

Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C.

### **3: Knowledge and Awareness About Chronic Hepatitis B and Hepatitis C**

An estimated 0.8–1.4 million people in the United States are chronically infected with hepatitis B virus (HBV) and 2.7–3.9 million people are chronically infected with hepatitis C virus (HCV). However, there is relatively poor awareness about these infections among health-care providers, social-service providers, and the general public. Lack of awareness about the prevalence of chronic viral hepatitis in the United States and about the proper methods and target populations for screening and medical management of chronic hepatitis B and hepatitis C probably contributes to continuing transmission; missing of opportunities for prevention, including vaccination; missing of opportunities for early diagnosis and medical care; and poor health outcomes in infected people.

As discussed in Chapters [1](#) and [2](#), surveillance data on the numbers of people acutely and chronically infected with HBV and HCV are imprecise and can be difficult to interpret. The prevalence of chronic infections remains high for several reasons, and the aging of the chronically infected population has contributed to the tripling of liver-cancer incidence during the last three decades (Altekruse et al., 2009; McGlynn et al., 2006). The persistently high prevalence of chronic HBV infection can be attributed in part to immigration of chronically infected people from HBV-endemic regions—including East Asia, Southeast Asia, and sub-Saharan Africa—to the United States. The high prevalence of chronic HCV infection is due in part to the lack of access to preventive measures, such as harm-reduction programs, and lack of access to antiviral treatments in high-risk populations.

This chapter is divided into two sections. The first addresses knowledge and awareness about hepatitis B and hepatitis C in health-care providers and social-service providers; the second addresses the topic with reference to the general population and at-risk populations. Each section begins by describing what is known about the levels of knowledge and awareness about hepatitis B and hepatitis C and how gaps in education about these diseases are affecting prevention, screening and testing, and treatment opportunities. Those summaries are followed by the committee's recommendations for addressing the gaps and the rationale and supportive evidence for the recommendations.

[Go to:](#)

## KNOWLEDGE AND AWARENESS AMONG HEALTH-CARE AND SOCIAL-SERVICE PROVIDERS

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The committee found that knowledge about chronic hepatitis B and hepatitis C among health-care providers, particularly primary-care providers (for example, physicians, physician assistants, and nurse practitioners), and social-service providers (for example, staff of drug-treatment programs, needle-exchange programs, and immigrant services centers) is generally poor. Although there have been no large-scale, controlled studies of health-care providers' knowledge about chronic hepatitis B and hepatitis C, it is clear that knowledge has been imperfect among providers in all the surveys whose results have been published. Subjects of deficient knowledge include

- The prevalence of chronic hepatitis B and hepatitis C in the general and high-risk populations in the United States.
- The clinical sequelae of chronic viral hepatitis.

- The characteristics of at-risk persons who should be tested for chronic HBV and HCV infection and vaccinated to protect them from hepatitis B.
- The approaches to primary and secondary prevention in addition to hepatitis B vaccination.
- The proper methods of testing and interpretation of test results.
- The proper followup management for chronic infection.

Provider guidelines for hepatitis screening, prevention, treatment, and followup have been in place for decades and are updated regularly (CDC, 1991, 1998, 2005, 2008b, 2008c; Ghany et al., 2009; Lok and McMahon, 2009; Mast et al., 2005, 2006). However, current studies of provider knowledge about chronic viral hepatitis have not identified why health-care providers fail to follow national recommended guidelines.

## Hepatitis B

Studies have shown that many primary care providers cannot differentiate between adult populations that should be screened for chronic hepatitis B because of their high prevalence of chronic infection (for example, people born in geographic regions with high HBV endemicity; see [Box 3-1](#)) and populations that should be vaccinated against HBV because of their high risk of becoming newly infected (for example, health-care workers, men who have sex with men, prison inmates, and household and sexual contacts of chronically infected individuals) (Euler et al., 2003b; Ferrante et al., 2008; Lai et al., 2007).



### BOX 3-1

Geographic Regions That Have Intermediate and High Hepatitis B Virus Endemicity. *Africa*: all countries *Asia and Middle East*: all countries

In a survey of primary care providers in San Francisco, all 91 respondents correctly answered that Chinese immigrants have a higher prevalence of chronic hepatitis B than non-Hispanic white or US-born Chinese people. However, a portion of the same group incorrectly identified HIV-infected persons (16%), men who have sex with men (18%), and injection-drug users (IDUs; 23%) as having a higher prevalence of chronic hepatitis B than Chinese immigrants (Lai et al., 2007). In the same study, 30% of the respondents were not able to identify the correct test to use for diagnosing chronic HBV infection.

A cross-sectional survey conducted among 217 members of the New Jersey Academy of Family Physicians found that a higher proportion of family physicians recommended screening for hepatitis B among men who have sex with men (93%), IDUs (95%), and HIV-infected patients (96%) than for immigrants from Southeast Asia (68%) or sub-Saharan Africa (57%)—areas that are highly endemic for HBV with over 8% seroprevalence of hepatitis B surface antigen (HBsAg) (Ferrante et al., 2008). Only 50% of survey participants recommended screening household contacts of persons who had chronic HBV infection—an established high-risk population. Finally, 21% of the New Jersey family physicians did not know what step to take next if a patient tested positive for HBsAg or would refer such a patient to a specialist for followup (Ferrante et al., 2008). However, 83% of the respondents were interested in receiving education about chronic viral hepatitis.

Chu (2009) presented data at the 2009 International Symposium on Viral Hepatitis and Liver Disease that showed that only 18–30% of Asian American primary care providers who treat Asian American

adult patients reported routinely testing them for HBV infection in their practice. That finding illustrates the incomplete knowledge even among primary care providers who themselves constitute a group at high risk for chronic HBV infection.

