prescription and over-the-counter drugs, for example Tylenol, that could cause liver damage

Treatment (20 minutes)

[NOTE FOR MODERATOR: Do not get into too many details about the current treatment options for Hepatitis C, because treatment options are changing rapidly, and the educational video will get out of date quickly if it goes into detail about these issues. We are looking for more general information about treatment options here.]

13. Next, I would like to talk about some of the options for treating Hepatitis C. In your opinion, what kinds of information would be most helpful for people who have just been diagnosed with Hepatitis C, so that they can make decisions about treatment options? Did you receive treatment for Hepatitis C? For those of you who got treatment, did your provider discuss with you the importance of not drinking alcohol during treatment? Are there any of you who wanted to get treatment but were unable to do so for some reason? Why were you unable to?
14. When you were first diagnosed, what did your provider tell you about the treatment options that were available to you? What are the most important things you would have liked to have known about your treatment options?

PROBE FOR:

- the effectiveness of treatment
 - the length of time it takes to treat the virus
 - the possible side effects of the treatment
 - the fact that treatment involves injections
15. Did your health care provider discuss the possible side effects of treatment with you before you began a treatment plan?
 16. What did your provider tell you about the **physical effects** of your treatment?
 17. What about its possible effect on your **mental health**, such as the risk of depression? Did your provider ask you if you had a history of depression before beginning treatment? [IF YES: Did your provider discuss this in relation to your treatment plan?]
 18. Did your provider prepare you for the possibility that the side effects might be severe enough that it could include an inability to work?
 19. As you know, one of the standard treatments for Hepatitis C involves patients administering an injection several times a week. Did your provider talk to you about the challenges you might face with this treatment, as recovering injection drug users?
 20. What else could your provider have done to help prepare you for treatment?
 21. Did you weigh the pros and cons of getting treatment, or did you decide right away that you would get treatment for the virus, regardless of the side effects you might experience as a result of the treatment? What resources did you have to help you make that decision? [PROBE FOR: success rate and side effects if not mentioned]

22. Are you aware of any alternative treatments for Hepatitis C? [PROBE FOR: herbal remedies; other] What do you know about these alternative treatments?

Educational Materials and Information (10 minutes)

23. Now I'd like to ask you about the educational materials that the Department of Public Health is developing. As I mentioned, they are developing an educational video for people who have just been diagnosed with the illness in order to answer their basic questions. What kinds of setting would you prefer to watch the video in? Are there other settings, besides the provider's office, where you think people should show this video or have educational material available? [For example: substance abuse providers, social service providers, specialists who treat Hepatitis C]
24. The Department of Public Health is also developing a brochure on Hepatitis C that will accompany the video, a Hepatitis C hot line patients can call to get answers to questions, and an informational web site on the Internet. Can you think of any other materials that would be helpful for new patients to have?

Co-Infection of Hepatitis C and HIV (5 minutes)

Finally, I would like to talk about patients who have been diagnosed with both Hepatitis C and HIV. You do not need to disclose anything about your own HIV status; these will be general questions about information you received.

21. When you were first diagnosed with Hepatitis C, were you told anything about the complications that face patients have HIV in addition to Hepatitis C? What were you told? Did your physician ask you about your HIV status?
22. What kinds of questions did you have about co-infection that you would have liked to have answered when you were first diagnosed?

PROBE FOR ISSUES LIKE:

- HIV may make Hepatitis C progress much more rapidly (on a seven to ten year time frame, rather than a twenty to thirty year time frame).
- Some medications that are used to treat HIV can damage the liver, which may increase the severity of the Hepatitis C infection.
- There is no consensus currently on how to treat people with Hepatitis C/HIV co-infections, and people with HIV may be less receptive to treatment for Hepatitis C in general.

Advocacy (5 minutes)

23. When you were meeting with your health care provider to find out about your diagnosis and discuss treatment options, did you feel that you were able to advocate for yourself? [IF NEEDED: That is, did you feel that you were able to act in your own best interests to ensure that you received high-quality medical care and received enough information about your illness?]

PROBE:

- To what extent did you feel you were able to request tests if you needed them, either to confirm a diagnosis or monitor the progression of the virus?
 - To what extent do you feel you can ask for and get information about new treatment options, including clinical trials, as they become available?
24. There is evidence that people who advocate for themselves have better health care outcomes. What information could help you to better advocate for yourself with physicians and other health care professionals?

