

HEPATITIS B IN AFRICAN IMMIGRANT COMMUNITIES: ASSESSING NEEDS AND STRATEGIES FOR IMPROVING AWARENESS, SCREENING AND LINKAGE TO CARE

A CDC Funded Project

Sierra Pellechio, BS, CHES

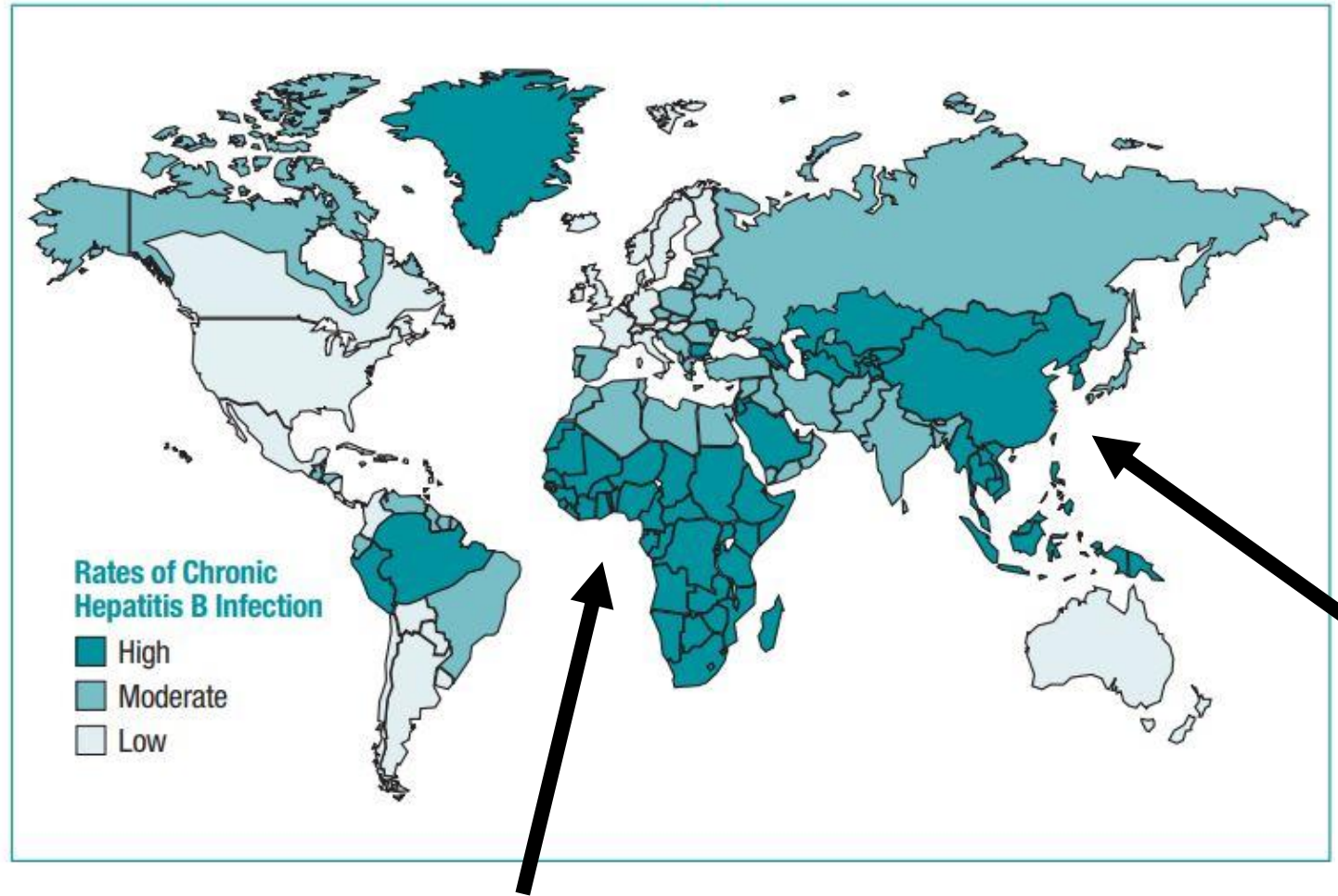
Health Outreach Coordinator



WHY IS THIS PROJECT NEEDED?

- Like Asia and the Pacific Islands, hepatitis B is also highly endemic to Africa
- >8% general population affected

Worldwide Rates of Chronic Hepatitis B



HEPATITIS B IN AI COMMUNITIES

- A 2004 medical record analysis found that African immigrant communities comprise approximately 29% of all chronic hepatitis B patients living in the U.S.*
- **Few studies have been done** to specifically understand barriers that **African immigrant communities face** regarding screenings for hepatitis B
- Need for data and culturally competent interventions
- African immigrants, like AAPI communities, are disproportionately affected by hepatitis B and are **facing an unmet need** for increased testing and healthcare services



*Kim, Benson & Therneau *et al.*, 2004

GOALS

Phase I

01

Gather data on individual, interpersonal, community, and society-level barriers associated with HBV screening, vaccination and linkage to care among African immigrant communities in the U.S.