At the 2007 Society of General Internal Medicine annual meeting, Dulay et al. (2007) reported on the results of a multiple-choice hepatitis B knowledge survey completed by 196 attendees at a university-based continuing-medical-education conference for primary care providers, including nurse practitioners and physician assistants. Of the respondents, 55% were not able to identify HBsAg as the determinant for chronic HBV infection. Knowledge about the appropriate use of the HBsAg test was substantially higher among primary care providers who were Asian (68%) than those of other ethnicities (43%), among physicians (56%) than nonphysicians (23%), and among providers who had more years of experience or more time spent in the clinic. Some 44% of the respondents did not know that chronic HBV infection could be controlled with medication, and 25% incorrectly responded that chronic HBV infection is curable.

Given that the probability of developing chronic hepatitis B is highest when infants are exposed to HBV through their mothers at birth, both the US Preventive Services Task Force and the US Centers for Disease Control and Prevention (CDC) recommend testing all pregnant women for HBsAg during an early prenatal visit even if they have been previously vaccinated or tested (CDC, 1991; U.S. Preventive Services Task Force, 2009). Currently, only 27 states have maternal HBsAg screening laws (CDC, 2008c). State screening laws do not necessarily translate into higher testing rates, because they often do not include an enforcement mechanism or sanctions for noncompliance (Euler et al., 2003b). In a study of family physicians in New Jersey, a state with a maternal screening law, Ferrante et al. (2008) found that 22% of respondents indicated that they did not recommend testing pregnant women for HBV infection.

At the 2009 International Symposium on Viral Hepatitis and Liver Disease, Chao et al. (2009b) presented results of a study of perinatal health-care providers' knowledge about hepatitis B and the management of HBsAg-positive pregnant patients recommended by the Advisory Committee on Immunization Practices (ACIP). Questionnaires were mailed or administered to 100 practicing obstetrician/gynecologists (OB/GYNs) and 31 peripartum nurses in Santa Clara County, CA, an area with one of the largest annual numbers of HBsAg-positive pregnant women in the United States. Although most of the OB/GYNs reported that they tested pregnant women for HBsAg and properly advised HBsAg-positive women that their newborns should receive the hepatitis B vaccine and hepatitis B immuno-globulin within 12 hours of birth, overall knowledge about hepatitis B was low. Only 26% of OB/GYNs and 10% of peripartum nurses knew that the prevalence of chronic hepatitis B is higher in Asians than in other ethnic populations; only 33% of OB/GYNs and 17% of peripartum nurses knew that there is a high risk of HBV infection becoming chronic in exposed newborns; and only 22% of OB/GYNs and 37% of peripartum nurses knew about the risk of death conferred by chronic hepatitis B. Only 62% of the OB/GYNs referred their HBsAg-positive pregnant patients for chronic-hepatitis management.

## **Hepatitis C**

Health-care providers' knowledge about hepatitis C appears to be similarly insufficient, although there is far less published research on this topic (Ascione et al., 2007; Ferrante et al., 2008; Shehab et al., 1999, 2001; Strauss et al., 2006).

In the study of New Jersey family physicians described above, Ferrante et al. (2008) found that although 95% would recommend testing of IDUs for HCV infection, only 81% would recommend HCV testing for people who received blood transfusions before 1992, and

only 65% would recommend testing of incarcerated persons—all populations that are at high risk for HCV infection and that fall within national testing guidelines. Although HCV testing of pregnant women is not supported by any evidence-based recommendations or guidelines, 34% of family physicians surveyed by Ferrante et al. would nevertheless recommend it. Of the respondents, 31% did not know what to do next or would refer a patient to a specialist after a positive test for HCV antibody, and 2% incorrectly assured patients that those who tested positive were immune to HCV. Physicians in practice for more than 20 years were found to have the lowest level of knowledge about HCV risk factors, whereas those in practice for 5 years or less had the highest knowledge level.

A survey of 593 fellows of the American College of Obstetricians and Gynecologists (ACOG), half of whom considered themselves to be primary care providers, assessed screening and counseling practices for HCV infection. About half (49%) reported that they tested for HCV infection in all obstetric and gynecologic patients who self-reported ever having injected illicit drugs, and 35% tested all patients who reported having received blood transfusions before 1992 (Boaz et al., 2003). Nearly half counseled HCV-infected patients to avoid breastfeeding, and 70% counseled HCV-infected patients to use condoms with their steady sexual partners; both kinds of advice are inconsistent with recommendations of CDC (CDC, 1998) and ACOG (2000, as cited in Boaz et al., 2003). Only 64% recommended that patients who had HCV infection avoid alcohol, which has been found to increase the risk of disease progression (Ascione et al., 2007).

An earlier mailed survey of 1,412 primary care providers in the United States also assessed knowledge about risk factors for HCV infection and management of hepatitis C (Shehab et al., 2001). Nearly three-fourths (73%) of the respondents had seen fewer than five hepatitis C patients within the preceding year, and almost half (44%) had no experience with treatment for HCV infection. Almost all knew the

most common risk factors for HCV infection— injection-drug use, blood transfusion during the 1980s, and multiple sex partners. One-fourth incorrectly indicated that blood transfusion continues to be a risk factor, and 19% erroneously believed that casual household contact is a major risk factor. Some 50% of the providers reported that they routinely ask their patients about risk factors for HCV infection; 78% test for HCV infection among patients who have increased liver enzymes with or without HCV risk factors, and 70% test all patients who have risk factors regardless of liver enzyme levels. When presented with a scenario on how to treat a hypothetical patient for chronic HCV infection, 27% of the respondents did not know which therapy to use. A previous study by the same researchers had also found substantial gaps in primary care providers' knowledge about hepatitis C (Shehab et al., 1999). The gaps persisted even though 95% of the respondents in the 2001 study reported having used at least one educational tool about hepatitis C in the preceding 2 years; this suggests that primary care providers misreport their exposure to educational materials about hepatitis C or that such materials do not communicate accurate information effectively.

