

Audience Profile for Hepatitis C Health Communication Initiative

A. General Public

Knowledge	Attitudes	Behaviors	Communication Issues
<p>Respondents are more likely to be aware of hepatitis A and B than of hepatitis C. Hepatitis B (57 percent) is the most well-known type of hepatitis, followed by hepatitis A (50 percent) and hepatitis C (22 percent).</p> <p>Of respondents who are aware of different types of hepatitis, those with more education are more likely to name hepatitis C.</p> <ul style="list-style-type: none"> ▪ 40 percent of those with college degrees ▪ 28 percent of those with some college education ▪ 22 percent of those with a high school degree or less ▪ 24 percent are aware of hepatitis as a liver disease <p>Cirrhosis is the most well-known liver disease.</p> <ul style="list-style-type: none"> ▪ 57 percent of respondents 	<p>While some believe hepatitis sufferers are stigmatized, few say a stigma would prevent them from seeking help.</p> <ul style="list-style-type: none"> ▪ Only 6 percent are somewhat or very likely to let stigma associated with hepatitis prevent them from seeking help ▪ Only 20 percent think that most people they know would be embarrassed or ashamed if other people knew they had hepatitis ▪ 42 percent agree that society attaches a stigma to people who contract hepatitis <p>Younger respondents and those with less income are more likely to think that most people they know would be embarrassed or ashamed if other people knew they had hepatitis.</p> <ul style="list-style-type: none"> ▪ 40 percent of respondents age 21-34 ▪ 23 percent of respondents age 35 and older ▪ 43 percent of those with income less than \$25,000 ▪ 42 percent of those with income \$25,000 to \$50,000 ▪ 13 percent of those with income greater than \$50,000 	<p>Actions taken by respondents as a result of seeing “Get hip, get tested, get treated” advertising:</p> <ul style="list-style-type: none"> ▪ 31 percent no action taken ▪ 4 percent have taken steps to prevent the disease ▪ 4 percent asked a doctor for information about hepatitis ▪ 4 percent got vaccinated for hepatitis ▪ 3 percent got tested for hepatitis ▪ 1 percent called the 800 number/ American Liver Foundation for more information <p>(Note: 54 percent of those interviews were not asked this question.)</p>	<p>SOURCES</p> <p>Those with incomes of \$50,000 or more are more likely to get information from nonprofit organizations.</p> <ul style="list-style-type: none"> ▪ 48 percent of those with income of \$50,000 or more ▪ 34 percent of those with income less than \$50,000 <p>40 percent receive health information from a nonprofit organization devoted to education and research.</p> <p>CHANNELS</p> <p>They recall seeing “Get hip, get tested, get treated” advertising in the following locations:</p> <ul style="list-style-type: none"> ▪ 13 percent television ▪ 12 percent Parade section of Sunday newspaper ▪ 9 percent bus poster ▪ 9 percent billboard ▪ 6 percent subway poster ▪ 5 percent bus shelter ▪ 4 percent commuter rail advertising ▪ 4 percent <i>People</i> ▪ 4 percent <i>Time</i> ▪ 3 percent <i>Newsweek</i>