Phase II

02

Use data to create educational materials to address and overcome these barriers and increase HBV knowledge, screening, vaccination and linkage to care in this community.

PHASE I METHODOLOGY

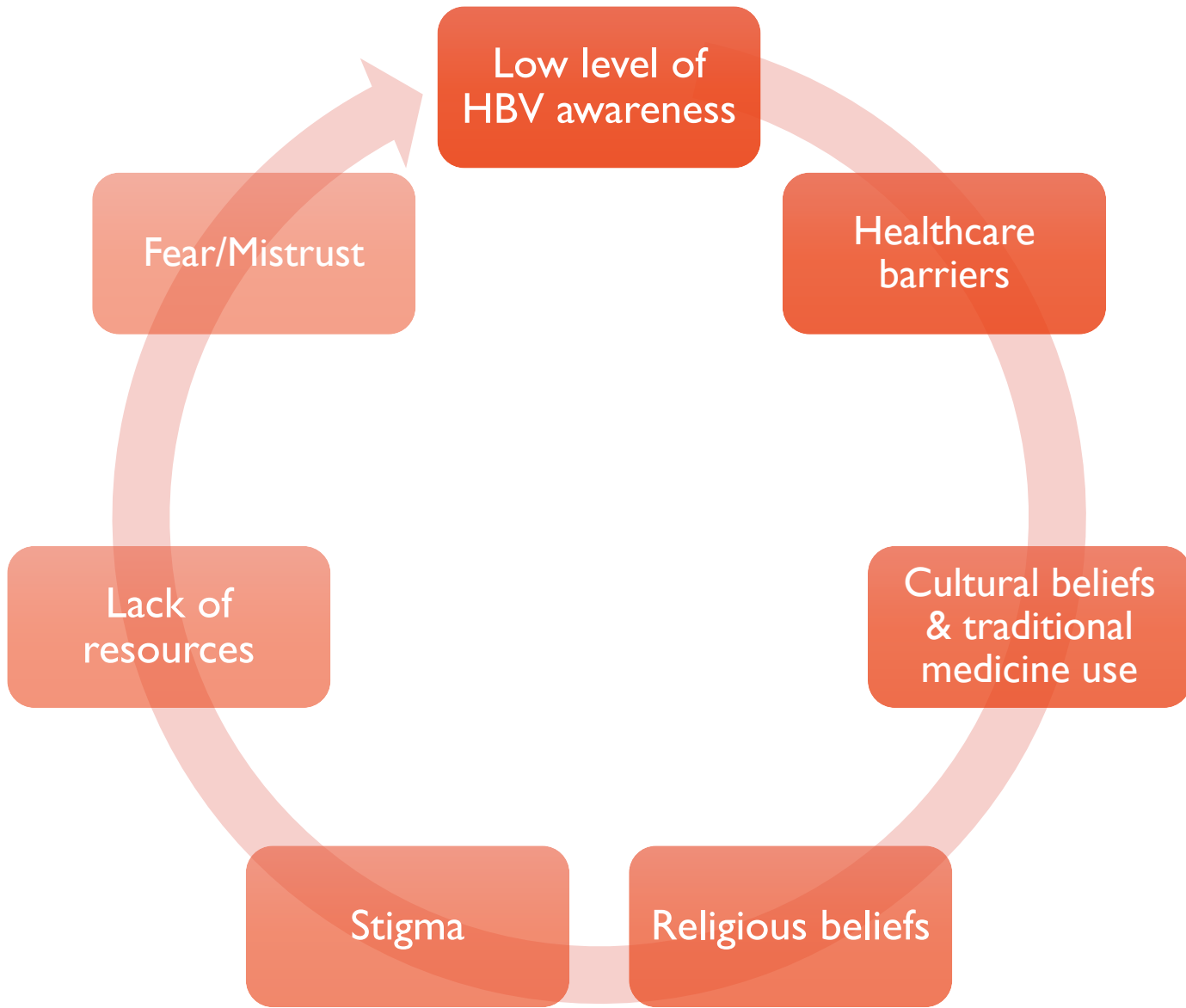
Constructed 16 member expert advisory board

1 hour individual interviews

Transcribed and coded

Focus group calls

Analyzed data



MAJOR FINDINGS OVERVIEW

HEALTHCARE BARRIERS



- Lack of knowledge about U.S. healthcare system
 - African health system is very different
 - Referrals and specialists
- Preventative mindset uncommon
 - Only going to doctor when sick
- Competing priorities (time/money/transportation)
- Language barriers
- Racism
- Mistrust
 - Doctors may have dishonorable intentions
 - Confidentiality concerns – community knowledge, employer, deportation risks
 - Will I be part of an experiment?