HCV-positive patients perceive that health-care providers are judgmental toward those with HCV infection because of its association with illicit drug use (Janke et al., 2008). Numerous studies have shown that healthcare workers have extremely negative views of IDUs and characterize them as manipulative, unpleasant, and uncooperative (McLaughlin et al., 2000; Paterson et al., 2007). Such attitudes among health-care providers can have a number of deleterious effects, including discouraging of at-risk persons from accessing testing and other services and reducing the effectiveness of HCV education and counseling messages (Zickmund et al., 2003).

Additional research has examined HCV knowledge among drug-treatment providers. Research conducted with 104 members of the staffs of two drug-free and two methadone-maintenance treatment

programs (MMTPs) in the New York metropolitan area demonstrated that knowledge about hepatitis C is inadequate (Strauss et al., 2006). Five of 20 items on an HCV knowledge assessment were not answered correctly by the majority of the participating staff, suggesting that staff may be systematically misinformed rather than merely uninformed about some important HCV issues that affect their clients. Total scores on the assessment averaged 70%, 71%, and 45% among the medically credentialed staff, noncredentialed staff in the MMTPs, and noncredentialed staff in the drug-free programs, respectively. The majority of those in the latter group had never participated in training specifically devoted to HCV; these staff may be sharing incorrect information with patients or, aware of their limitations in HCV knowledge, failing to provide patients much needed HCV information. It is critical that both medically credentialed and noncredentialed staff in the programs receive effective HCV training so that they can support their patients' HCV education and information needs appropriately.

## **Recommendation**

Many providers are not aware of the high prevalence of chronic hepatitis B and hepatitis C in some populations. Improved understanding of risk factors for acute and chronic HBV and HCV infections and collection of data on them, including country of birth and ethnicity, and the use of risk-factor screening will lead to increased identification of cases, increased provision of preventive resources, increased vaccination to protect those at risk for hepatitis B infection, and reduction in disparities in the burden of chronic viral hepatitis.

On the basis of the evidence described above, the committee concludes that insufficient provider knowledge leads to critical missed opportunities for providers to educate patients about prevention of hepatitis B and hepatitis C, to identify patients who may be at risk for

these infections, and to test for chronic HBV and HCV infection in patients and their sexual, family, and household contacts in the case of hepatitis B and in drug-use networks in the case of hepatitis C. To address that issue, the committee offers the following recommendation:

**Recommendation 3-1. The Centers for Disease Control and Prevention should work with key stakeholders (other federal agencies, state and local governments, professional organizations, health-care organizations, and educational institutions) to develop hepatitis B and hepatitis C educational programs for health-care and social-service providers.**

Educational programs and materials for health-care and social-service providers should focus on improving provider awareness and adherence to practice guidelines for hepatitis B and hepatitis C. The educational programs should be targeted to primary care providers, appropriate social-service providers (such as staff of drug-treatment facilities and immigrant-services centers), and licensed and unlicensed alternative-medicine professionals (such as acupuncturists and traditional Chinese medicine practitioners) that serve at-risk populations. At-risk populations include foreign-born people from HBV- or HCV-endemic countries, clients of sexually-transmitted-disease (STD) clinics and HIV clinics, IDUs, others at risk because of a history of percutaneous exposures, and close contacts of people who have chronic hepatitis B and chronic hepatitis C.

The educational programs should include at least the following components:

- Information about the prevalence and incidence of acute and chronic hepatitis B and hepatitis C both in the general US population and in at-risk populations, particularly foreign-born populations in the case of hepatitis B, and IDUs and incarcerated populations in the case of hepatitis C.

- Guidance on screening for risk factors associated with hepatitis B and hepatitis C.
- Information about hepatitis B and hepatitis C prevention, hepatitis B immunization, and medical monitoring of chronically infected patients, specifically,
  - Information about methods of testing and interpretation of results.
  - Information about medical management and long-term care:
    - How to select candidates for antiviral therapy.
    - Importance of liver-cancer screening.
    - When to refer patients to a specialist.
- Information about prevention of HBV and HCV transmission in hospital and nonhospital health-care settings.
- Information about discrimination and stigma associated with hepatitis B and hepatitis C and guidance on reducing them.
- Information about health disparities related to hepatitis B and hepatitis C.

CDC should examine interventions that target several venues and types of providers, such as educational institutions, health-care facilities, substance-abuse service providers, and alternative-care providers.

#### *Educational Institutions*

Schools of medicine, nursing, physician assistants, complementary and alternative medicine, and public health should develop improved curricula to ensure that their graduates are knowledgeable about chronic hepatitis B and hepatitis C. The curricula should include

information on disease prevalence, risk factors, preventive actions, appropriate diagnostics, selection of persons for testing, and appropriate followup for chronically infected patients and those susceptible to infection.

Continuing-medical-education courses and activities about viral hepatitis conducted online or at provider meetings should be regularly offered to family-practice physicians, internists, OB/GYNs, pediatricians, nurses, and physician assistants. Drug-treatment counselors' education and certification examinations should also include hepatitis B and hepatitis C. Questions about chronic hepatitis B should be included on board-certification or recertification examinations for internists, family-practice physicians, pediatricians, and OB/GYNs; and questions about chronic hepatitis C should be included in board examinations for internists and family-practice physicians. Although there has been no systematic effort to determine whether continuing-medical-education courses and certification examinations include questions about hepatitis B and hepatitis C, the shortcomings in knowledge among health-care providers suggest that current efforts are insufficient, and that new approaches are needed to improve knowledge.

Educational programs should include targeted outreach to and enrollment of providers who work in high-risk venues (for example, STD and HIV clinics) and in areas where there are many at-risk foreign-born clients, such as hospitals, clinics, and community health centers that serve large populations of Asian and Pacific Islander (API) and foreign-born patients from other highly endemic regions.