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<p>Respondents feel they are more likely to get hepatitis if they had blood transfusions before 1990.*</p> <ul style="list-style-type: none"> ▪ 70 percent of respondents ▪ 71 percent of whites ▪ 65 percent of Hispanics ▪ 75 percent of African Americans ▪ 67 percent of those with high school education or less ▪ 73 percent of those with some college education or more <p>Respondents consider hepatitis as a serious disease because it can be fatal.</p> <ul style="list-style-type: none"> ▪ 28 percent of respondents mentioned hepatitis can be fatal ▪ 12 percent of respondents mentioned hepatitis affects the liver ▪ 12 percent of respondents mentioned hepatitis is highly contagious ▪ 2 percent of respondents mentioned hepatitis is incurable/never fully recover ▪ 2 percent of respondents mentioned hepatitis is difficult to cure ▪ 2 percent of respondents mentioned hepatitis causes long-term illness 	<p>If they thought they might have hepatitis or have been exposed to hepatitis, they would very likely take the following actions:</p> <ul style="list-style-type: none"> ▪ 72 percent would get tested if a doctor suggests it ▪ 72 percent would take steps to protect others from exposure ▪ 71 percent would call or visit their doctor ▪ 67 percent would share concerns with family members or others in household ▪ 42 percent would share concerns with friends ▪ 4 percent would keep their concerns to themselves 		<ul style="list-style-type: none"> ▪ 3 percent <i>TV Guide</i> ▪ 2 percent <i>Jet</i> <p>Most receive health information about liver diseases from TV and word of mouth:</p> <ul style="list-style-type: none"> ▪ 21 percent television advertising ▪ 20 percent word of mouth (friends/relatives) ▪ 18 percent school/education ▪ 15 percent newspaper articles ▪ 14 percent magazine articles ▪ 14 percent personal experience ▪ 12 percent books ▪ 8 percent physicians ▪ 7 percent at work or on the job <p>70 percent receive information about diseases that affect themselves and their families from their doctor’s office or a clinic.</p> <p>Other preferred channels for receiving information about diseases that affect themselves and their families:</p> <ul style="list-style-type: none"> ▪ 15 percent doctor’s office or clinic ▪ 10 percent television ▪ 10 percent direct mail ▪ 6 percent newspapers

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<p>Agreement with statement: Although hepatitis A, B, and C are different diseases, they all have about the same effect on health.*</p> <ul style="list-style-type: none"> ▪ 24 percent of respondents overall ▪ 15 percent of whites ▪ 27 percent of Hispanics ▪ 30 percent of African Americans <p>SYMPTOMS</p> <p>Hepatitis symptoms most familiar to respondents include:</p> <ul style="list-style-type: none"> ▪ 22 percent mentioned jaundice ▪ 22 percent mentioned fatigue/tiredness/lack of energy ▪ 19 percent mentioned yellow eyes or skin ▪ 6 percent mentioned flu-like symptoms ▪ 5 percent mentioned nausea ▪ 5 percent mentioned vomiting 			<ul style="list-style-type: none"> ▪ 6 percent magazines ▪ 3 percent Internet ▪ 3 percent radio ▪ 3 percent nonprofit organization <p>Magazine articles are more likely to reach those who are more educated and have higher incomes.</p> <ul style="list-style-type: none"> ▪ 71 percent of those with a college degree ▪ 57 percent of those with some college ▪ 55 percent of those with a high school diploma or less ▪ 71 percent of those with incomes of \$50,000 or more ▪ 58 percent of those with incomes less than \$50,000 <p>Women are more likely than men to get information from a doctor’s office or clinic.</p> <ul style="list-style-type: none"> ▪ 79 percent women ▪ 60 percent men

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<p>RISK FACTORS</p> <p>Sharing needles and injection drug use are the most well-known risk factors for hepatitis.</p> <ul style="list-style-type: none">▪ 70 percent mentioned sharing needles▪ 65 percent mentioned injection drug use▪ 57 percent mentioned contaminated food or water▪ 54 percent mentioned tattooing▪ 51 percent mentioned unprotected sex with an infected partner▪ 56 percent mentioned body piercing▪ 48 percent mentioned sharing razors▪ 35 percent mentioned sharing toothbrushes▪ 29 percent mentioned kissing▪ 23 percent mentioned visiting an infected person▪ 25 percent mentioned sneezing or coughing▪ 14 percent mentioned toilet seats			

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<p>TREATMENT OPTIONS</p> <p>Nearly half of respondents (49 percent) are unaware of treatment options for hepatitis B or C.</p> <ul style="list-style-type: none"> ▪ 7 percent mentioned vaccine/immunization ▪ 4 percent mentioned avoid alcohol ▪ 4 percent mentioned good nutrition/diet ▪ 4 percent mentioned adequate rest ▪ 4 percent mentioned transplantation ▪ 4 percent mentioned interferon ▪ 1 percent mentioned medication 			

SOURCE: All data in this section, except where noted with an asterisk (*), were derived from the American Liver Foundation study. Data from those sections noted with an asterisk were gathered in the Porter Novelli Health Style Study.

