



# **Boosting Diverse Communities Participation in Clinical Trials:**

## **What People Living with Hepatitis B Must Know**



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## **Acknowledgements**

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**Mi Dong** *Asian Center of Southeast Michigan*

**Ibrahima Sankare** *African Services Committee*

**Mohamed Ali** *Somali Health Board*

**Dung Hua** *Vital Access Care Foundation*

**Ellen Tham** *Center for Asian Health, Cooperman Barnabas Medical Center*

**Rensely and Kenson Alik**, *Micronesian Education for Liver Wellness Program*

**Ashley Che, Tanya Machado**





## Background

- The World Health Organization's (WHO) 2024 Global Hepatitis Report estimates that there are **254 million People Living With Hepatitis B** (PLWHB).
- Hepatitis B Virus (HBV) related deaths **increased** from 820,000 in 2019 to 1.1 million in 2022.
- **U.S.: up to 2.4 million PLWHB**
  - Predominantly **foreign-born people from HBV-endemic regions** (disproportionately affected).
- Participants in HBV clinical trials **do not reflect the global demographic distribution** of HBV prevalence.
- Many of the **countries heavily burdened** by HBV in Africa, South-East Asia and the Western Pacific are **underrepresented in trials**





## Problem Statement

- U.S. clinical trial data shows **persistent underrepresentation** of racial and ethnic minority populations.
  - White participants comprise >50% of trial enrollment across programs.
- Asian, Black and Hispanic populations remain underrepresented, despite FDA emphasis on diversity.
- Participation is especially low among communities from regions with high HBV burdens.
- **Key barriers:** mistrust of research, inaccessible information, lack of time and resources, low awareness of clinical trials
- **Underrepresentation** of highly impacted population in trials **limits the generalizability** of results and **reduces confidence in the treatment efficacy** for affected communities.





## Aim of the Paper

This study sought to:

- Understand **existing knowledge and perceptions** about trials
- Identify **trusted information sources** and **preferred communication** platforms
- **Outline informational needs** among PLWHB representing diverse minority communities





# Study Design Overview

Mixed-Methods Study

Quantitative

Qualitative

Global SURVEY



## Focus Groups in Qualitative Research





## Community Partners' Role in Study Methodology

- **Input on study design:** Reviewed survey & interview guides to ensure cultural relevance & appropriateness.
- **Recruitment support:** Helped identify & engage participants from diverse communities.
- **Trust-building:** Increased participants' comfort and willingness to participate.
- **Support during data collection:** Facilitated focus groups and interviews.
- **Impact:** Enhanced representativeness, acceptability, and validity of findings.





# Demographics Overview

**Table 1.** Survey Respondents' Demographics, 2023

Survey Respondents' Demographics (N = 680)	N (%)
<b>Gender</b>	
Male	476 (70%)
Female	184 (27%)
Prefer not to answer	13 (2%)
Missing	7 (1%)
<b>Race</b>	
White (Caucasian)	83 (12%)
Black or African American	431 (63.4%)
Asian	139 (20%)
American Indian /Alaskan Native /Native Hawaiian / Pacific Islander	3 (0.4%)
Prefer not to answer	1 (0.2%)
More than one race	10 (2%)
Missing	13 (2%)
<b>Ethnicity</b>	
Hispanic or Latino	28 (4%)
Not Hispanic or Latino	456 (67%)
Prefer not to answer	184 (27%)
Missing	12 (2%)
<b>Age Group</b>	
18-30 years	140 (21%)
31-45 years	362 (53%)
46-60 years	108 (16%)
61 years and above	40 (6%)
Missing	30 (4%)
<b>Previous Clinical Trial Participation</b>	
Yes	31 (5%)
No	597 (95%)