CULTURAL BELIEFS/TRADITIONAL MEDICINE USE

- Traditional healers
 - Consulting for diagnosis and sending herbs
 - Herbal treatments may be first resource, then doctor if they don't work
 - Treat symptoms over cause
- Consult family/friends before providers
 - Medicine sharing
- Discomfort with discussing personal issues with a doctor
 - Cultural practice, past experiences
- Prevention is not common
- Reliance on elders, hope and prayer
- Myths around disease

RELIGIOUS BELIEFS



- Large cultural role
- Role of God in illness
 - Can inflict/take away illness based on lifestyle choices
 - “Out of your hands”
- Multi-prong approach
 - Prayer, traditional medicine first, then doctor
 - Increase likelihood of feeling better
- Religious leaders can be key in promoting hepatitis B awareness and testing

STIGMA (DEBATED)

Stigma Exists

- Transmission route
 - Implied promiscuity, drug user
- HIV association
- Diagnosis
- Fears of community judgement or isolation
- Electing to be screened may imply you did something wrong

No Stigma Exists

- Too little awareness to have stigma

FEAR/MISTRUST



- Reservations around interacting with the health system
 - Will I be deported?
 - Will I lose my children?
 - Will I be tested on?
 - Will I be tested for other diseases without my knowledge?
- Word of mouth about bad experiences spreads myths in the community
- Fear of social stigma, if test positive
- Fear of cost
 - Unknown costs associated with appointments, very different from African health systems
- Fear labels
 - Liken it to a “curse”

LACK OF RESOURCES

- Money
- Health insurance
- Knowledge of where to go
- Time
- Transportation



LOW LEVEL OF HEPATITIS B AWARENESS

- People were more familiar with diseases like diabetes and hypertension
 - Less stigmatized
 - Easier to access
- Hepatitis B is thought of as a “whole body” illness, like HIV and cancer
 - More stigma, taboo to discuss
 - Unknown risk
 - Transmission myths
 - Asymptomatic disease; no cues to testing

WHAT ARE THE NEEDS?

How can we address this issue?

WHERE DO PEOPLE LOOK FOR HEALTH INFORMATION?

- Friends and family
 - Can promote myths and misunderstandings
- ★ • Religious and community leaders
 - False claims about religious leader's powers
 - Opportunity for integrating positive health messages
- Internet
 - Bridge language barrier gaps
 - Misinformation
- Back home (Africa)
 - Friends, family, herbal healers
 - Can put off seeing U.S. doctor for belief their health is being taken care of already

NEEDS FOR COMMUNITY PROVIDERS



- Need targeted programming
 - Lack of resources/strategies – a framework
- Need funding
 - Advocacy
 - Funding for screening and education
 - Need to make hepatitis B a known issue
- Cultural competency training
 - For providers
- Need data
 - State, local data
 - Data is limited and not disaggregated
 - Can guide funding and awareness

WHAT KINDS OF EDUCATIONAL MATERIALS WOULD BE MOST USEFUL?

- Small information cards
 - Portable, visual, can take with them to their doctor
- Infographics and posters
 - Picture heavy, can get around language barriers
- Messaging strategies
 - Must be specific to African immigrants (not just Black populations in general)
 - Visual and audio are best – limit text
 - Be aware of diversity of languages – some are not even written
- Brochures for doctor offices
- Translated materials



INTEGRATING MESSAGING INTO THE COMMUNITY

- Religious and community workers
 - Trusted, integrated in community
- Health fairs and community events at churches and mosques
- Adult education centers
 - Places AIs spend time
 - Strong relationships with educators
- Community and religious leaders
- Radio/PSAs



SUMMARY OF FINDINGS

The African Immigrant community faces unique barriers and challenges to accessing healthcare and getting screened for hepatitis B

Barriers exist on individual, community and societal levels

Wide-spread low-level of awareness of hepatitis B

Stigma plays a role in HBV knowledge and willingness to test

Tight-knit community with deep rooted cultural and religious beliefs

Traditional medicine use and connection to culture is important to be considerate of when educating

Vital to incorporate religious and community leaders in interventions

Radio is a good way to reach the community

Further research is needed to propel funding and future interventions

PHASE II (CURRENT)

- Develop educational materials to promote hepatitis B awareness, testing and linkage to care
- Materials will be pilot tested in the community
- PowerPoint with audio for self-learning for community health workers to become educated on hepatitis B
 - Teaches skill building and problem solving for overcoming myths when educating
- Flipchart for direct community education
 - Script for educators on one side
 - Picture based visual for community

POWERPOINT DRAFT



A Community Health Worker's Guide to
Hepatitis B

*Understanding Hepatitis B and Promoting
Testing in African Immigrant Communities*