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B. Transfusion Recipients

Knowledge	Attitudes	Behaviors	Communication Issues
<p>Most were more likely to be aware of hepatitis A and B than of hepatitis C.</p> <p>Most were unaware of who is at risk, how hepatitis C is transmitted, and whether there is a test for hepatitis C.</p> <p>Some participants had the following misinformation regarding hepatitis C.</p> <ul style="list-style-type: none"> ▪ One participant believed incorrectly that the hepatitis C virus was “highly contagious.” The participant also mentioned incorrectly that the hepatitis C test result was valid for only the day of testing and that the results can change. ▪ Another participant believed incorrectly that one could get hepatitis C from sharing drinking glasses. <p>Some were aware of possible symptoms of hepatitis C.</p> <ul style="list-style-type: none"> ▪ Some participants have heard of hepatitis C and the possible symptoms of jaundice and fatigue. <p>Most participants believed incorrectly that their physicians were performing hepatitis C testing during routine blood tests.</p> <ul style="list-style-type: none"> ▪ Participants believed that blood work during routine physicals/check-ups with their doctors included a test for hepatitis C. ▪ A Hispanic participant stated that she didn’t need testing because she goes to the doctor for regular check-ups. 	<p>TESTING</p> <p>Some participants expressed anger because the hepatitis test was not a part of routine blood testing.</p> <p>Most participants did not feel motivated to seek testing until they had the opportunity to review the CDC pamphlet and poster.</p> <p>BENEFITS OF TESTING</p> <p>Most commonly chosen benefits were:</p> <ul style="list-style-type: none"> ▪ To find out whether I have/have not been infected with hepatitis C ▪ To learn how I can keep from getting infected if I don’t have hepatitis C ▪ To get counseling for what I should do next if I have hepatitis C ▪ To learn how I can prevent spreading hepatitis C to others if I have hepatitis C ▪ To get treated if I have hepatitis C <p>Least chosen benefits were:</p> <ul style="list-style-type: none"> ▪ To learn how I can protect my liver from further harm if I have hepatitis C ▪ To get vaccinated against hepatitis A and/or hepatitis B 		<p>SOURCES</p> <p>The following were named as credible sources:</p> <ul style="list-style-type: none"> ▪ Celebrities like Naomi Judd ▪ Doctors ▪ Surgeon General ▪ Friends/family members <p>Credible organizations:</p> <ul style="list-style-type: none"> ▪ CDC ▪ NIH ▪ Health maintenance organizations ▪ Health departments ▪ American Red Cross <p>CHANNELS</p> <p>Recommendations for reaching the audience are:</p> <ul style="list-style-type: none"> ▪ Bus advertising ▪ Newspapers ▪ Internet ▪ Subway/metro placards ▪ News broadcasts and news magazines such as “20/20” ▪ Doctors’ offices

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B. Transfusion Recipients

Knowledge	Attitudes	Behaviors	Communication Issues
<p>Participants said they would like the answers to the following questions related to hepatitis C testing:</p> <ul style="list-style-type: none"> ▪ Is the test accurate? ▪ Are test results confidential? ▪ Would test results affect their health insurance or future employment? ▪ Is the treatment painful? ▪ Will insurance cover the cost of testing and counseling? ▪ Could I be a carrier for hepatitis C? ▪ When and how often should I get tested? ▪ Will the test indicate whether my blood transfusion was the source of infection? 	<p>BARRIERS FOR TESTING</p> <p>Most commonly chosen barriers were:</p> <ul style="list-style-type: none"> ▪ I don't know how serious hepatitis C is. ▪ I am not sure how well the treatment works. ▪ I don't know about treatment options. ▪ I am concerned about the cost of testing and counseling. <p>Least chosen barriers were:</p> <ul style="list-style-type: none"> ▪ I am concerned about someone else finding out my test results. ▪ I am concerned it will affect my employment/insurance. ▪ I am concerned about the social stigma/embarrassment. <p>A few participants felt they definitely would get tested; therefore, they did not choose any of the barriers.</p>		<p>Rural participants mentioned additional places they would most likely notice information on hepatitis C:</p> <ul style="list-style-type: none"> ▪ Laundromat ▪ Pharmacy ▪ Emergency room waiting area <p>The Hispanic group suggested local Spanish radio stations and channels such as Univision or Telemundo.</p> <p>Participants in the Hispanic focus group stated they would most likely notice information about hepatitis C in the following additional places:</p> <ul style="list-style-type: none"> ▪ Churches ▪ Libraries ▪ Schools ▪ Day care centers ▪ Spanish newspapers <p>MESSAGES</p> <p>Pamphlet</p> <ul style="list-style-type: none"> ▪ Some participants were frightened by information in the pamphlet stating many people with the disease have no symptoms.

