

# Demographic factors, knowledge, and experiences associated with engagement in care in Australians diagnosed with Hepatitis B

*Thomas Tu, Sylvester Okeke, Harout Ajoyan, Sumaya Mozumder, Mylisa Vu, Robyn Horwitz, Elena Cama, Jacob George, Loren Brener*



*Group Leader, Viral Hepatitis Pathogenesis Lab  
Storr Liver Centre, Westmead Hospital, Westmead Institute for Medical  
Research, and the University of Sydney*

*Founder/Director of HepBcommunity.org*

*Founder/Director/Secretary of Hepatitis B Voices Australia*



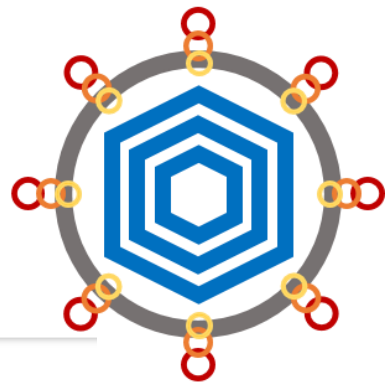
# Where we are failing for hep B

Table A.2: Progress made towards 2022 National Hepatitis B Strategy targets for diagnosis, care and treatment, 2018–2022

Indicator	2018	2019	2020	2021	2022	National Strategy target by 2022	Year Australia projected to reach 2022 target
Diagnosis	68.0%	68.1%	70.2%	72.7%	72.1%	<b>80.0%</b>	<b>2037</b>
Care (treatment or monitoring*)	25.0%	25.3%	24.9%	26.0%	25.5%	<b>50.0%</b>	<b>2047</b>
Treatment	10.6%	11.1%	11.8%	12.7%	12.9%	<b>20.0%</b>	<b>2036</b>

How do we ask people what the barriers are, if they aren't engaged in care?

# HepBcommunity.org



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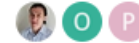
☰ Topic

Replies

Views

Activity

Upcoming HBV treatments



5

55

2h

last visit

INTRODUCTION THREAD: People affected by Hep B



13

101

9h

How have you dealt with discrimination because of your HBV status?



4

40

3d

NEW FEATURE = Verified Expert badges

■ Site Feedback



4

45

10d

Plans for future improvements

■ Site Feedback



3

40

11d

Hep B connect logo ideas

■ Site Feedback



6

65

16d

INTRODUCTION THREAD: Experts



4

58

16d

List of threads to start

■ Staff



0

10

16d

Privacy on this forum



1

22

22d

# Community forum for trustworthy information

If you have hep B,  
you are not alone



- Information & support
- Guidance from experienced community members
- Safe & confidential



Free registration





**HepBcommunity.org**

An online forum for people affected by hep B

Supported by Hepatitis B Foundation, World Hepatitis Alliance, Storr Liver Centre (Westmead Hospital), and Australian Centre for Hepatitis Virology. Artwork: Beci Orpin

Replies Views Activity




 **Thomas Tu**   
Thomas Tu  
Verified Science Expert

Dr Thomas Tu's research is focused on the Hepatitis B virus, particularly how it maintains itself in the liver and how it causes disease. He is particularly...

[sydney.edu.au/medicine-health/about/our-people/academic-staff/t-tu.html](https://sydney.edu.au/medicine-health/about/our-people/academic-staff/t-tu.html)  
Sydney

Posted 3 hours ago Joined 9 Sep Read 3h

**Experience in:** Living with Hepatitis B and scientific research (molecular biology of HBV)

   +15 More


 **Suwang88**   
Su H Wang  
Verified Health Expert

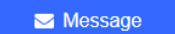
Posted 24 Oct Joined Sep 12, 2020 Read 4h (4m recently)

**Experience in:** Primary care based HBV care, HBV in pregnancy

   +12 More

 2 posts in topic

 **Prince Okinedo**  
Prince Okinedo




 8 posts in topic


Prince O Okinedo is a Pharmacist and a patient advocate for better funding and management of viral hepatitis B in Delta State, Nigeria. Founder of HRPATITIS B...