APPENDIX B: MODERATOR GUIDE FOR PEOPLE WHO RECEIVED TRANSFUSIONS/TRANSPLANTS

Purpose

You have all been asked to participate in this discussion because you have been diagnosed with Hepatitis C, and you contracted the illness through a blood transfusion or organ transplant.

The reason we are having this discussion today is that the Department of Public Health is in the process of creating some educational materials for people who have been diagnosed with Hepatitis C. The purpose of this group is to get input from you that will help the Department of Public Health develop these educational materials.

Ground Rules

- Audio taping/Mirror
- Candid point of view is essential/No “right” answers/Okay to disagree
- No side bar discussions/Speak one at a time
- Role of Moderator—unbiased and not an expert

Introductions (5 minutes)

- Name, where lives, and how long since diagnosed with Hepatitis C.

Questions, Concerns When First Diagnosed (25 minutes)

First, I would like you all to think back to when first met with your health care provider and found out that you had Hepatitis C.

19. What type of physician originally diagnosed your Hepatitis C (e.g. primary care physician vs. specialist)? What information did your health care provider give you at that first visit that was particularly helpful? What questions or concerns did you have when you were first diagnosed that were not answered during that visit? What kinds of issues were most confusing or unclear for you during that first meeting with your provider? Who gave you information at that first visit—was it your physician, a nurse, or both?
20. From what you know or have heard, what kinds of tests are there for screening for Hepatitis C?
21. [IF NEEDED: There are two major screening tests for Hepatitis C: an **antibody test** such as an EIA or an ELISA, which is usually the first test patients are given; and an **antigen test** such as PCR for viral RNA, which is usually performed to confirm a diagnosis of Hepatitis C]. Were you aware that there were two separate screening tests for Hepatitis C when you were first diagnosed?
22. Did your physician explain the two types of screening to you when you were being tested for the illness? Did you have any questions about the tests at that point that you would have liked your provider to answer? Did you get both tests?

23. Some people with Hepatitis C are given a liver biopsy—how many of you heard of that? What information can you get from a liver biopsy? Do you know whether or not getting a liver biopsy is a dangerous procedure?
24. Are you aware that there are different strains of Hepatitis C? How many different major strains are there? What do you know about the differences between them in terms of progression and effectiveness of treatment?
25. When you were first diagnosed with Hepatitis C, did you know what strain of the virus you had? Did you have any questions about the three major strains of the virus that you would have liked your provider to answer? [IF NEEDED: There are three most common strains in the US: Type I, Type II, and Type III. Type I is the most prevalent (over 70% of cases of Hepatitis C are Type I), and is the least responsive to treatment. Types II and III are typically more responsive to treatment and less likely to progress.]

Prevention (10 minutes)

26. What are the **main** ways that Hepatitis C is transmitted? From what you know or have heard, how can people protect themselves from getting the Hepatitis C virus? [FOCUS ON MAJOR BEHAVIORS]
27. From what you know or have heard, after you have been successfully treated for Hepatitis C, is it possible to get re-infected with the virus? [IF NEEDED: or do you think you're immune to it after that, like the measles?]
28. From what you know or have heard, if you have one strain of Hepatitis C, is it possible for you to become infected with another strain of Hepatitis C? For example, if you've been diagnosed with Type II Hepatitis C, is it possible for you to become infected with Type I Hepatitis C?
29. What did your physician tell you about passing the virus onto others through sexual transmission? Do you have a sense of whether Hepatitis C is easily transmitted through sexual activity?
30. I'd also like to talk about slowing down the progression of Hepatitis C. As you may know, physicians have some suggestions for people with the virus about ways that they can slow the illness down. From what you know or have heard, what kinds of things can you do to slow down the progression of this virus?

PROBE FOR:

- abstaining from alcohol
- having a healthy lifestyle, including eating well and getting enough sleep
- getting vaccinations for Hepatitis A and B
- taking care with prescription and over-the-counter drugs, for example Tylenol, that could cause liver damage

Treatment (20 minutes)

31. Next, I would like to talk about some of the options for treating Hepatitis C. In your opinion, what kinds of information would be most helpful for people who have just been diagnosed with Hepatitis C, so that they can make decisions about treatment options? Did you receive treatment for Hepatitis C? For those of you who got treatment, did your

provider discuss with you the importance of not drinking alcohol during treatment? Are there any of you who wanted to get treatment but were unable to do so for some reason? Why were you unable to?