#### *Hospital and Other Health-Care Facilities*

Health-care workers and their patients are at risk for exposure to infected blood and body fluids and therefore vulnerable to infection with HBV and HCV. As discussed in [Chapter 2](#), there have been several outbreaks of hepatitis B and hepatitis C in health-care settings

in recent years (CDC, 2003b, 2003c, 2005, 2008a, 2009a; Fabrizi et al., 2008; Thompson et al., 2009). Hospitals and nonhospital health-care facilities (such as dialysis units, endoscopy clinics, and long-term-care facilities) should develop educational programs to reinforce the importance of adhering to recommended standard precautions and procedures to prevent the transmission of bloodborne infections in both inpatient and outpatient health-care settings (Thompson et al., 2009). Health-care workers should be routinely vaccinated to protect them from hepatitis B. Although the ACIP recommends that health-care workers receive the hepatitis B vaccine, and the Occupational Safety and Health Administration requires employers to offer the hepatitis B vaccine to all health-care workers who may be exposed to blood (29 CFR 1910.1030), about 25% of health-care workers remain unvaccinated (Simard et al., 2007). Successful interventions to prevent exposures known to transmit bloodborne infections have included general safety training; training specific to prevention of needle-stick injuries; modification of practice, staffing, and workload adjustments; and use of protective devices, such as needles that automatically retract (Clarke et al., 2002; Holodnick and Barkauskas, 2000; Hooper and Charney, 2005; Stringer et al., 2002; Trim, 2004).

#### *Substance-Abuse-Related Service Providers*

Staff of drug-treatment programs, needle-exchange programs, and correctional facilities should be participants in viral-hepatitis educational programs. Studies have shown that IDUs who used needle-exchange programs or who had been in drug treatment were more likely than others to report their HCV-antibody status accurately (Hagan et al., 2006). Very high proportions of IDUs have been in jail or prison (Milloy et al., 2008); therefore, periods of incarceration may present a prime opportunity for providing hepatitis C education to this high-risk population. In many communities that have needle-exchange programs, the majority of IDUs have participated in them (Hagan et al., 1999; Lorvick et al., 2006). Over the period during which a person

may inject illicit drugs, the likelihood that he or she has been in a drug-treatment program rises (Galai et al., 2003; Hagan et al., 1999). Thus, the committee believes that providing standardized education to staff of drug-treatment and needle-exchange programs and correctional facilities will increase the likelihood that at-risk and HCV-infected persons in these settings receive consistent and accurate information.

#### *Alternative-Care Providers*

Alternative-care providers would also benefit from participating in educational programs about viral hepatitis. In California, four annual educational symposia, in 2004–2007, were arranged by a collaboration of academic, professional, and community-based organizations to improve HBV-related knowledge among traditional Chinese medicine practitioners and acupuncturists—providers who serve a largely API population, a patient population that has a high prevalence of chronic hepatitis B and the associated risk of hepatocellular carcinoma (Chang et al., 2007). A precourse survey was administered; about half the participants did not know ways to prevent HBV transmission, the age group most likely to develop chronic infection, which blood test to use to diagnose chronic infection, or the risk of death from liver disease or cancer in people who had chronic hepatitis B. The postcourse survey showed a statistically significant improvement in HBV-related knowledge: about 80% of participants were able to answer questions about prevention and diagnosis of and treatment for HBV infection correctly.

[Go to:](#)

## **COMMUNITY KNOWLEDGE AND AWARENESS**

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The committee has found that knowledge and awareness about hepatitis B and hepatitis C are lacking in members of the public and, most important, in members of specific at-risk populations. Lack of

knowledge and awareness about hepatitis B and hepatitis C in the community often leads to misinformation, missing of opportunities for prevention and treatment, and stigmatization of infected populations. The consequences for members of at-risk communities are important in that missing opportunities for prevention can lead to infection of additional people with HBV and HCV. Once infected, they frequently are unaware of their infection and so run the risk of unknowingly infecting others and of not receiving appropriate medical management. Although there have been no large-scale, population-based, controlled studies of community knowledge about hepatitis B and hepatitis C, all published surveys have shown that knowledge about these diseases is sparse.

## **Hepatitis B**

As mentioned earlier, APIs are at high risk for chronic hepatitis B. A number of studies have assessed awareness and knowledge about hepatitis B in API populations, including Vietnamese, Cambodian, Korean, and Chinese Americans, who are known to have a higher prevalence of chronic HBV infection than the general US population (Hwang et al., 2008; Ma et al., 2007b, 2008; Taylor, 2006; Taylor et al., 2000, 2002, 2004, 2005a, 2005b; Thompson et al., 2002; Wu et al., 2007). For example, among Vietnamese Americans, about 64% had never heard of the hepatitis B vaccine (Ma et al., 2007b), about 70% were unaware that Asian Americans are at high risk for chronic hepatitis B (Hwang et al., 2008), most were uninformed about routes of HBV transmission (Taylor et al., 2000, 2005a, 2005b), and only one-third had a doctor's recommendation to undergo HBV testing (Taylor et al., 2004). In populations of low socioeconomic status, fewer than 10% had been tested for or vaccinated against HBV (Ma et al., 2007a, 2007b). In a group of Cambodian Americans, fewer than 50% had ever heard of or been tested for HBV, and fewer than 25%

knew that chronic infection is lifelong and incurable (Taylor et al., 2002).

Misinformation about HBV transmission creates obstacles for prevention and treatment. In qualitative interviews, most Korean Americans expressed the belief that sharing of contaminated food and eating utensils was the most common route of HBV transmission, whereas few mentioned that HBV can be sexually or parenterally transmitted, and none mentioned vertical mother-to-child transmission (Choe et al., 2005). Among Chinese Americans, fewer than half had been tested or vaccinated (Taylor et al., 2006; Thompson et al., 2002), up to 53% believed HBV could be transmitted by contaminated food (Wu et al., 2007), up to 61% were unaware that chronic hepatitis B is typically asymptomatic, and 46% believed that there is a curative treatment for chronic hepatitis B (Wu et al., 2007); about 65% of those who were chronically infected were unaware of their infection status (Lin et al., 2007).