Asaba

Posted 2 Sep Joined May 11, 2022 Read 12h (8m recently)

**Experience in:** Pharmaceutical care, Lived experience

   +9 More

 **david.carter**  
David Carter

 5 posts in topic




Hello!

I am a legal academic at UNSW Sydney in the Faculty of Law & Justice. I work on...

[healthpluslaw.org.au](https://healthpluslaw.org.au)

Posted 21 Oct Joined 10 Aug Read 29m (14m recently)

**Experience in:** Legal Academic (UNSW Sydney) who works on hepatitis B and the law.

   +5 More

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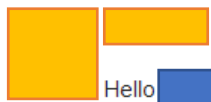




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  how are you doing?  
Are you in the trial yet?



    Reply

  3d  
Hello  Yes, next week I have my week 16 appt, and will get my 3rd injection. I'm tolerating that just fine, no issues at all. At week 24 is when the interferon comes in, so I'm a little nervous about that. You must be on interferon by now, or almost there, correct? Since the labs are blinded they are just giving basic lab results just to know the body is doing fine. I hope you doing great in the study!!!

1     Reply

  3d  
You are right!  
I am on week 35 in the study and for 8 weeks already on Interferon. The first Interferon injection is on week 28 😊, a four weeks break. I was nervous too before starting Interferon, but Praise God, He so good to me! I am doing great, I have only site injection reaction and some changes in lab results.  
Every blessing,  
 😊

    Reply

  2d  
Thank you for the information since you are a little ahead of me! I wish you a continued easy time symptom wise and hope for hbsag loss for you! Keep in touch and I'll do the same!

- Immediate replies
- Comfort of own home
- Sharing experiences and navigation
- Community connection
- Misinformation addressed by experts
- **Circumvent stigma**