32. When you were first diagnosed, what did your provider tell you about the treatment options that were available to you? What are the most important things you would have liked to have known about your treatment options?

PROBE FOR:

- the effectiveness of treatment
- the length of time it takes to treat the virus
- the possible side effects of the treatment
- the fact that treatment involves injections

33. Did your health care provider discuss the possible side effects of treatment with you before you began a treatment plan?
34. What did your provider tell you about the **physical effects** of your treatment?
35. What about its possible effect on your **mental health**, such as the risk of depression? Did your provider ask you if you had a history of depression before beginning treatment? [IF YES: Did your provider discuss this in relation to your treatment plan?]
36. Did your provider prepare you for the possibility that the side effects might be severe enough that it could include an inability to work?
25. What else could your provider have done to help prepare you for treatment?
26. Did you weigh the pros and cons of getting treatment, or did you decide right away that you would get treatment for the virus, regardless of the side effects you might experience as a result of the treatment? What resources did you have to help you make that decision? [PROBE FOR: success rate and side effects if not mentioned]
27. Are you aware of any alternative treatments for Hepatitis C? [PROBE FOR: herbal remedies; other] What do you know about these alternative treatments?

Educational Materials and Information (10 minutes)

28. Now I'd like to ask you about the educational materials that the Department of Public Health is developing. As I mentioned, they are developing an educational video for people who have just been diagnosed with the illness in order to answer their basic questions. What kinds of setting would you prefer to watch the video in? Are there other settings, besides the provider's office, where you think people should show this video or have educational material available? [For example: substance abuse providers, social service providers, specialists who treat Hepatitis C]
29. The Department of Public Health is also developing a brochure on Hepatitis C that will accompany the video, a Hepatitis C hot line patients can call to get answers to questions, and an informational web site on the Internet. Can you think of any other materials that would be helpful for new patients to have?

30. There are two major groups of people who contract Hepatitis C: people like yourselves who have contracted the illness because they received an organ transplant or blood transfusion prior to 1992, and people who contracted the illness as a result of using injection drugs. If you were watching an educational video about Hepatitis C, would it make a difference to you whether the video also presented information that was intended for people recovering from using injection drugs? For example, part of the video might discuss the challenges that former injection drug users will face as a result of having to receive injections to treat the virus. What impact would this have on your feeling about the videotape, if any? Why would you feel this way?

Co-Infection of Hepatitis C and HIV (5 minutes)

Finally, I would like to talk about patients who have been diagnosed with both Hepatitis C and HIV. You do not need to disclose anything about your own HIV status; these will be general questions about information you received.

25. When you were first diagnosed with Hepatitis C, were you told anything about the complications that face patients have HIV in addition to Hepatitis C? What were you told? Did your physician ask you about your HIV status?
26. What kinds of questions did you have about co-infection that you would have liked to have answered when you were first diagnosed?

PROBE FOR ISSUES LIKE:

- HIV may make Hepatitis C progress much more rapidly (on a seven to ten year time frame, rather than a twenty to thirty year time frame).
- Some medications that are used to treat HIV can damage the liver, which may increase the severity of the Hepatitis C infection.
- There is no consensus currently on how to treat people with Hepatitis C/HIV co-infections, and people with HIV may be less receptive to treatment for Hepatitis C in general.

Advocacy (5 minutes)

27. When you were meeting with your health care provider to find out about your diagnosis and discuss treatment options, did you feel that you were able to advocate for yourself? [IF NEEDED: That is, did you feel that you were able to act in your own best interests to ensure that you received high-quality medical care and received enough information about your illness?]

PROBE:

- To what extent did you feel you were able to request tests if you needed them, either to confirm a diagnosis or monitor the progression of the virus?
 - To what extent do you feel you can ask for and get information about new treatment options, including clinical trials, as they become available?
28. There is evidence that people who advocate for themselves have better health care outcomes. What information could help you to better advocate for yourself with physicians and other health care professionals?