The committee was unable to find studies that looked at hepatitis B awareness among other foreign-born immigrants from highly endemic regions such as sub-Saharan Africa, the Middle East, and Eastern European nations (see [Box 3-1](#)). Some educational resources have been translated into a few languages. For example, New York City has translated its hepatitis B educational materials into Chinese, Korean, Spanish, and French (New York Department of Health and Mental Hygiene, 2008).

The incarcerated population has a high risk of being infected with HBV. About 30% of patients who had acute hepatitis B reported a history of incarceration before HBV infection (Charuvastra et al., 2001; Goldstein et al., 2002). Knowledge about HBV transmission in this population is poor and results in missing of opportunities for vaccination and prevention. A voluntary, anonymous survey of 153 male and female inmates of the Rhode Island Department of

Corrections revealed that over half the 30% who reported having risk factors for HBV infection did not consider themselves to be at risk for hepatitis B (Vallabhaneni et al., 2004), and 44% of the inmates were not aware that HBV can be transmitted through unprotected sexual activity.

Several studies have found that knowledge about hepatitis B is low among men who have sex with men, another population at high risk for HBV infection (McCusker et al., 1990; Neighbors et al., 1999; Rhodes et al., 2000). A 1990 study found that 68% of men who have sex with men and are patients at a community health center reported that they were aware of the vaccine, and 25% of those who knew about it had been vaccinated (McCusker et al., 1990). Most of the participants who knew about the hepatitis B vaccine had learned about it from newspapers targeting the gay population (64%); a minority had learned about it from health-care providers (44%), friends (37%), and brochures from health-care facilities or gay organizations (36%). A 1999 study had similar findings: 33% of the participants were unaware of the hepatitis B vaccine, and 63% had not been tested for hepatitis B; of those who were aware of the vaccine, only 22% had received the full vaccine series (Neighbors et al., 1999). A similarly low level of hepatitis B knowledge was found among patrons of gay bars in Birmingham, Alabama, where 32% reported having no information about hepatitis, 96% reported engaging in high-risk sexual behavior, and those who had not been vaccinated against HBV (58% of respondents) had much poorer knowledge about hepatitis B prevention than those who had been vaccinated (Rhodes et al., 2000).

### *Stigma*

For many people born outside the United States, a cultural stigma is attached to a diagnosis of chronic hepatitis B. For example, in China, there is pervasive discrimination against people who are chronically infected with hepatitis B, who are frequently expelled from schools,

fired from jobs, and shunned by other community members despite the recent passage of national antidiscrimination laws (China Digital Times, 2009). In a 2007 survey covering 10 major cities in China, hepatitis B was cited as one of the top three reasons for job discrimination (China Daily, 2007). Given the deeply ingrained stigma of hepatitis B in some endemic countries, it is not surprising that many immigrants remain reluctant to undergo testing and seek medical attention for a positive test result even after moving to the United States. Because that cultural aversion to hepatitis B testing and management is due largely to a lack of knowledge about routes of HBV transmission and means of prevention, any effort to deliver viral-hepatitis services to the foreign-born population must include an educational component to dispel myths (for example, that HBV can be transmitted through food, water, and casual contact) and to establish facts, particularly ones that encourage testing, vaccination, and followup.

#### *Education Programs*

Several educational programs targeting API communities have been successful in disseminating hepatitis B awareness and promoting prevention. Successful programs often build on community partnerships and combine educational resources with increased access to testing, prevention, and care for participants (CDC, 2006; Chao et al., 2009a; Juon et al., 2008; Lin et al., 2007). The Hepatitis B Initiative is a community-based hepatitis B outreach program that partnered with nine Korean American and Chinese American churches in the Baltimore and Washington, DC, metropolitan area to provide culturally and linguistically tailored, faith-based HBV education, testing, and vaccination (Juon et al., 2008). The initiative has generated community support and awareness through word of mouth, articles in local Asian ethnic media, educational sessions and luncheons for API community leaders, and a national conference for API pastors. In 2003–2006, the program tested 1,775 participants for

HBV and found that 2% were chronically infected and 61% were not vaccinated. Among 924 unvaccinated participants, nearly all received the first dose of hepatitis B vaccine, 89% received the second, and 79% completed the three-dose series. The Asian American Hepatitis B Program, a collaboration of community groups and academic and community health centers in New York City, provides hepatitis B screening, vaccination, and treatment. The program found that about 15% of newly tested persons had chronic HBV infection, all of whom were born outside the United States and half of whom had been in the country for more than 10 years (CDC, 2006).

The Jade Ribbon Campaign is a program focused on reducing the nationwide health disparity in hepatitis B. This program sponsors community HBV screening and education clinics and partners with over 400 community-based organizations and federal and state agencies to provide culturally and linguistically tailored information and multimedia public-service announcements about hepatitis B burden, risk factors, transmission, prevention, detection, treatment, and followup to the API community and health professionals (Asian Liver Center, 2009; CDC, 2009b). The program's clinics have found that about 45% of participants were not vaccinated against HBV, 9–13% of participants were chronically infected, and up to two-thirds of those who were chronically infected were unaware of their infection status. Of those who said that they had been vaccinated against HBV, 20% were unprotected and 5% chronically infected (Chao et al., 2009a; Lin et al., 2007). This model has been adapted by a number of cities around the country (Chang et al., 2009; Fernandez, 2008; Hsu et al., 2007; Larkin, 2007; McBride, 2008; *San Francisco HepB Free*, 2009; Tsai et al., 2008; Zola et al., 2009).