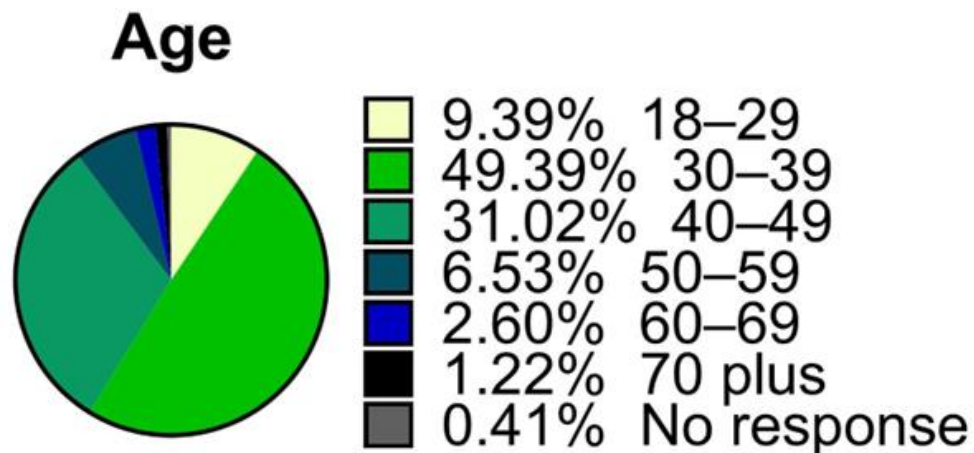
# Survey overview

## Investigating Treatment Engagement and Monitoring among people living with hepatitis B (ITEM-B)

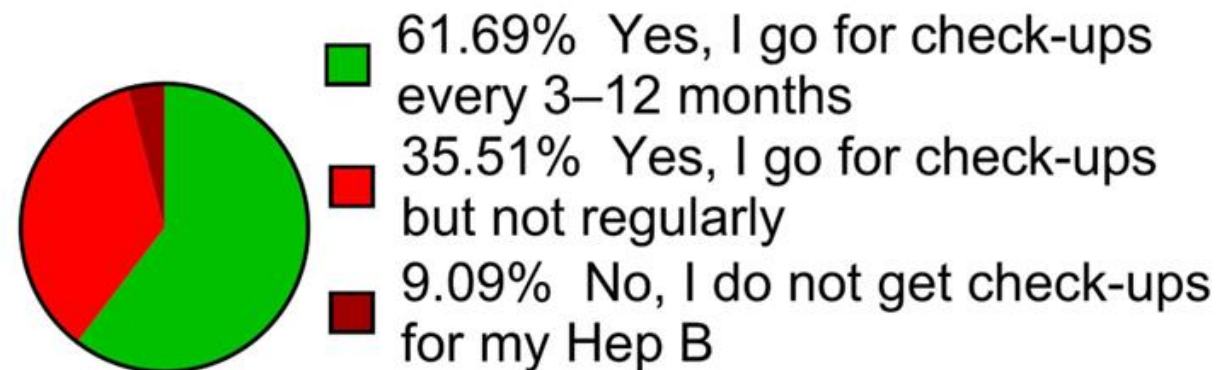
Investigator sponsored research project supported by Gilead  