DRAFT FOR EXPERT REVIEW



DRAFT

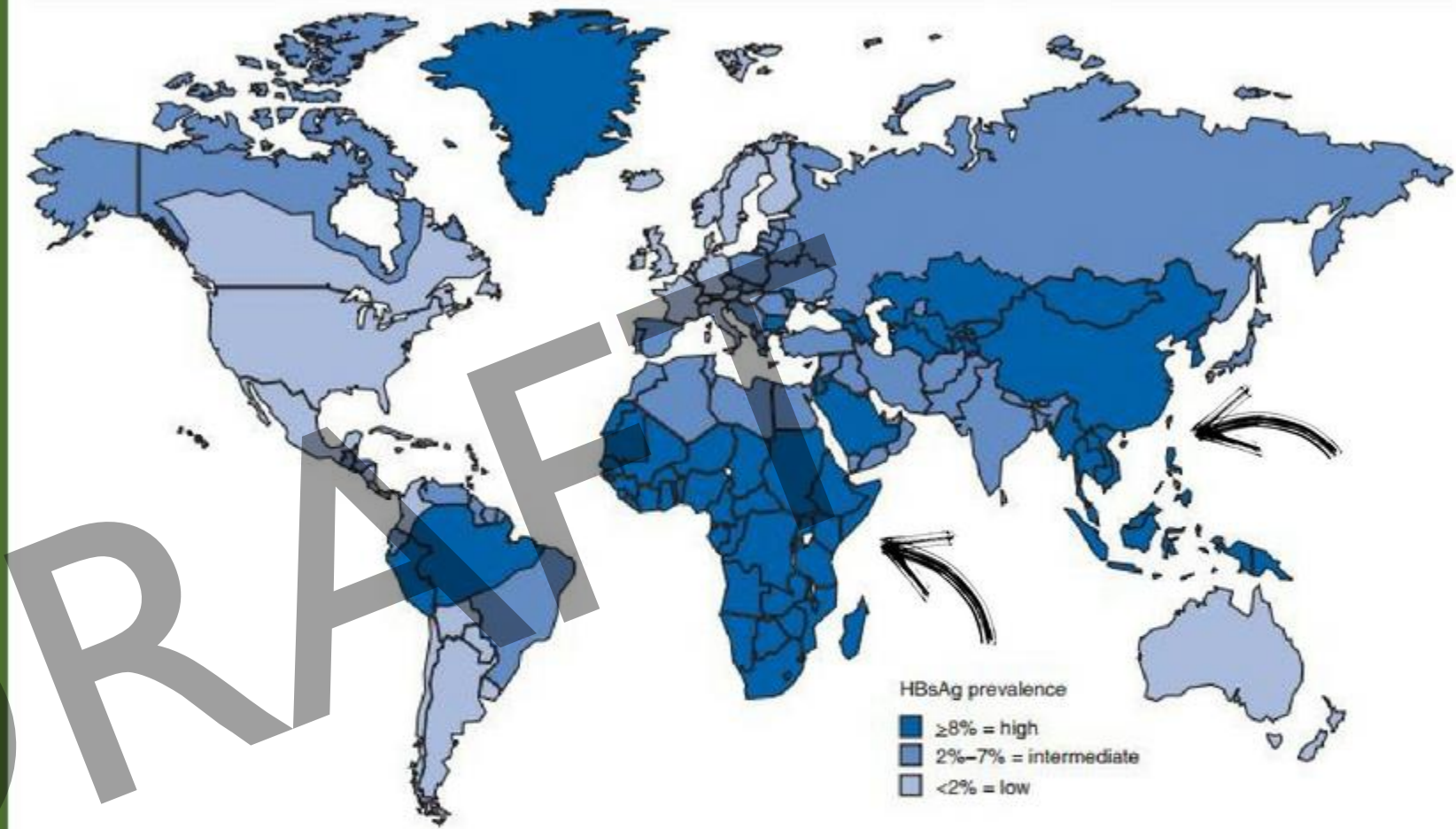
Why is Hepatitis B Relevant to Me?

Because...

Hepatitis B is one of the world's most common infections.