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B. Transfusion Recipients

Knowledge	Attitudes	Behaviors	Communication Issues
	<p>TESTING SITE</p> <p>Most prefer to get tested in their own physicians' office.</p> <ul style="list-style-type: none"> ▪ Participants in the Hispanic group and rural group mentioned they would be willing to get tested at a local clinic that also conducted STD and HIV testing. ▪ Only one participant in the urban group thought that he would be comfortable going to the local health department for testing. 		<ul style="list-style-type: none"> ▪ Most participants in the Hispanic group felt that the pamphlet provided enough information, and they described the pamphlet as easy to understand. ▪ The majority of urban and Hispanic participants perceived the main message of the pamphlet to be: "Get tested for hepatitis C." ▪ Nearly all the participants in the urban and rural groups indicated the pamphlet was confusing and raised many concerns and questions. ▪ Several women expressed concern about whether hepatitis C can be transmitted during pregnancy. ▪ The Hispanic group recommend that the pamphlet be available in different languages. <p>Recommendations for the pamphlet</p> <ul style="list-style-type: none"> ▪ "Have you had a blood transfusion?" and reason for testing should be placed on the front cover. ▪ Bold letters should be used for "Have you had a transfusion?" ▪ Should say "before 1990." Participants in the urban group were confused by the two dates stating which years recipients of transfusions are at risk (transfusions before 1990 or before 1992). ▪ Place the definition of hepatitis C on the front of the pamphlet. ▪ Clarify in the definition how serious hepatitis C is. ▪ Place "Have you had a blood transfusion?" on the front of the pamphlet to make the connection between blood transfusions and hepatitis C more evident. ▪ Clarify what is meant by "casual contact" and why the risk of infection is higher with multiple sex partners. ▪ Indicate how often people should get tested.

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B. Transfusion Recipients

Knowledge	Attitudes	Behaviors	Communication Issues
			<p>Poster</p> <ul style="list-style-type: none"> ▪ Majority of participants preferred the CDC poster to the CDC pamphlet because of the poster’s images as well as the use of personal language and bulleted items. They indicated that the poster would lead them to seek out further information from a doctor or educational materials. ▪ Participants indicated that the word “routinely” in the poster implied that testing needs to be done periodically. <p>Recommendations for the poster</p> <ul style="list-style-type: none"> ▪ Add a bullet that suggests next steps to take for people who test positive for hepatitis C. <p>Participants from the Hispanic group had the following suggestions:</p> <ul style="list-style-type: none"> ▪ Use images of people of various ages ▪ Use images of people of various races/ethnicities ▪ Use images of pregnant women and babies <p>Participants from the rural group suggested:</p> <ul style="list-style-type: none"> ▪ Display the poster near a supply of the pamphlets ▪ Clarify how often testing should be done.

SOURCE: All data in this section were derived from the Westat focus groups with transfusion recipients.

