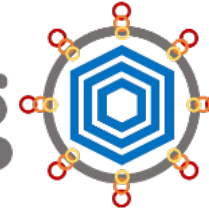


HepBcommunity.org



The
Westmead
Institute
FOR MEDICAL RESEARCH

Lived experiences as guiding lights to a more effective hepatitis B response

A/Prof Thomas Tu (@thatliverguy.bsky.social)

*Co-founder and Chair, Hepatitis B Voices Australia
Group Leader, Westmead Institute for Medical Research
Founder and Director, HepBCommunity.org*

Acknowledgement of community



People with hepatitis B are *experts* by virtue of their experiences. Their expertise is central to making change.

All people with lived and living experience of, or affected by, viral hepatitis (particularly hep B)

Additional thanks to:

- Hepatitis B Voices Community Panel Members
- HepBCommunity.org forum users
- Community advisory teams
- Survey participants

Where are we failing?

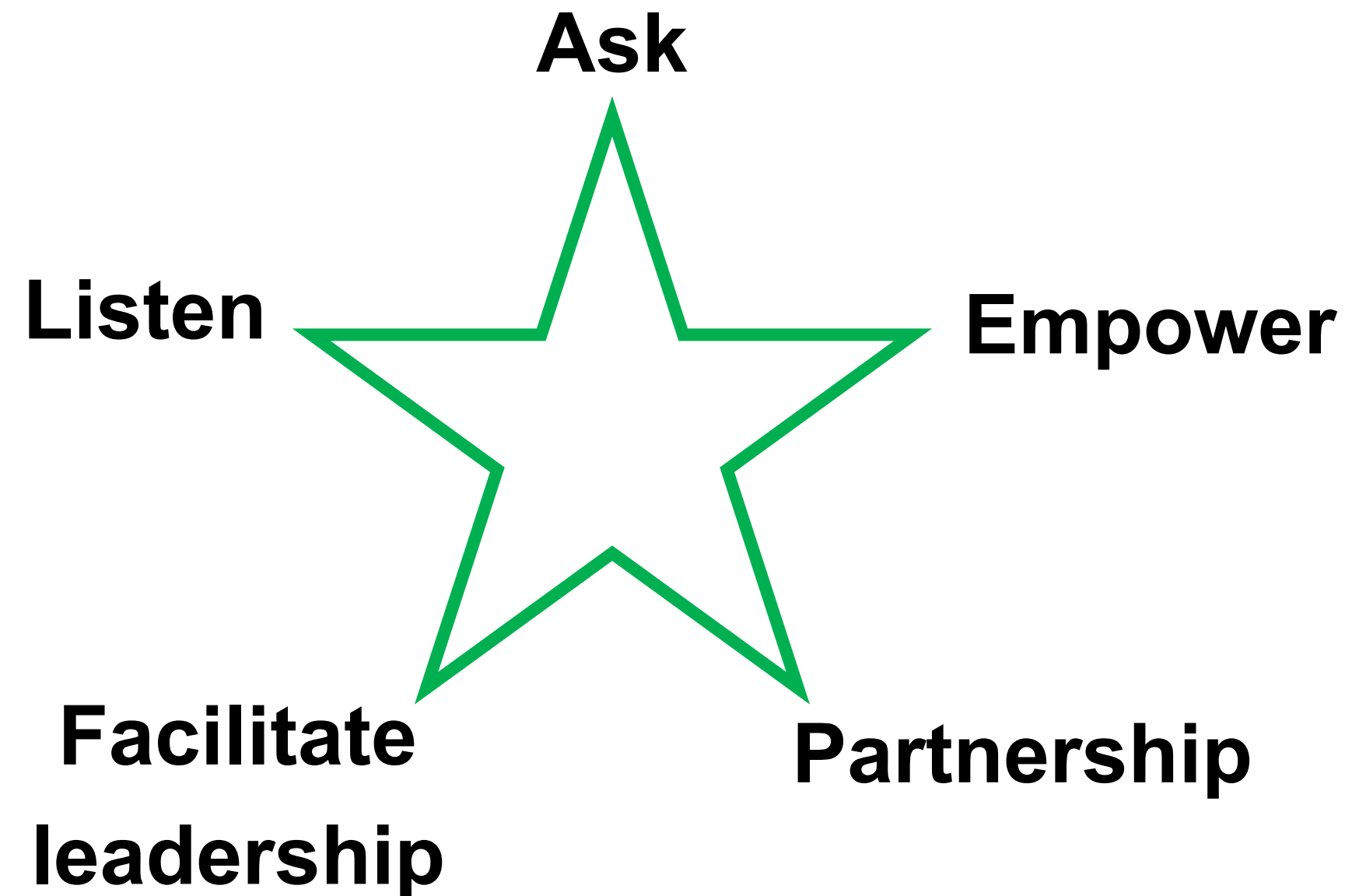
<u>% of people with hepatitis B who are...</u>	<u>2019</u>	<u>'20</u>	<u>'21</u>	<u>'22</u>	<u>'23</u>	<u>'24</u>	<u>2022 Aus. target</u>	<u>2030 WHO target</u>
...diagnosed	69	70	72	72	69	67	80	90
...engaged in care	25	25	26	26	25	28	50	80
...being treated	11	12	13	13	13	13	20	N/A*