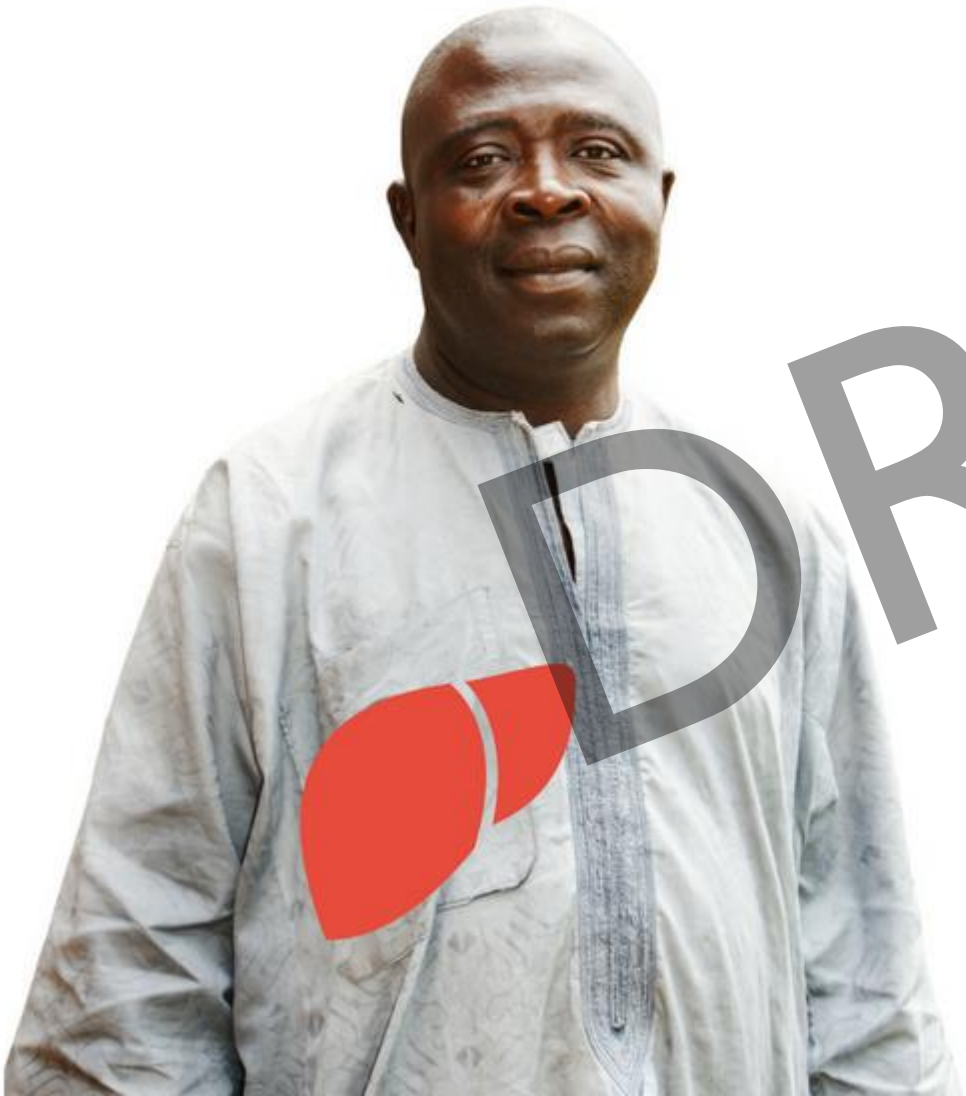
Hepatitis B is more common among people who were born in Africa and other parts of the world.

In African communities in the U.S., between 5% and 18% of people have hepatitis B.