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C. Persons Infected with Hepatitis C

Knowledge	Attitudes	Behaviors	Communication Issues
<p>TRANSMISSION</p> <ul style="list-style-type: none"> ▪ Participants were aware that the hepatitis C virus is most easily transmitted by blood. ▪ Participants were informed by their physicians not to share toothbrushes or razors and to make sure no one came into contact with their blood. ▪ Three female participants with long-term infection who had spouses who recently tested negative did not believe that hepatitis C was sexually transmitted. ▪ One participant indicated that he received a standard printout information from his doctor about modes of transmission that stated there were no known documented cases of sexual transmission of hepatitis C. 	<p>SCREENING AND DIAGNOSIS</p> <ul style="list-style-type: none"> ▪ All participants with advance stages of liver disease expressed dissatisfaction about the way they were informed about their diagnosis and possible long-term consequences. ▪ The participants with advanced stages of liver disease felt that their doctors did not give them any hope for possible recovery from hepatitis C. <p>TREATMENT AND CARE</p> <ul style="list-style-type: none"> ▪ Only one person reported a “successful” response to interferon treatment. ▪ A few participants were concerned about their ability to pay for future treatment since they were self-employed and had no health insurance. ▪ One participant felt that his physicians had not addressed his concern and would not spend time to explain the effects of his dual diagnosis of hepatitis B and C. ▪ None of the participants with advanced stages of liver disease felt that their doctors would respect their choice to try alternative medicines. 	<ul style="list-style-type: none"> ▪ None of the participants had requested to be tested for hepatitis C. ▪ Some participants experienced extreme fatigue for about a year before seeking help from a doctor. <p>TREATMENT AND CARE</p> <ul style="list-style-type: none"> ▪ One participant discontinued treatment with interferon due to a serious side effect. She began to take herbal medicines and reported that her liver enzyme level reduced significantly. ▪ Several participants indicated that they changed gastroenterologists because of the doctors’ unwillingness to provide treatment options and to talk with them directly. 	<p>SOURCES</p> <p>Sources of information for participants who were not in advanced stages of liver disease:</p> <ul style="list-style-type: none"> ▪ American Liver Foundation ▪ Support groups ▪ Internet ▪ Medical journals ▪ Mayo Clinic ▪ physicians ▪ newspapers <p>Primary sources of information for participants with advanced stages of liver disease were:</p> <ul style="list-style-type: none"> ▪ Support group ▪ Health food store ▪ Books on diet and nutrition ▪ Others with hepatitis C or liver disease ▪ Physician <ul style="list-style-type: none"> ▪ Some participants indicated that they had to ask their doctors all of the questions in order to obtain useful information. ▪ Some participants were pleased with the way their diagnosis was communicated to them by their doctors. ▪ Participants reported that they had to do their own research to learn more about hepatitis C, alternative treatments, and side effects of interferon treatment. ▪ Most of the participants were disappointed that their gastroenterologists were not more knowledgeable and

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C. Persons Infected with Hepatitis C

Knowledge	Attitudes	Behaviors	Communication Issues
	<ul style="list-style-type: none"> ▪ Participants stated that their doctors did not suggest that spouses or family members be involved in treatment decisions. ▪ Participants indicated that family members were involved in treatment decisions only on their own insistence. ▪ Participants reported receiving conflicting messages about alcohol consumption and the use of Tylenol as a pain reliever. 		<p>supportive about the use of herbal medicines, nutritional counseling, or benefits of regular exercise.</p> <ul style="list-style-type: none"> ▪ One person was notified of a positive diagnosis from a letter after donating blood. Others were diagnosed by primary care physicians. ▪ Some of the participants reported that their symptoms were discounted by a series of doctors for a long period of time prior to being diagnosed with hepatitis C. They were made to feel that “it was all in their head” and were offered anti-depressant medication. ▪ Participants were aware and respectful of the fact that hepatitis C is a relatively new disease and doctors do not have a lot of information; however, they felt that doctors should share the information they do have in a compassionate manner. <p>MESSAGES</p> <p>Recommendation for improving communication between patients and physicians</p> <ul style="list-style-type: none"> ▪ Take time with patients ▪ Relate diagnosis gently since it is very difficult for people to absorb the information ▪ Maintain eye contact ▪ Offer additional sources of information ▪ Have printed materials available for the patient and that are targeted for family members to explain the emotional aspects and the progression of the disease ▪ Do not over schedule office hours