Stagnant and ineffective response



How do we stop failing?

Understand and connect with the people not engaging with care



Rather than...

Tell/dictate
Seek validation
Prejudge
Saviour relationships
Extractive transactions



Our Lived Experience program

- 1) Listen: ***Patient-reported impacts of hepatitis B***
- 2) Ask: ***Community experiences around laboratory tests***
- 3) Empower: ***HepExplain***
- 4) Facilitate leadership: ***National Consensus Community***

Statement on Hepatitis B Priorities

- 5) Partnership: ***Collaborative partnership between research and community partners: a formula for equitable partnerships and codesigned interventions***
(Spotlight session 5C)





HepBcommunity.org

Replies Views Activity

 **Thomas Tu** 
Thomas Tu
Verified Science Expert

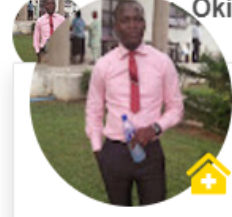
Dr Thomas Tu's research is focused on the Hepatitis B virus, particularly how it maintains itself in the liver and how it causes disease. He is particularly...

sydney.edu.au/medicine-health/about/our-people/academic-staff/t-tu.html
Sydney

Posted 3 hours ago Joined 9 Sep Read 3h

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

Leader Champion Verified Science Expert +15 More

 **Prince_Okinedo**
Prince Okinedo

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

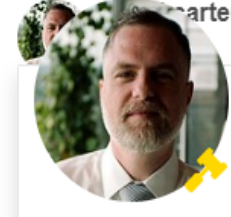
Member Anniversary Appreciated +9 More

 **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

Regular Verified Health Expert Anniversary +12 More

 **david.carter**
David Carter

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

healthpluslaw.org.au

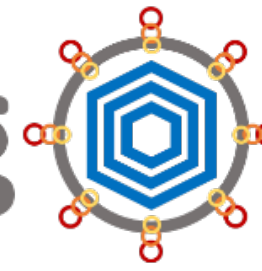
Posted 21 Oct Joined 10 Aug Read 29m (14m recently)

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

Regular Autobiographer Editor +5 More

- >3000 global users
- >16k posts
- >2.2M page views
- Multi-language support





  3d
 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!