Recruited on HepBCommunity.org - 248 participants in Australia

### ***Inclusion criteria:***

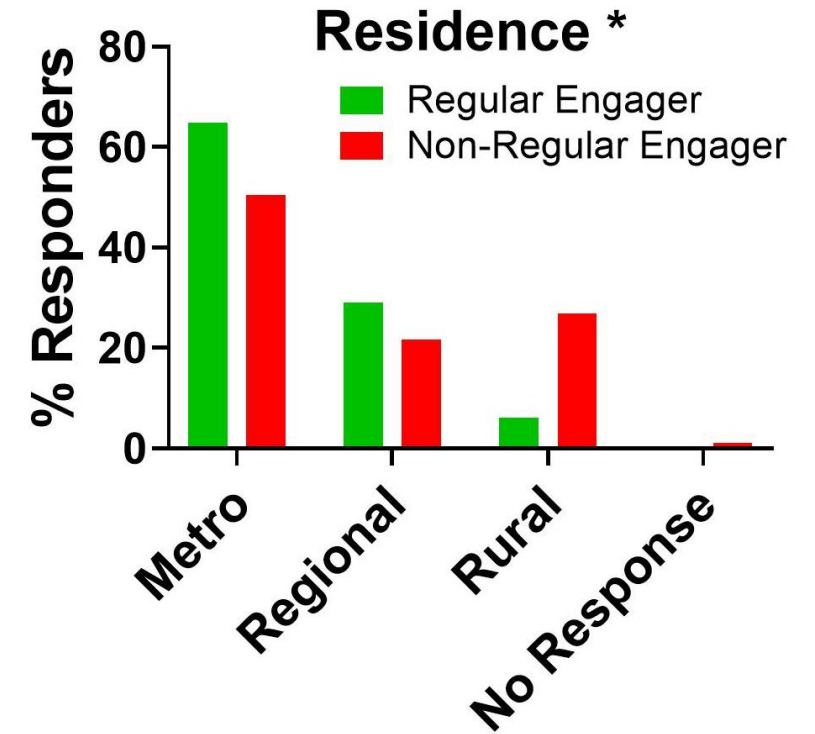
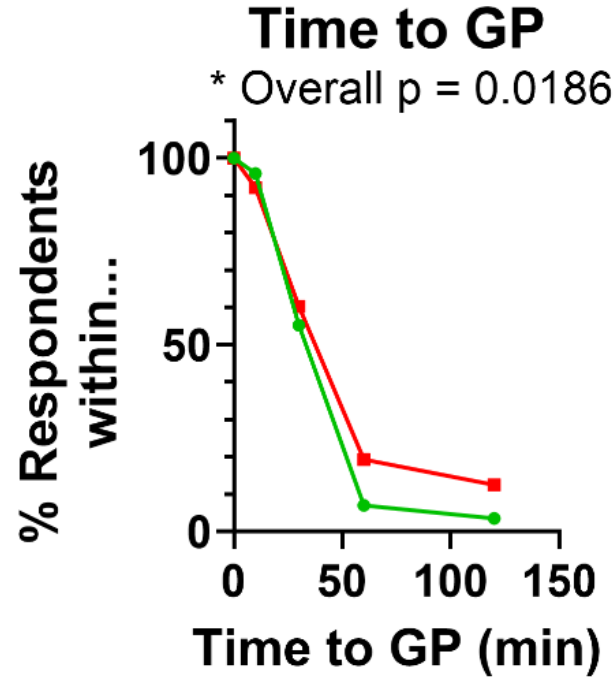
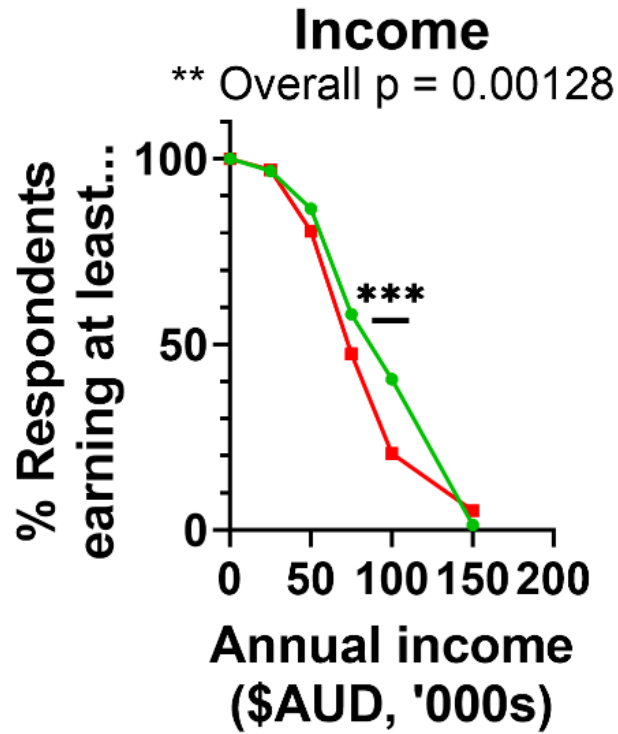
>18 years; Proficient in English; Diagnosed with Hepatitis B