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C. Persons Infected with Hepatitis C

Knowledge	Attitudes	Behaviors	Communication Issues
			<p>One participant recommended the following for ways that physicians can communicate with patients in a realistic and compassionate way about the uncertainties of hepatitis C:</p> <p align="center"><i>It can be pretty serious, but most of the time it is not. Right now we don't have a very good treatment, but we do have interferon. In the next 8-10 years, there will probably be something better coming down the road. But for now we can try interferon. And let me tell you about the side effects. Let's also look at stress, diet, nutrition, and an exercise program and getting enough sleep. Also read this book; it can be very helpful in managing this disease.</i></p> <p>CHANNELS</p> <p>Participants with advanced stages of liver disease reported not receiving any written materials about hepatitis C at the time of their diagnosis.</p> <p>Participants were dissatisfied with an instructional video on how to self-administer interferon injections because it did address in detail the possible side effects.</p> <p>Some of the participants felt that a video, pamphlet, and support group combination was used as a substitute for interpersonal communication.</p>

SOURCE: All data in this section were derived from the Macro focus groups with patients infected with hepatitis C.

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D. Persons with Bleeding Disorders

Knowledge	Attitudes	Behaviors	Communication Issues
<p>Men</p> <ul style="list-style-type: none"> ▪ Men were aware of hepatitis C because most of them (5 out of 8) tested positive. ▪ Men were aware that hepatitis C is a serious disease that will affect many people. ▪ Some were notified of their hepatitis C status from the hemophilia treatment centers. ▪ They want more information on the differences between hepatitis A, B, and C. More information on vaccines for hepatitis A and B. <p>Women</p> <ul style="list-style-type: none"> ▪ Women were aware of hepatitis C because their child was positive or a relative was positive from blood transfusion. ▪ Women felt that they didn't have enough information about hepatitis C. ▪ Some women were aware of at-risk groups for hepatitis C such as injection drug users and recipients of blood products. ▪ One woman has had so many transfusions, surgeries, and blood products that she was not sure of her source of infection with hepatitis C. 	<p>Participants feel there has been more emphasis on HIV than hepatitis.</p> <ul style="list-style-type: none"> ▪ The focus was so much on HIV that not enough attention was on hepatitis C. (Men) ▪ Hepatitis C is not a top priority because it is a chronic disease. (Men) ▪ One hematologist told a participant that since there are so many types of hepatitis (A, B, C, D, E, G) out there, she shouldn't bother testing. (Women) ▪ Some felt that doctors did not take hepatitis C seriously enough given that it will affect their children 10-20 years down the road. (Parents) ▪ Most of the men indicated that hepatitis C was not a focus due to HIV. (Men) <p>All were concerned about hepatitis; parents had more concerns than the participants in the men's and women's groups.</p> <ul style="list-style-type: none"> ▪ All my children are vaccinated for hepatitis A and B. (Women) ▪ It's scary to think what I could be infected with. (Women) ▪ Someone should be telling me how to prevent further liver damage from hepatitis C. (Parents) ▪ People need to be educated about hepatitis A, B, and C, and HIV. (Women) 	<p>Most parents seemed to take the initiative to learn about hepatitis C themselves and to take their children to a liver specialist. (Parents)</p>	<p>SOURCES</p> <p>Some women indicated that they trust their doctors since they are up to date, knowledgeable, above board, and honest. (Women)</p> <p>Recommendation for spokesperson</p> <ul style="list-style-type: none"> ▪ Naomi Judd (Women) <p>MESSAGES</p> <p>Parents want all the information in a way they can easily understand. (Parents)</p> <ul style="list-style-type: none"> ▪ If it is serious, maybe I can do something to prevent hardship on my son. (Parents) ▪ Be upfront, honest, someone I can trust; don't sugarcoat or hedge with me. (Parents) <p>Women felt that more publicity is needed about hepatitis C. (Women)</p> <p>Even though some women were aware of other types of hepatitis (A, B, D, E, and G), they indicated that the pamphlet did not have any information on the other types of hepatitis. (Women)</p>