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

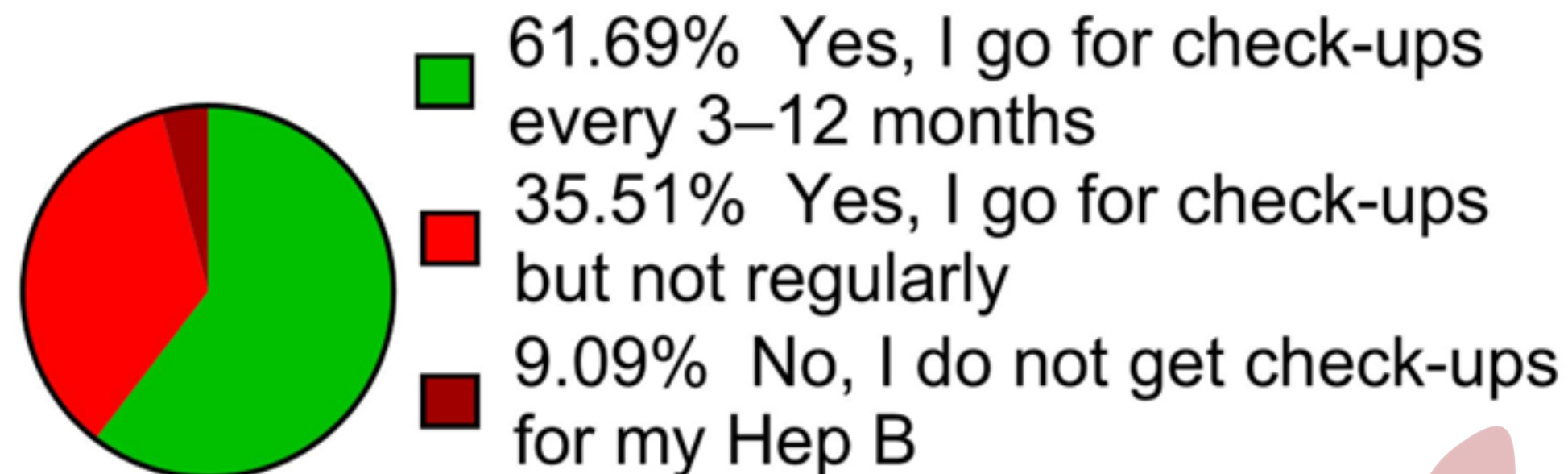


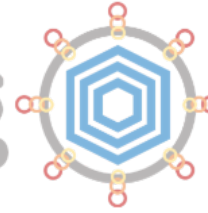
Accessing people not engaged in care

Investigating Treatment Engagement and Monitoring among people living with hepatitis B (ITEM-B) Tu et al. 2025 (Discover Public Health)

Recruited on HepBCommunity.org: 248 participants in Australia

Engagement in care



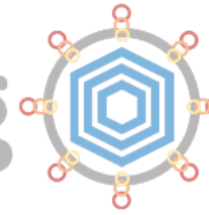


Listening: Patient-reported impacts of hepatitis B

A novel content analysis study of online forum posts

Study team: Kiri Lay, Marion Heriveau, Joanna Forbes



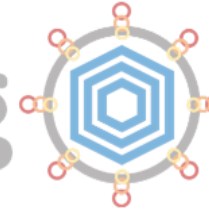


Background

- Patient Reported Outcome Measures (PROMs) measure impacts from the patient perspective = **a way to listen**
- Existing PROMs for chronic Hep B.
 - Chronic Liver Disease Questionnaire (CLDQ) Younossi et al. 1999, Gut
 - Chronic Hepatitis B Quality of Life (CHBQOL) Zhu et al. 2019, Qual Life Res.

Weaknesses

- Designed through interview and survey by clinicians and researchers
- Participants already engaged in tertiary care



Methods

Data extraction of all posts on HepBcommunity.org

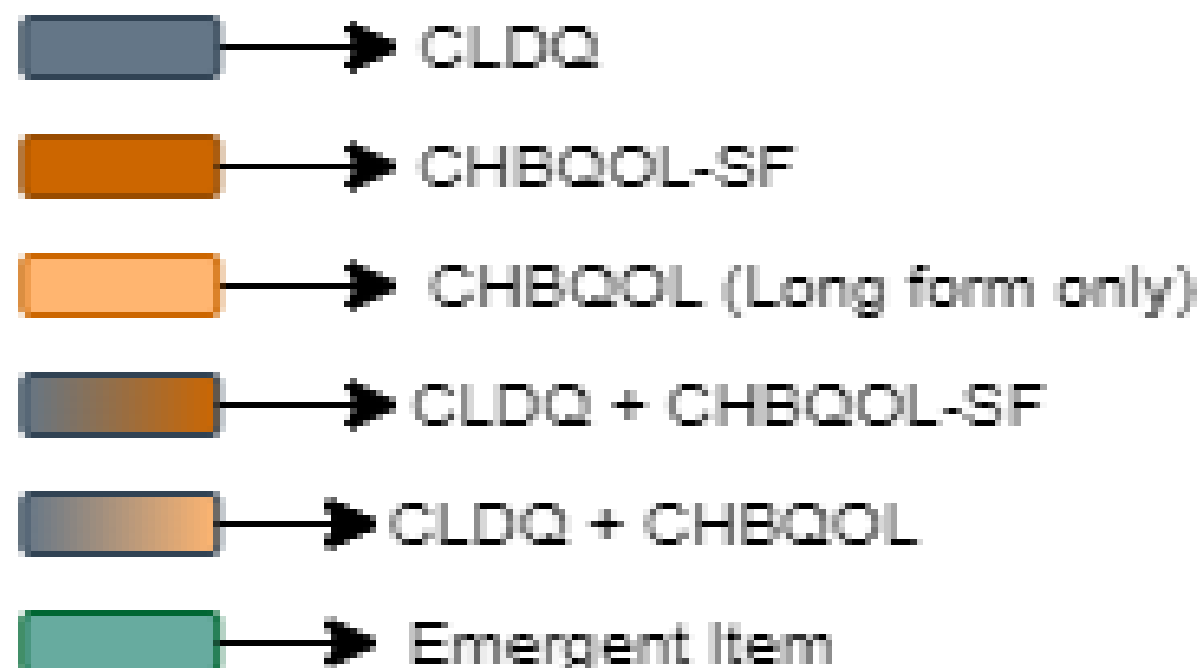
- Custom Python script to download and anonymise all public posts