As discussed in [Chapter 4](#), the ACIP recommends that all newborns, previously unvaccinated children and adolescents, and previously unvaccinated adults at high risk for infection be vaccinated against hepatitis B (Mast et al., 2005, 2006). The latter group includes adults

at risk for infection by sexual exposure, IDUs, household contacts of chronically infected persons, developmentally disabled persons in long-term-care facilities, persons at risk for occupational exposure to HBV, hemodialysis patients, persons with chronic liver disease, and travelers to HBV-endemic regions, including Asia, Africa, much of Eastern Europe, the Amazon Basin, the Caribbean, and the Pacific Islands (see [Box 4-1](#)). There is a shortage of hepatitis B education, vaccine promotion, and awareness programs for nearly all those at-risk populations, and programs need to be developed to target HIV-positive people, IDUs, and people from highly HBV-endemic regions (Rein et al., 2009). Although a handful of studies have evaluated cross-sectional hepatitis B knowledge levels in some of the populations, the committee knows of no programs that have demonstrated a quantitative improvement in knowledge about hepatitis B after the implementation of a targeted, evidence-based educational program.

A potential model to target at-risk populations is to develop pilot sites similar to CDC's Racial and Ethnic Approaches to Community Health, REACH 2010. The REACH 2010 program provided grants to communities to address services for specified illnesses in particular racial and ethnic populations. The program targeted blacks, American Indians, Alaska Natives, Asian Americans, Hispanics, and Pacific Islanders—all populations that have a high prevalence or incidence of hepatitis B and some hepatitis C also. Viral hepatitis was not part of the program (Collins, 2006; Giles et al., 2004).

## **Hepatitis C**

Although fewer studies have been conducted to assess awareness of hepatitis C in specific populations, the literature suggests that knowledge about this disease is poor. In a cohort of 3,768 women who had or were at risk for HIV infection, about one-fourth of those with chronic HCV infection were not aware of their infection status (Cohen

et al., 2007). Younger and black women were less likely to be aware of their HCV infection status, whereas women who had past alcohol treatment, a history of injection-drug use, or increased alanine aminotransferase (a liver enzyme) were more likely to be aware that they were positive for HCV infection. Of those aware of their chronic HCV infection, the health-care providers of 47% had recommended that they have a liver biopsy, and 56% of these had undergone a biopsy; 39% of those who were aware of their HCV infection status had been offered treatment, and 57% of these had received treatment. Similarly, in the Collaborative Injection Drug User Study Drug User Intervention Trial (DUIT), which enrolled 3,004 young IDUs in five US cities, 72% of anti-HCV-positive and 46% of anti-HCV-negative IDUs were not aware of their HCV serologic status (Hagan et al., 2006). History of drug treatment or needle exchange was associated with increased awareness of HCV serologic status, so these programs may be key locations for provision of HCV screening in this population. In a questionnaire survey given to 150 patients who were seeking substance-abuse treatment at a Department of Veterans Affairs medical center, 90% of patients who were HCV-infected were not aware of their status, and 41% of the IDUs did not know or were unsure of how HCV is transmitted or about the complications of hepatitis C (Dhopesh et al., 2000)..

Stein et al. (2001) surveyed 306 former IDUs about their knowledge of HCV transmission, infection status, and risk of liver disease. They found that nearly all the participants knew that HCV is transmitted by sharing contaminated needles. Among people who had not been tested or did not know their test results, some 82% were HCV seropositive. One-third of the people reporting that they were seronegative were actually seropositive—a demonstration that, as in other surveys, self-reported infection status is unreliable. Of respondents, 81% estimated their risk of developing liver disease, specifically cirrhosis, in the next 10 years at 50% or greater.

The risk associated with the shared use of injection paraphernalia other than syringes is poorly understood (Rhodes et al., 2004). Among IDUs who have chronic HCV infection and are aware of their infection, the pattern is similar: the majority understand that they can transmit their infection by passing on their used syringes to others, but there is less certainty regarding the shared use of cookers, cottons, and rinse water (Rhodes and Treloar, 2008; Wright et al., 2005).

There is substantial confusion among IDUs regarding the interpretation of HCV screening tests. In an Australian study, 42% of IDUs believed that being antibody-positive meant that they were immune to HCV infection (O'Brien et al., 2008). Misunderstanding of the meaning of antibody-test results was also observed in a qualitative study of IDUs in London, England (Rhodes et al., 2004).

### *Stigma*

A number of studies have examined the psychologic consequences of HCV infection and concluded that hepatitis C is a highly stigmatized disease, owing in large part to its association with injection-drug use (Conrad et al., 2006; Crofts et al., 1997; Dunne and Quayle, 2001; Grundy and Beeching, 2004). There is also a public perception that HCV is highly contagious and that it is life-threatening in most cases (Conrad et al., 2006); this has led to discrimination on the part of people who inappropriately perceive themselves to be at risk from casual contact with an HCV-positive person. In a study of patients in a liver clinic in Iowa, 57% of HCV-positive people reported having experienced stigma associated with their infection (Zickmund et al., 2003). Many patients who have HCV infection wish to disclose their HCV status to family, intimate partners, and others in an effort to protect them from infection and to obtain psychosocial support. Even in work settings, people have been eager to disclose their HCV status so that in the event of injury co-workers would take extra care in avoiding exposure to contaminated blood. However, many people

report that informing others of their HCV status has led to inappropriate reactions, such as “[I’m] not allowed to use the cups because they don’t really know ... how to pass it on” (Conrad et al., 2006). In another study, a patient reported that “they didn’t want me drinking out of the water fountain” (Zickmund et al., 2003).

#### *Education Programs*

Although only a handful of studies have examined the influence of education on HCV-related risk behavior in IDUs, the results are consistent in showing that enhanced education and counseling are associated with safer injection practices (Garfein et al., 2007; Latka et al., 2008; Tucker et al., 2004). In the DUIT study by Garfein et al. (2007), young HIV-seronegative and HCV-seronegative IDUs were enrolled in a randomized trial of an intervention that sought to train them to be peer educators. The goals of the peer-education intervention (PEI) were to develop mastery over knowledge and skills necessary for prevention of HIV and HCV infection so that they could pass the knowledge on to their peers. Behavior change was measured in the PEI subjects and in subjects randomized to an equal-attention control group. Reductions in injection risk behavior were observed in both study arms, but the PEI group reported significantly greater reductions.