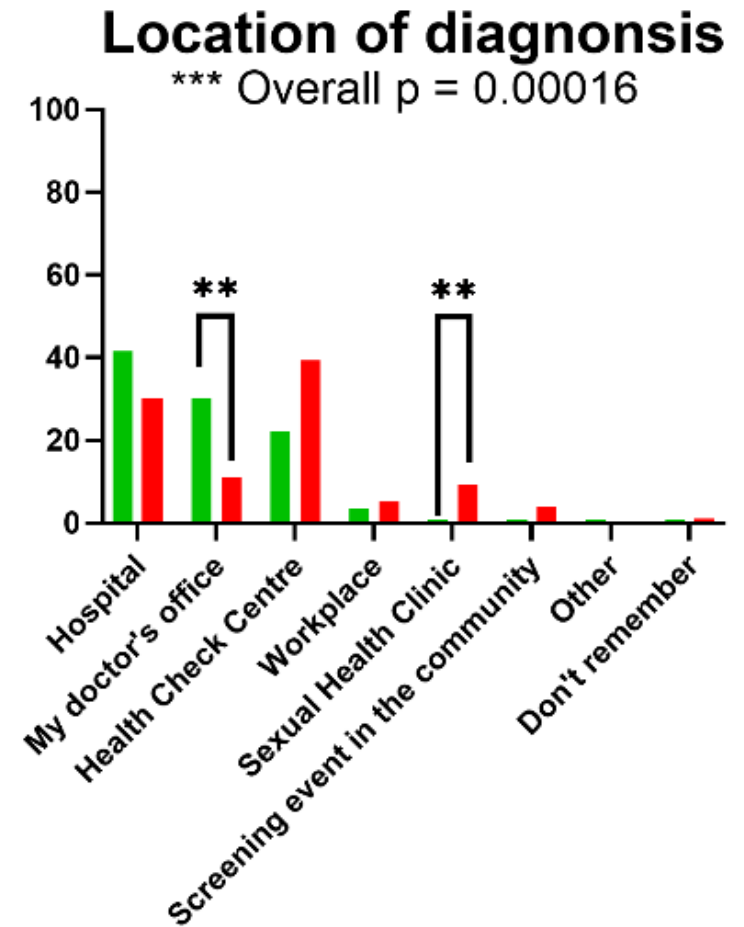
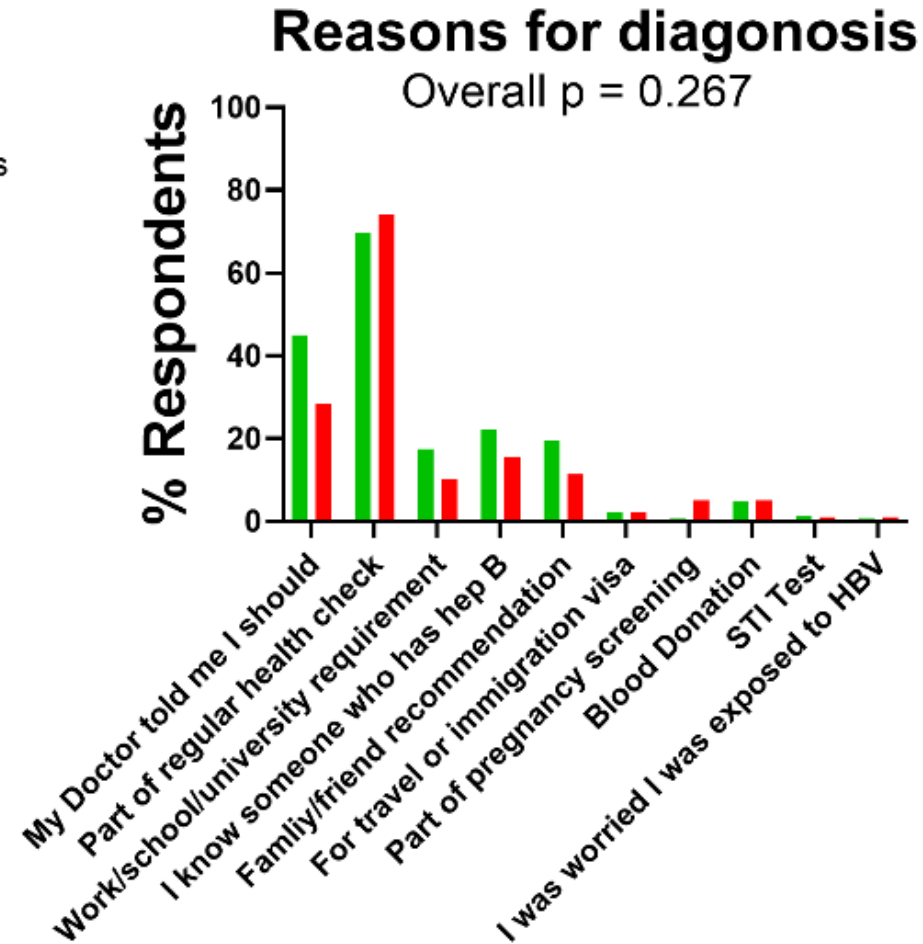
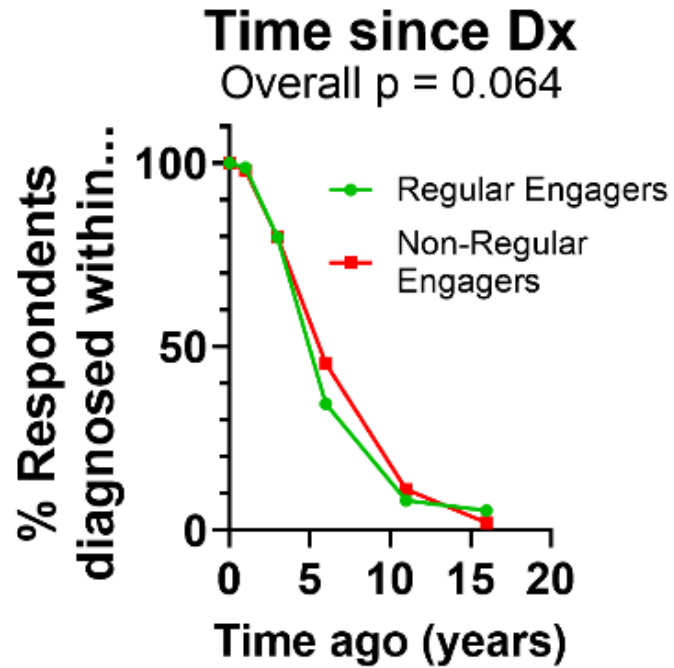
### **Engagement in care**