**Table 2.** Survey Respondents' Hepatitis B Data, 2023

Survey Respondents' Hepatitis B Characteristics (N = 680)	N (%)
<b>Time Since Hepatitis B Diagnosis</b>	
Less than 5 years	285 (42%)
6-10 years	144 (21%)
More than 10 years	231 (34%)
I don't remember	16 (2%)
Missing	4 (1%)
<b>Currently or Previously on Prescribed Antiviral Medication</b>	
Yes, I'm currently taking medication	205 (30%)
No, but I used to take medication	151 (22%)
No, I have never taken medication for HBV*	319 (47%)
Missing	5 (1%)
<b>Frequency of Hepatitis B Medical Visits</b>	
Every 6-12 months	281 (41%)
Every 1-2 years	111 (16%)
When I have a new symptom	64 (9%)
I don't have access to a medical provider	153 (23%)
Consult with a natural healer or an herbalist	23 (3%)
Other	24 (4%)
Missing	24 (4%)

\*HBV refers to hepatitis B virus.

**Quantitative arm: 680 respondents**

## Gender:

- Male (70%)

## Race:

- Black or African American (63%)

## Age:

- 31 - 45 years (53%)

## Country of Residence:

- Nigeria (34%)
- U.S. (12%)
- Philippines (7%)

## Time Since Hepatitis B Diagnosis

- Less than 5 years (42%)



**Table 3.** Focus Group and Interview Participant Demographics, 2023

Focus Group Demographics (N = 36)	N (%)
<b>Gender</b>	
Male	16 (44%)
Female	20 (56%)
<b>Race/Ethnicity</b>	
Black or African American*	13 (37%)
Black	2 (6%)
Somali	6 (17%)
West African	5 (14%)
White (Caucasian)	3 (8%)
Asian	17 (47%)
Chinese	5 (14%)
Filipino	1 (3%)
Korean	3 (8%)
Vietnamese	8 (22%)
Native Hawaiian or Other Pacific Islander	3 (8%)
Chuukese (Micronesia)	2 (6%)
Marshallese	1 (3%)
<b>Age group</b>	
18-30 years	2 (5%)
31-45 years	9 (25%)
46-60 years	15 (42%)
61 years and above	10 (28%)
<b>Previous Clinical Trial Participation</b>	
Yes	4 (11%)
No	32 (89%)

\*None of the focus group or interview participants self-identified as African American.

# Demographics Overview

**Qualitative arm: 36 PLWHB participants**

## Six Community Focus Groups (FGs):

- Vietnamese (8)
- Korean (3)
- Chinese (5)
- West African (Senegalese, Burkinabé, Cameroonian) (5)
- Somali (6)
- Caucasian (3)

## Six individual interviews

- Filipino, Black (2), Marshallese, Chuukese (2)

**Table 4.** Focus Group and Interview Participants' Hepatitis B-Related Characteristics, 2023

Focus Group, Interview Participants' Hepatitis Characteristics (N = 36)	N (%)
<b>Time Since Hepatitis B Diagnosis</b>	
Less than 5 years	11 (30.5%)
6-10 years	1 (2.7%)
More than 10 years	20 (55.6%)
I don't remember	4 (11.1%)
<b>Currently or Previously on Prescribed Antiviral Medication</b>	
Yes, I'm currently taking medication	17 (47.2%)
No, but I used to take medication	3 (8.3%)
No, I have never taken medication for HBV*	16 (44.4%)
<b>Frequency of Hepatitis B Medical Visits</b>	
Every 6-12 months	26 (72.2%)
Every 1-2 years	3 (8.3%)
When I have a new symptom	1 (2.7%)
I don't have access to a medical provider	2 (5.6%)
Consult with a natural healer or an herbalist	2 (5.6%)
Other	1 (2.7%)
Missing	1 (2.7%)

\*HBV refers to hepatitis B virus.





## Results Overview

**Limited existing knowledge** and **misconceptions** influence individuals' decisions to participate in trials.

- Participants **described informational needs** and **provided recruitment recommendations**.
- Findings **can inform trial developers** on how to communicate clinical trial information to diverse PLWHB, enhance recruitment & enrollment efforts.