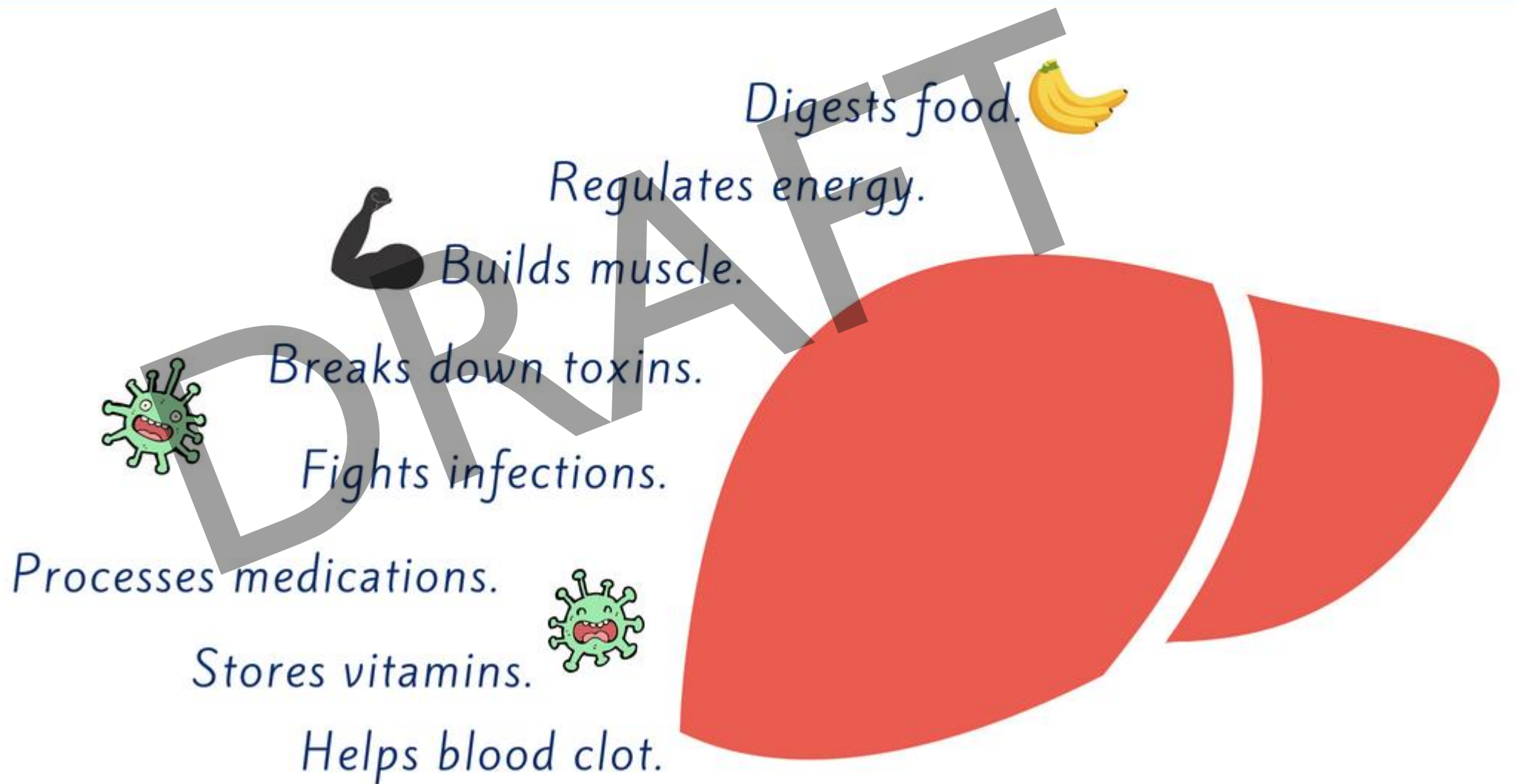


What is Hepatitis B?

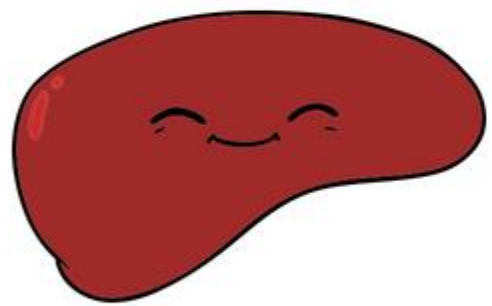


Hepatitis B is a viral infection that can cause serious liver disease and even liver cancer.

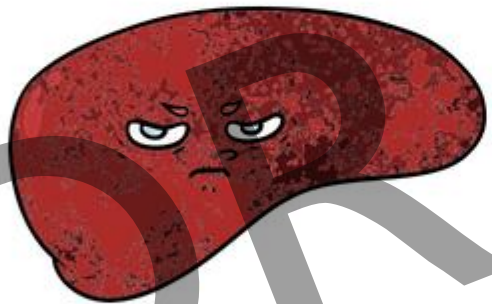
Keeping your liver healthy is important because it has many jobs in your body.



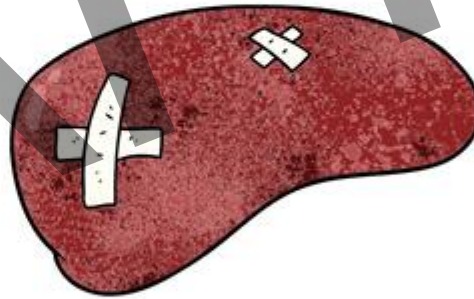
Hepatitis B can lead to liver damage and liver cancer over time.



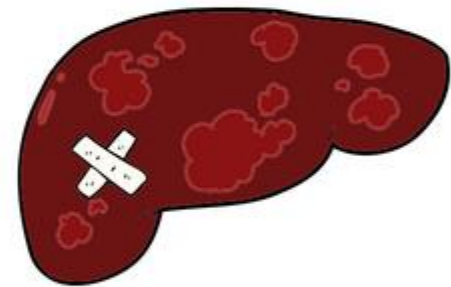
Healthy liver



Inflamed liver
"Fibrosis"



Scarred liver
"Cirrhosis"



Liver cancer




You cannot live without
your liver!

DRAFT



The good news:
hepatitis B is a disease that
people can live with for a
long time. By taking care of
your health, people can have
a long and productive life.



You can help keep
your community
healthy by learning
about hepatitis B and
promoting awareness
and testing.

Hepatitis B is one of the world's most common infections.

Worldwide

Almost 292 million people
are living with hepatitis B

In the United States 

2 million people have hepatitis B infections

About 30% of people living with hepatitis B in the U.S. are estimated to be African-born.

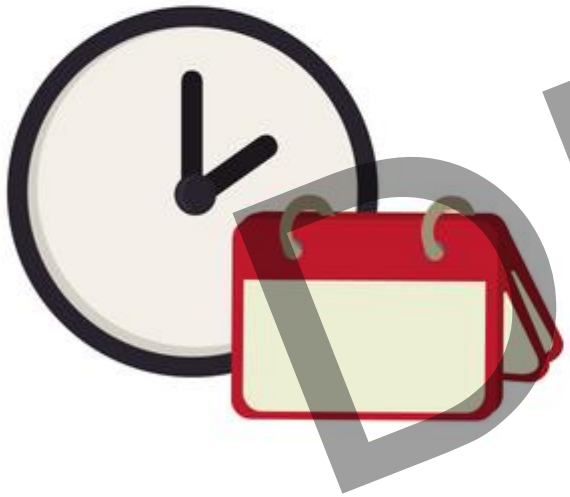


Most people with hepatitis B do not know that they are infected!