# Being poorer and further from care was linked to lower engagement



# Diagnostic context (but not time or reason) was linked to engagement

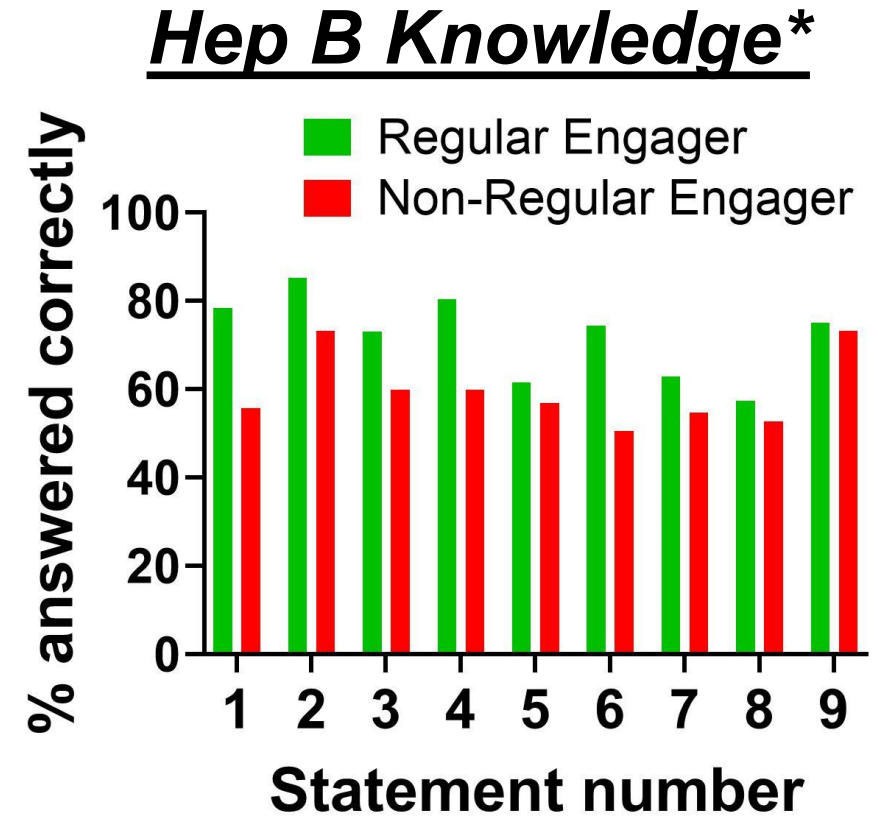


Regular Engagers

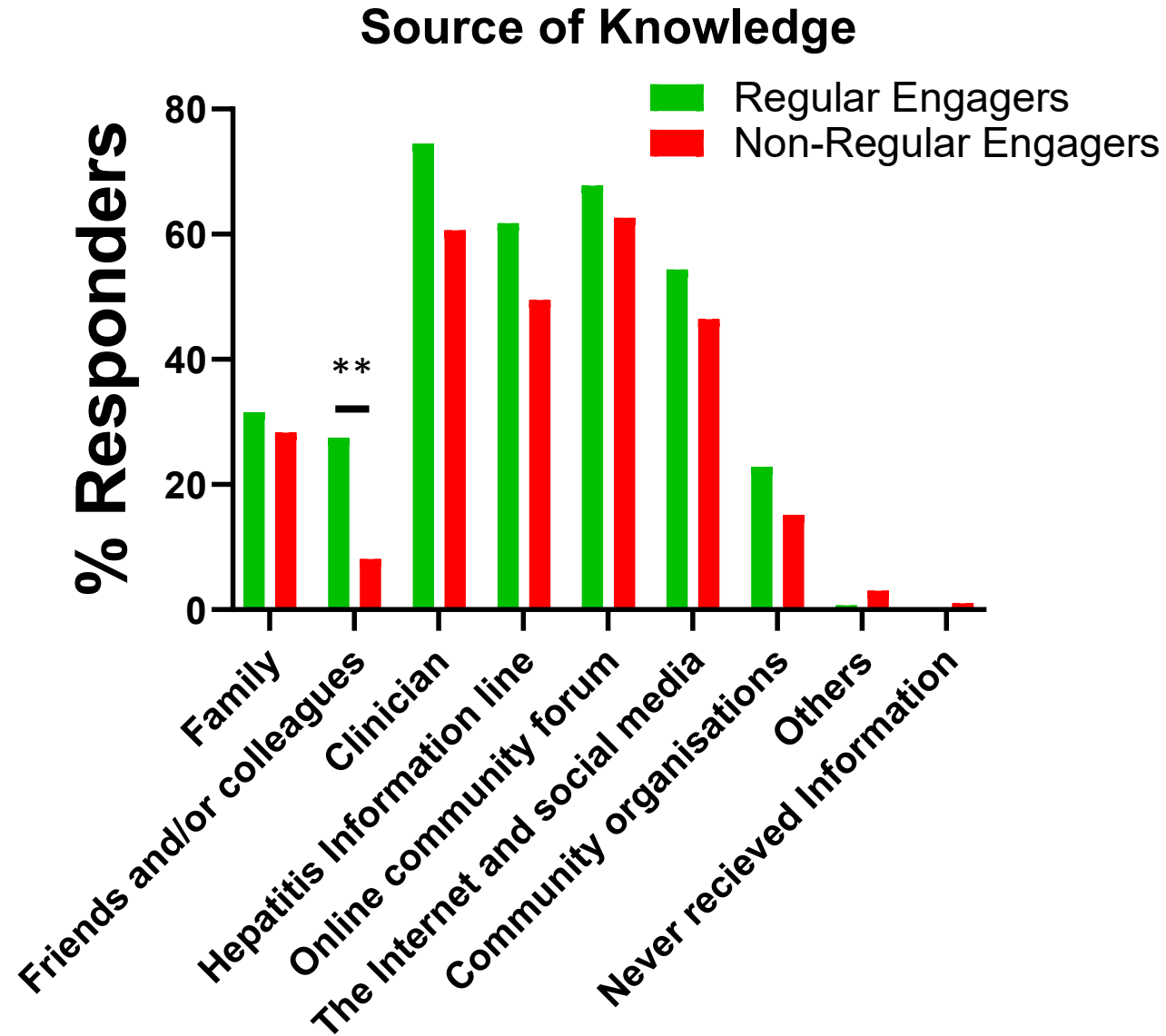
Non-Regular Engagers

# HBV-specific knowledge was lower in people not engaged in care

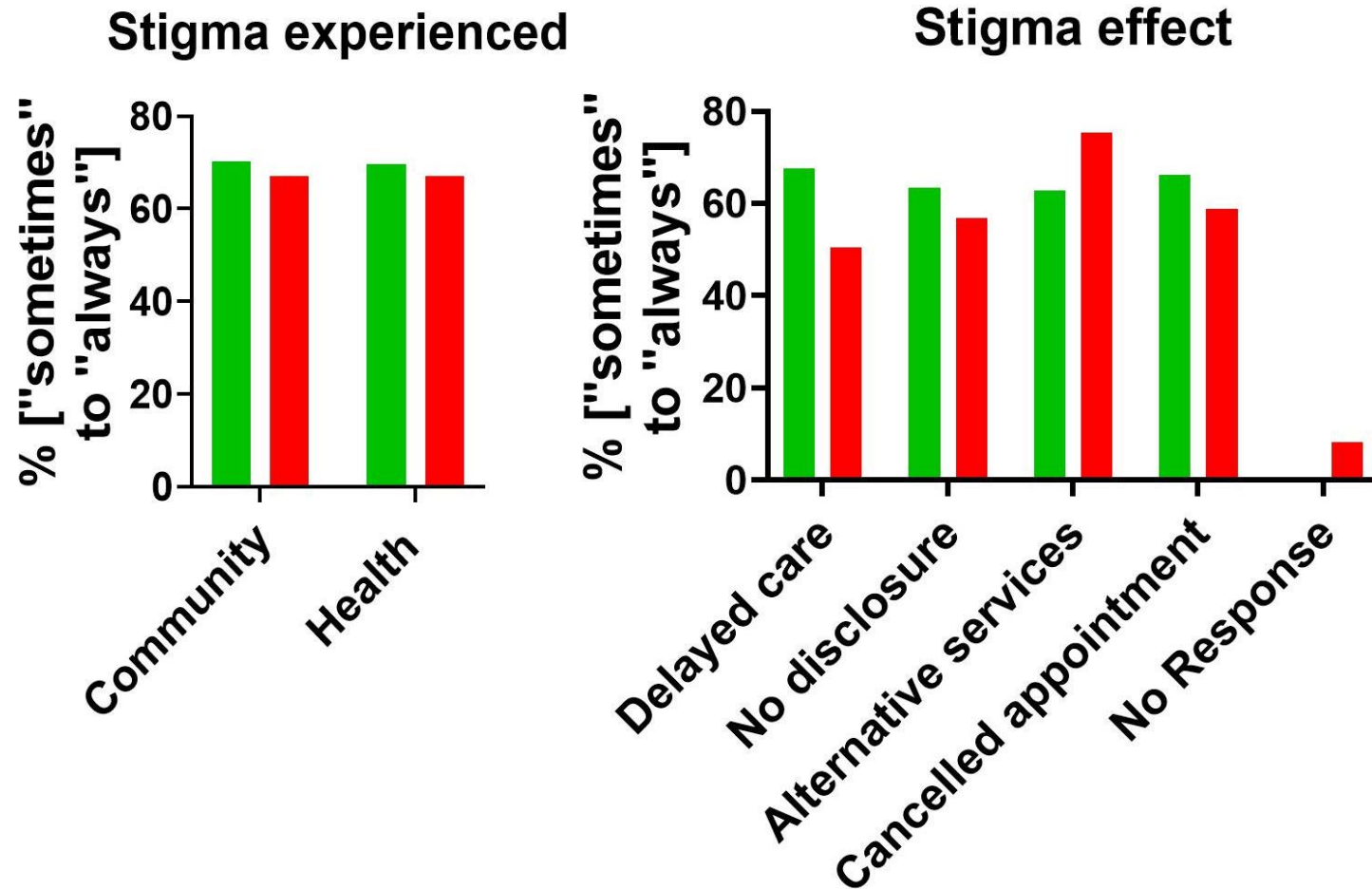
- 1) **A blood test is needed to know if you have hepatitis B**
- 2) A vaccination can protect people against hepatitis B
- 3) There are no treatments for hepatitis B infection
- 4) **Hepatitis B can turn your skin and eyes yellow**
- 5) If you look and feel healthy, you don't have hepatitis B
- 6) **Chronic hepatitis B can cause liver damage and cancer**
- 7) Hepatitis B can be spread by sharing toothbrushes and razors
- 8) Hepatitis B can be spread by sharing food, drinks, utensils, and hugging and kissing
- 9) Hepatitis B can be spread from mother to baby during birth



# Friends and family were common sources of information for engagers



# Stigma was similarly high in both groups



# Conclusions

## **Factors associated with linkage to care**

Income, distance to care

Diagnostic context

Colleagues/friends as a source of HBV information

HBV knowledge (though relatively high in both)

## **Factors similar across responders**

Frequent experience of stigma/discrimination

# Key actions and take-aways

Develop cheaper and decentralised care pathways

Enhance information and follow-up at low engagement clinical settings

Expand peer education (colleagues/friends)

Partner with [HepBCommunity.org](https://www.hepbcommunity.org) for further studies

# Acknowledgements

## All contributors to HepBCommunity.org and affected community

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Paul Hartmann

Bright Ansah

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*Sumaya Mozumder (past project manager)*

*Mylisa Vu (past project manager)*

Prof Jacob George (SLC)

Prof John Tavis (ICE-HBV)

Dr Andrew Vaillant (Replicor)

Prof Tim Block (HBF)

A/Prof Mark Douglas (SLC)

Prof Carla Treloar (CSRH)

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