A parallel study, the Study to Reduce Intravenous Exposures (STRIVE), enrolled young HCV-seropositive IDUs (most of whom were chronically infected) and randomized them into a PEI or control condition. Significantly greater reductions in injection practices that could transmit HCV to other IDUs were observed in the PEI group (Latka et al., 2008). Thus, enhanced education and skill-building can lead to safer injection practices and may contribute to avoidance of infection in susceptible IDUs and reduction in transmission of infection to other IDUs. That strategy parallels the Prevention for Positives initiatives for HIV (CDC, 2003a).

Patients in drug-treatment programs have considerable needs for education about hepatitis C. In spite of the disproportionate prevalence of HCV infection in drug users, research conducted with 280 patients who never injected drugs (non-injection-drug users, NIDUs) and past or current IDUs in 14 US drug-treatment programs showed that many remain uninformed or misinformed about the disease (Strauss et al., 2007). The 280 participating patients scored, on the average, 56% on a 20-item true–false HCV knowledge assessment, demonstrating inadequate knowledge about hepatitis C. IDUs scored significantly higher, on the average, than did NIDUs (60% vs 51%), but their scores also suggest many gaps in their knowledge about hepatitis C. Fewer than half of all the patients correctly endorsed facts concerning HCV transmission, the duration of hepatitis C treatment, the potential effectiveness of hepatitis C medication in active drug users, the course of HCV infection, and the possibility of spontaneous clearance of the infection.

To address the knowledge gaps, all the programs offered at least one form of hepatitis C education: all offered one-on-one sessions with staff, 12 of the programs offered hepatitis C education in a group format, and 11 offered education through pamphlets and books. However, only 60% of all the participating patients used any of their programs' hepatitis C education services. Those who did avail themselves of the hepatitis C education opportunities generally assessed them favorably. Of all the patients, many were unaware that hepatitis C education was offered in their programs through individual sessions with staff, group meetings, and books and pamphlets (42%, 49%, and 46% of the patients, respectively), and 22% were unaware that any hepatitis C education opportunities existed (Strauss et al., 2007). Thus, efforts need to focus especially on ensuring that all drug-treatment program patients are made aware of and encouraged to use hepatitis C education services in their programs. Such awareness and encouragement, however, will be useful only if staff of drug-treatment

programs have up-to-date knowledge about the virus and treatment options so that they can share hepatitis C information with their patients accurately.

## **Recommendation**

On the basis of the above findings, the committee offers the following recommendation to increase educational and awareness opportunities about hepatitis B and hepatitis C.

**Recommendation 3-2. The Centers for Disease Control and Prevention should work with key stakeholders to develop, coordinate, and evaluate innovative and effective outreach and education programs to target at-risk populations and to increase awareness in the general population about hepatitis B and hepatitis C.**

CDC should work with other federal agencies and state and local governments to form partnerships with health-care providers, private organizations (including employers and nonprofit organizations), schools, and appropriate community organizations to develop awareness programs and campaigns to educate the general public and at-risk populations about hepatitis B and hepatitis C. The programs should include shared resources that are linguistically and culturally appropriate and support integration of education about viral hepatitis and liver health into other health programs that serve at-risk populations. Successful programs like those discussed above should serve as models for interventions and existing materials, such as the American Congress of Obstetricians and Gynecologists patient education materials on viral hepatitis (American College of Obstetricians and Gynecologists, 2007, 2008, 2009), should be used as a basis for producing linguistically and culturally relevant materials.

Innovative approaches should be developed to address populations that have access to few educational programs including foreign-born

people from the highly HBV endemic regions, men who have sex with men, IDUs, and household and sexual contacts of people who are chronically infected with HBV and HCV.

Programs should be evaluated to ensure that they are effectively targeting the general public and at-risk people and populations. The general public should be targeted because HBV and HCV infections occur in people not easily identifiable as belonging to an at-risk population or people who fail to report potential risk factors (Daniels et al., 2009). The results of evaluation of the programs will inform future initiatives. The programs should incorporate interventions that meet the following goals:

- Promote better understanding of HBV and HCV infections, transmission, prevention, and treatment in at-risk and general populations.
- Promote increased hepatitis B vaccination rates among children and at-risk adults.
- Educate pregnant women and women of childbearing age about hepatitis B prevention.
- Reduce perinatal HBV infections and improvement of at-birth immunization rates.
- Increase testing rates in at-risk populations.
- Reduce stigmatization of chronically infected people.
- Promote safe injections among IDUs and safe drug use among NIDUs.
- Provide culturally and linguistically appropriate educational information for all persons who have tested positive for chronic HBV or HCV infections and those who are receiving treatment.

- Encourage notification of household and sexual contacts of infected people to be tested for HBV and HCV and encourage hepatitis B vaccination of close contacts.

#### *General Public Awareness and Education*

Lack of knowledge about HBV and HCV transmission contributes to the stigma of infection and is a barrier to testing, prevention, and care. Public HIV-awareness campaigns led to reduced stigma and discrimination toward patients with HIV infection (Brown et al., 2003). As in the case of HIV/AIDS, increasing general public knowledge about hepatitis B and hepatitis C can be expected to reduce discrimination toward infected people, reduce transmission, and increase early diagnosis and treatment that ultimately save lives.

Broader community education should include print and multimedia educational materials about viral hepatitis for the public, large employers, and health insurers. It should work to mobilize and facilitate a grassroots movement among community stakeholders, including health-care providers, employers, mainstream and ethnic media, community-based organizations, and students. Large employers, such as multinational corporations, are potentially important partners in hepatitis prevention and control in that they provide health benefits to about two-thirds of Americans who have health insurance and are commonly employers of foreign-born people from HBV-endemic countries both in the United States and overseas.