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D. Persons with Bleeding Disorders

Knowledge	Attitudes	Behaviors	Communication Issues
<p>Men, Women and Parents</p> <ul style="list-style-type: none"> ▪ Some parents believed hepatitis C was included in their children’s blood tests at the hemophilia treatment center every 6 months. (Parents) ▪ A few persons from the women’s and men’s groups were aware of diagnostic test involves measurement of liver function/enzymes. (Men) (Women) <p>TREATMENT</p> <p>Men</p> <ul style="list-style-type: none"> ▪ Some men were aware that there is no cure for hepatitis C. (Men) <p>Women</p> <ul style="list-style-type: none"> ▪ Some women were aware that there is no vaccine for hepatitis C. <p>Men, Women, and Parents</p> <ul style="list-style-type: none"> ▪ Some participants were aware that a treatment for hepatitis C is interferon. (Parents) (Women) (Men) 	<p>Bloodborne viruses such as HIV, HCV need to be monitored. (Men)</p> <ul style="list-style-type: none"> ▪ “It is imperative for a national focus by the CDC; HIV is probably just the virus du jour.”(Men) ▪ All men were aware of hepatitis C, that it is “persistent/intractable.” (Men) <p>TESTING</p> <p>Some parents and men were concerned that the hepatitis C test results were not given to them or that they were not informed of a positive test result in a timely manner.</p> <ul style="list-style-type: none"> ▪ Parents reported that they were very angry they weren’t notified immediately about a positive hepatitis C test result. (Parents) ▪ One parent indicated that now she always obtains a copy of the blood results because she was not told of her son’s exposure to hepatitis C and had to find out by looking over doctor’s shoulder. (Parents) ▪ One participant was not informed that he was hepatitis C positive until 1994. (Men) <p>Some mentioned that prevention is very important. (Parents)</p>		<p>CHANNELS</p> <p>Recommendations for reaching the audience are:</p> <ul style="list-style-type: none"> ▪ Direct mailing (Parents) ▪ Hemophilia treatment centers (Women) (Men) (Parents) ▪ National/local hemophilia association (Women) ▪ Mass mailing/direct mail (Women) ▪ Internet (Men)

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Knowledge	Attitudes	Behaviors	Communication Issues
	<p>Testing is good, but one parent said testing at the source is better. Therefore, the parent indicated a need to monitor companies that make the blood products. (Parent)</p> <p>Hemophilia community is being tested, but other populations in the general public should be tested also. (Women)</p> <p>As long as confidentiality is assured, UDC program should be mandatory, not optional. I believe we can all benefit. (Women)</p> <p>If UDC program detects hepatitis A/B, then vaccinate. (Women)</p> <p>BARRIERS TO TESTING</p> <p>Parents and women were concerned with confidentiality of test results that may affect future employment/insurance. (Women)</p> <ul style="list-style-type: none"> ▪ Some felt that the researchers have ways to trace the number back to the individual. ▪ If the government is involved, who would have access to the test results. 		

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D. Persons with Bleeding Disorders

Knowledge	Attitudes	Behaviors	Communication Issues
	<p>TREATMENT</p> <p>Concern about difficulty of the treatment for hepatitis C. (Women)</p> <ul style="list-style-type: none"> ▪ “Treatment with interferon is like hell.” <p>HEALTH PROFESSIONALS</p> <p>Concern about the lack of awareness and knowledge among health care professionals. (Men)</p> <ul style="list-style-type: none"> ▪ Participants felt that there was a lack of information even in the medical community. ▪ How long have they known about hepatitis C; what is it? ▪ Some of the participants felt that the medical professionals don’t take hepatitis C seriously. 		

NOTE: Three focus groups were conducted on blood safety programs, Universal Data Collection (UCD) and Creutzfeldt-Jakob Disease (CJD) program.

SOURCE: The data in this section were derived from three Westat focus groups: one with men with bleeding disorders, one with women with bleeding disorders, and one with parents of children with bleeding disorders.