There are 2 kinds of hepatitis B infections.

Acute



Short-term infection

Chronic



Lifelong infection

The age when someone becomes infected determines what type of infection they will have.

Acute

An infection that lasts less than 6 months




- Less common
- Usually occurs by getting infected as an adult
- Usually clears from the body within 6 months

Chronic

An infection that lasts for life



- More common
- Usually occurs by getting infected during childhood
- Usually lasts for life



*Most people become infected at birth or early childhood.
Most of these develop into chronic, lifelong infections.*



The good news is that there is a safe and effective vaccine that can prevent babies and children from becoming infected!

Someone can also get hepatitis B through:

Direct blood to blood contact with someone who is infected



Unsterile medical equipment

Sexual transmission
There is a risk during any type of sexual contact



Household contact
Sharing hygiene equipment
(razors, toothbrushes, earrings etc.)



Tattoos, piercings, barbers, scarification or circumcision practices

Sharing needles



Hepatitis B is **NOT** spread by:

Food

Or sharing meals with someone who is infected



Sneezing or coughing on someone



Touching



Water

Drinking from a cup of someone who is infected or sharing a toilet



Breastfeeding



Hugging



Kissing





- ▶ Although hepatitis B is common in Africa, most people do not know they are infected.
- ▶ People can be afraid to get tested. They may incorrectly believe they would have symptoms, or hold on to myths or do not have access to health care.
- ▶ Being unaware of one's infection puts a person's life at risk. Without regular health care and treatment if necessary, a person living with hepatitis B faces a risk of dying early.



The test for hepatitis B is a simple blood test.

It can be done at the family doctor, liver specialist or at a community health fair.



It is quick and easy and the results will be available in a few days.

Following-up on the test is important.

A few days after the test, they should receive a call or letter with the test results.



If the results show that they are infected, they will need a follow-up appointment, ideally with a liver specialist.

People who test positive for hepatitis B can stay healthy by:

1

Leading a healthy lifestyle.

- A nutritious diet
- Regular exercise
- Avoiding alcohol and cigarettes



2

Seeing their doctor 1-2 times a year.

- A liver specialist is best
- They will check-up on the liver and make treatment recommendations



You can educate
about hepatitis B and
promote testing in
your community.

You have the power
to save lives!






Talking about hepatitis B in a culturally sensitive way can be challenging.



Knowing the common misconceptions and how to overcome them can help dispel stigma and convey accurate information.



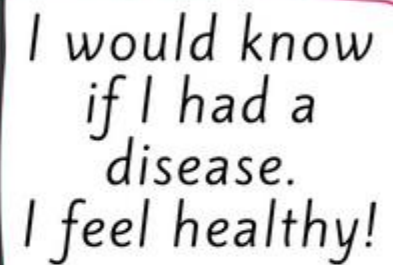
MISCONCEPTION #1:




I don't have any symptoms, so I can't have hepatitis B!



I feel good. There is no reason to be tested.



I would know if I had a disease. I feel healthy!





Most people with hepatitis B usually don't have any symptoms.

Remember:

Preventative medicine may not be as familiar. People may be used to treating illnesses only when they have symptoms. Because hepatitis B often doesn't present symptoms, there may be no urgency to testing and management.

Let community members know that people with hepatitis B often have no symptoms, even though their liver could be damaged.

Remind people that they have the power to improve their lives. By being proactive about their health, they can prevent complications in the future.

The hepatitis B test is a simple blood test. It is the only way to know for sure if someone is infected!



MISCONCEPTION #2:

People with hepatitis B have done something immoral to get it.

I have been a good person. Only bad people get diseases. I couldn't have hepatitis B!

If my neighbors see me getting tested, they will assume I did something wrong.

Hepatitis B may be associated with moral wrongdoing and certain risky behaviors. People may be hesitant to talk about testing for fear of stigma.

Remember:

Hepatitis B is a virus that anyone (who isn't vaccinated) can get. It does not discriminate.

- ▶ Let community members know that hepatitis B is a disease that can be spread multiple ways. People with this disease usually contract it while they are young, and have not done anything wrong.

Frame testing as a way to take care of your overall health.

- ▶ Everyone should know their status. Promote the idea of testing as another piece of taking care of one's overall health and wellbeing.

The more we talk about hepatitis B in the community, the less stigma and misconceptions that will exist.

- ▶ Encourage people to protect the health of their community by getting tested themselves and being an advocate for their community's health as a whole.