The lack of knowledge and awareness about hepatitis B and hepatitis C in the general population suggests that integration of viral-hepatitis and liver-health education into existing health-education curricula in schools will help to eliminate the stigma of those chronically infected and improve prevention of viral hepatitis. There is evidence that adolescents are unaware of hepatitis B and hepatitis C risks and how to prevent becoming infected (Moore-Caldwell et al., 1997; Slonim et al., 2005). Many schools already require health education on HIV,

which has transmission routes similar to those of hepatitis B and hepatitis C (CDC, 2008b). Several school-based programs have been demonstrated to reduce HIV risk in students and could serve as models for viral hepatitis education initiatives (Gaydos et al., 2008; Kennedy et al., 2000).

#### *Community-Based Outreach to Foreign-Born*

Immigrants from HBV-endemic countries make up the largest population of people who have chronic hepatitis B in the United States, and it is essential that they receive culturally and linguistically tailored information about transmission and risks of HBV infection and that it promote testing, vaccination, and medical management.

Rein et al. (2009) estimated that there are 55 active community-based hepatitis B outreach programs in the country that were targeting mostly APIs, of which they contacted 31. Although those programs have done much to inform APIs about hepatitis B, there is a need for additional programs that target APIs, given the burden of hepatitis B within that population.

There is also a need for education programs that target foreign-born people from other HBV-endemic regions. The models used by programs designed for APIs could be modified to address the needs of other populations. Community-based education and screening programs—including outreach at cultural festivals, health fairs, and places of worship—have been shown to be effective in improving APIs' knowledge about hepatitis B (Chao et al., 2009a; Hsu et al., 2007; Juon et al., 2008; Lin et al., 2007) and could potentially be effective with other ethnic populations. Each year, around 20,000 people are tested through those programs, and HBsAg is detected in about 8% of the tested population (Rein et al., 2009). Some 30% of the programs were supported by local government funding, 27% by state funding, and 10% by federal funding. Other sources include pharmaceutical and insurance companies, research and service grants,

community hospitals, and other private funding sources (Rein et al., 2009).

Rein et al. (2009) also found that there were few or no hepatitis B outreach programs in most regions of the United States (the Southeast, the Midwest, and the Southwest outside of California and the Houston area). Education and prevention programs should be expanded to provide services in underserved regions of the United States given that the highest rates of acute hepatitis B incidence are in the south (Daniels et al., 2009).

#### *Correctional Facilities*

About 2 million people are incarcerated in the US correctional system. The major risk factors for viral hepatitis in people in correctional facilities are injection-drug use, tattooing, and sexual activity (see Chapters [4](#) and [5](#) for additional information about incarcerated populations). Because people in the correctional system are more likely to be infected or to become infected with HBV and HCV than the US general population, it is important to provide educational opportunities about hepatitis B and hepatitis C in correctional facilities. Increased knowledge and awareness about the diseases will lead to a greater understanding among inmates about how to prevent them, the advantages of hepatitis B vaccination, why they should be tested for chronic hepatitis B and hepatitis C, and what to do about a positive test result for either infection. Niveau (2006) reviewed risk factors for acquiring infectious diseases in correctional settings and found that effective preventive measures included information dissemination and education. Inmate peer-based health education has been effective in primary prevention of HIV (Hammett, 2006). The addition of hepatitis education to existing peer-based inmate educational programs is feasible and will probably incur minimal additional cost. Boutwell et al. (2005) called education of prisoners about hepatitis C as part of a larger program of prevention, testing, and

treatment a “cornerstone of the public health response to the hepatitis C epidemic in the United States” and recommended research into program implementation.

#### *Drug-Treatment Facilities and Needle-Exchange Programs*

Drug-treatment and needle-exchange programs reach a substantial proportion of active injectors who have HCV infection or are at risk of acquiring it. Because the programs have regular, long-term contact with many IDUs, there are multiple opportunities to disseminate information about hepatitis B and hepatitis C, including the benefits of hepatitis B vaccination, how to avoid reinfection with HCV, and the importance of followup care for those chronically infected.

Although education programs developed for needle exchange, drug treatment, and corrections facilities will reach substantial proportions of those at risk, important segments of IDU populations will not be reached by them. Women and young people who inject drugs are less likely than others to attend needle-exchange and drug-treatment programs (Bluthenthal et al., 2000; Miller et al., 2001). Novel programs are needed that will access the hidden injectors, and outreach and peer-education programs are potentially effective ways to achieve this goal.

#### *Perinatal Facilities That Care for Pregnant Women*

The risk of chronic infection after exposure to HBV is highest in early life, and most people who have chronic hepatitis B were infected at birth or during early childhood. Each year in the United States, about 24,000 HBsAg-positive women give birth and about 1,000 newborns develop chronic HBV infection (Ward, 2008). The latter occurs largely because of failure to adhere to ACIP recommendations and timely administration of the birth dose of the hepatitis B vaccine and hepatitis B immunoglobulin.

Although it is recommended that household contacts be tested because of high risk of infection, fewer than 50% are tested, and fewer than 50% of those tested and found to be HBV-negative or of unknown status are vaccinated (Euler et al., 2003a). Therefore, perinatal-care facilities and their staffs (including OB/GYNs and their clinic staffs) provide an excellent opportunity to educate pregnant women about the importance of HBsAg testing, interpretation of the results, and the importance of newborn hepatitis B vaccination. The women should be given culturally and linguistically appropriate educational information about the importance of administration of the birth dose of the hepatitis B vaccine and hepatitis B immunoglobulin within 12 hours of birth if needed, completion of the hepatitis B vaccine series by the age of 6 months, and postvaccination testing. There is a need to develop a novel program to educate pregnant women in perinatal-care facilities about hepatitis B to prevent perinatal transmission, to refer women who are chronically infected for medical care, and to refer family and household contacts for testing, vaccination, and care if needed.