## Key Findings: Existing Knowledge & Willingness to Participate

- Only **27%** of survey respondents had received information about trials
- **Some Existing Trial Knowledge:** Chinese, Somali, White, Black participants
- **Limited Existing Trial Knowledge:** Vietnamese, West African, Marshallese, Chuukese, Filipino participants
- Despite low awareness, **85%** were *willing to participate if offered the opportunity*
  - 13.4% undecided
  - **1.4% unwilling**

**Diverse communities are receptive to learning about hepatitis B trials.**

- **68%** of survey respondents wanted to learn more about participating in future trials



# Key Findings: Need for More Information

## Digital Sources

Internet (71%)



Social Media (19%)



Government Websites (4%)

Vietnamese, Black, Korean participants

## In-Person Sources

Healthcare Providers  
(27%)



Vietnamese, West African,  
Chinese, Black participants

Faith Leaders, Trusted  
Community & Patient  
Organizations (13%)



Somali, West African  
participants

*‘Has your doctor ever talked to you about participating in a clinical trial?’*

- Healthcare provider has never discussed trials with them: **83%**
- Have not received information about clinical trials from treating physicians:
  - Filipino, Marshallese, Chuukese, Korean, White participants



# Key Findings: Community Suggestions to Improve Awareness

## Tailored Recruitment Strategies

Radio



Newspapers



Social Media



Messaging Platforms

(Zalo, KakaoTalk, Line, WeChat)



Trusted Sources

(Community Leaders, Healthcare Providers)



In-Language Communication



***“Information matters, information plays an important role. You must be informed to participate, if you are not informed, how will you participate?”***

(West African participant)

Table 5. Community-Identified Informational Needs

Clinical Trial Information: What People Want to Know	Community Group
<b>Clinical Trial Procedure</b>	
Study Objectives	West African, Chinese, White
Study Outcomes, Goals	West African
Phase of trial	Chinese, White
Duration	Korean, Chinese, White, Black
Location	Vietnamese, West African
Research Team & Doctors	Vietnamese
Previous Research Results	White
Number of Participants	Chinese, Black
Personal Commitments	Chinese, White, Black
<b>Trial Medication</b>	
Medications' intended purpose (cure versus treatment)	West African, Somali
Function of medicine	Korean, Chinese, Filipino, Marshallese
Safety profile	Vietnamese, Korean, Filipino
Side effects	Vietnamese, Korean, Filipino, Marshallese, Black
Health affects	West African
Potential harms	Korean, Marshallese, Black
Benefits	Somali
Instructions to take the medication	West African
Has medication been tested (certified for human use)	Somali
Success of medicine in other patients with similar health conditions	Marshallese





# Community-based Organizations: Impact on Clinical Trials

Community-based organizations (CBOs), are **gatekeepers to potential participants**, they are the **key to bringing trial information to potential participants**.

- **Missed Opportunity:** Only a few survey respondents & community members reported learning about clinical trials from CBOs and leaders

Clinical trial teams must establish **continuous communication** with CBOs and leaders

- Inform CBOs of future research opportunities
- Provide CBOs with access to accurate clinical trial information to relay to community

**Strong, ongoing partnerships** between trial teams and CBOs can enhance engagement efforts with underrepresented communities

- **Work with CBOs early:** ensure study procedures are responsive to community needs; develop culturally appropriate outreach plans
- CBOs can...
  - **Inform their community** about research opportunities
  - **Facilitate** enrollment and retention efforts





# Lessons Learned From CBO Collaboration

## 1. Recruitment & Stigma

## 2. Recruitment strategies:

- One-on-one recruitment (long time, more effort)
- Social media (email flooded with ineligible participants, scammers)

## 3. The need for **more training** for some community staff who facilitated focus groups

- Leading questions

## 4. **Flexibility with honorariums**

- Cash, gift cards, online payments, checks

## 5. **In-language surveys not promoted correctly**

- Different social media platforms, messaging apps





# Discussion

1. Is any of the study **collaborating CBOs** in the room?
  - Please share your reflection on the experience participating in research!
2. **To all attendees:** from your perspective/ experience, how can CBOs get more involved in research?





***Shout Out to Hep B United Partners***





*BioSocial Health J.* 2025;2(3):  
133-146.

doi: [10.34172/bshj.101](https://doi.org/10.34172/bshj.101)











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