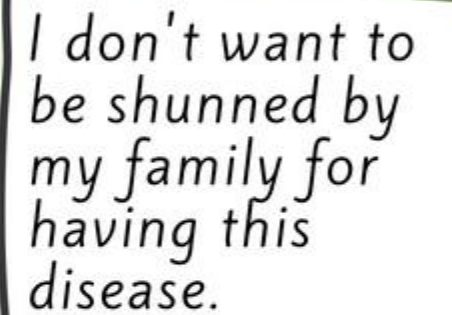
MISCONCEPTION #3:

A woman with short dark hair, wearing a light-colored jacket and dark pants, stands on the left side of the image. She is holding a white rectangular sign with black text. The background behind her is orange with a white scalloped border.

People with hepatitis B will be treated differently by their community.

A speech bubble with a black outline and a white background, containing black text. It is positioned above the man on the right.

I also don't want my neighbors to see me getting tested, they will judge me.

A speech bubble with a black outline and a white background, containing black text. It is positioned to the right of the man.

I don't want to be shunned by my family for having this disease.



Dispelling stigma and religious myths can be challenging.



Remember:

Be mindful of the stigma that may exist around discussing diseases, such as hepatitis B.

▶ *Frame testing for hepatitis B as something to do to "maintain someone's overall health and well-being."*

Religious beliefs may be strong in the community. Do not invalidate their beliefs.

▶ *Stress that western medicine and traditional beliefs can go hand-in-hand. God would want them to take care of their health.*

Be aware that people may fear community judgement from getting tested in a public place or from getting a diagnosis.

▶ *Assure them that they have not done anything wrong to get hepatitis B, and their community will not treat them differently even if they have hepatitis B.*


MISCONCEPTION #4:

A woman with short dark hair, wearing a grey jacket and black pants, stands against an orange background. She is holding a white rectangular sign.

Hepatitis B is a death sentence.

A speech bubble with a black outline and a drop shadow, containing text.

There is no point in knowing I have a disease because I cannot change my fate.

A speech bubble with a black outline and a drop shadow, containing text.

I would rather not know!

People may feel that they do not have control over the progression of their hepatitis.

Remember:

It can be scary to get diagnosed with a chronic disease. But people with hepatitis B can still live long, healthy and normal lives.

▶ Hepatitis B is a slowly progressing disease. The biggest danger is not knowing someone is infected! Assure them at being aware of their hepatitis B is a good thing, and with monitoring they can stay healthy.

People may be worried that a hepatitis B diagnosis will change their whole life - but it doesn't have to!

- ▶ By seeing a liver specialist once or twice a year, they can check up on their liver health and continue to live normally.
- ▶ There are treatments available that can prevent liver damage!





You play an important role in your community,
and you have the power to promote awareness and testing for hepatitis B!



Key tips:

- ▶ *Never invalidate someone's concerns. Always encourage community members to become empowered and look into their health so they can stay healthy for themselves and their families.*
- ▶ *A hepatitis B diagnosis is not a death sentence. Assure the community that by seeing a doctor, and taking treatment (if needed), it is very easy to manage hepatitis B!*
- ▶ *If someone tests positive for hepatitis B, there are many resources available to help them manage their infection, even if they do not have insurance.*
- ▶ *A hepatitis B diagnosis isn't a death sentence, and by living a healthy lifestyle and monitoring it with the doctor, people can live normally!*

You are not alone! There are resources available to you in your Toolkit for additional information and support.



How can I locate doctors for testing and care?

- ↪ The Hepatitis B Foundation's Liver Specialist Directory
www.hepb.org/physiciandirectory
- ↪ Federally Qualified Health Center (FQHC) Locator
www.findahealthcenter.hrsa.gov

Where can I find more information on hepatitis B?

- ▶ Centers for Disease Control and Prevention (CDC)
 - Basic information about hepatitis B, guidelines and downloadable PDFs
 - Printable fact sheets, PSA videos, infographics, quizzes and more in multiple languages
 - Free posters
- ↪ www.cdc.gov/knowhepatitisB
- ▶ The Hepatitis B Foundation
 - Phone and email helplines
 - Comprehensive information
 - Printable fact sheets
 - Inspiring videos
- ↪ www.hepb.org

There are many ways you can integrate hepatitis B education into your community.

You can:

Host an education session or health fair.



Display educational fact sheets, brochures and posters in your office.



Talk to community members about their health and hepatitis B risk.



Promote a local health fair that is testing for hepatitis B.

Share CDC and Hepatitis B Foundation's posts on social media.






Your toolkit contains
more details and
support for integrating
these ideas.



Thank you for helping
spread the word about hepatitis B!





*Please fill out a short
2 minute survey so we know how
useful this information was to you.*

Click Here!

FUTURE PROGRAM EXPANSION

- Dissemination plan
 - Sending PowerPoint, physical flipchart and resource kit to CHIPO partners
- Radio PSAs, collaborations with African radio stations or podcasts
- Collaborations with churches and mosques for education and screening
- Brochure, small information card and poster creation
- Provider education; webinars and additional training materials

THANK YOU! QUESTIONS?

We will update the group when these materials have been finalized and are ready for use.

Sierra.Pellechio@hepb.org