Analysis: coding in Nvivo

- Deductive framework comprising items from two existing HBV PROMs
- Manual inductive addition of emergent items/codes (until saturation)
- Manual deductive coding with revised framework, including emergent codes, until saturation (2000 posts)
- Subsample (200, 10%) double coded => >95% agreement between coders

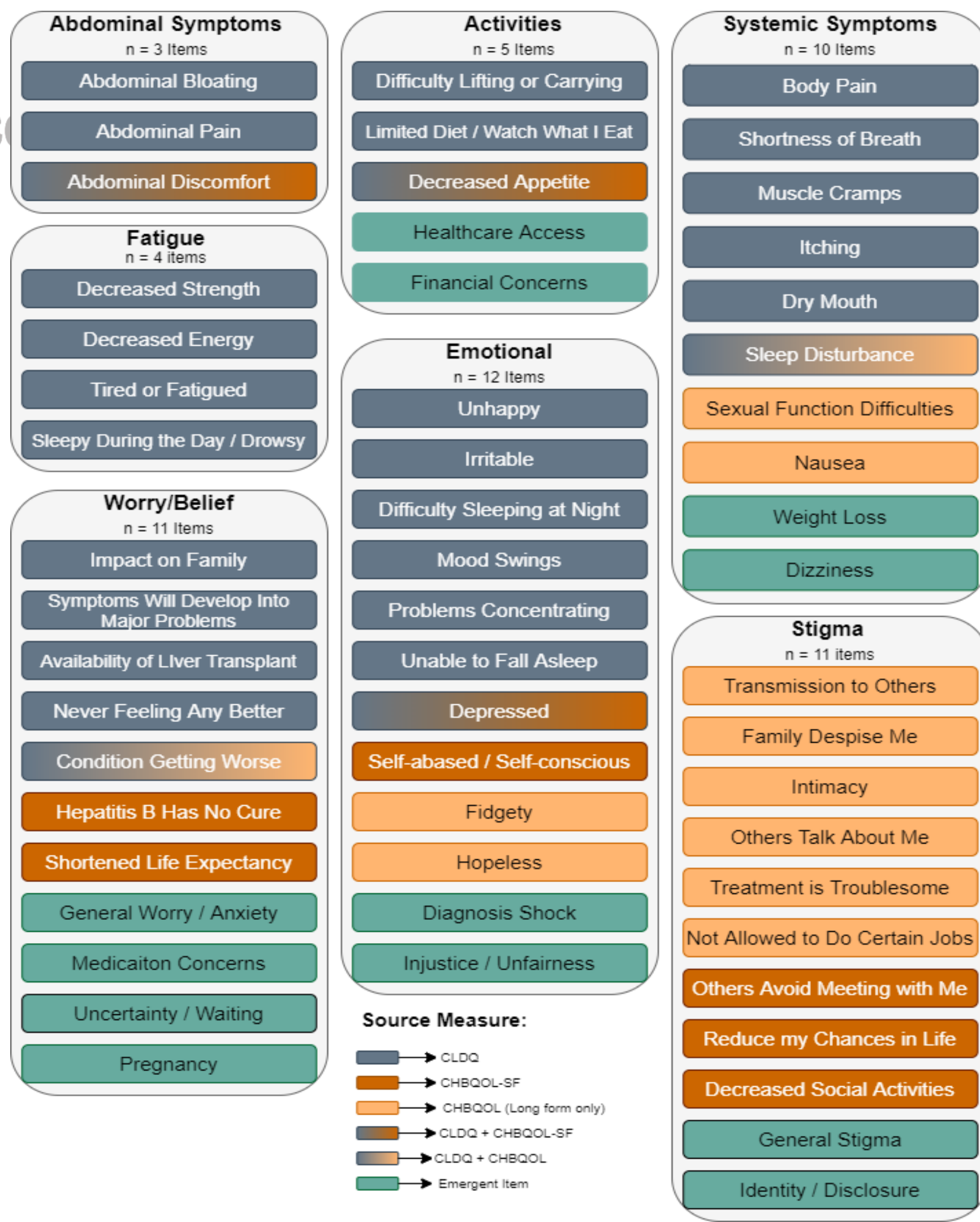
Results

HepBco



Final framework

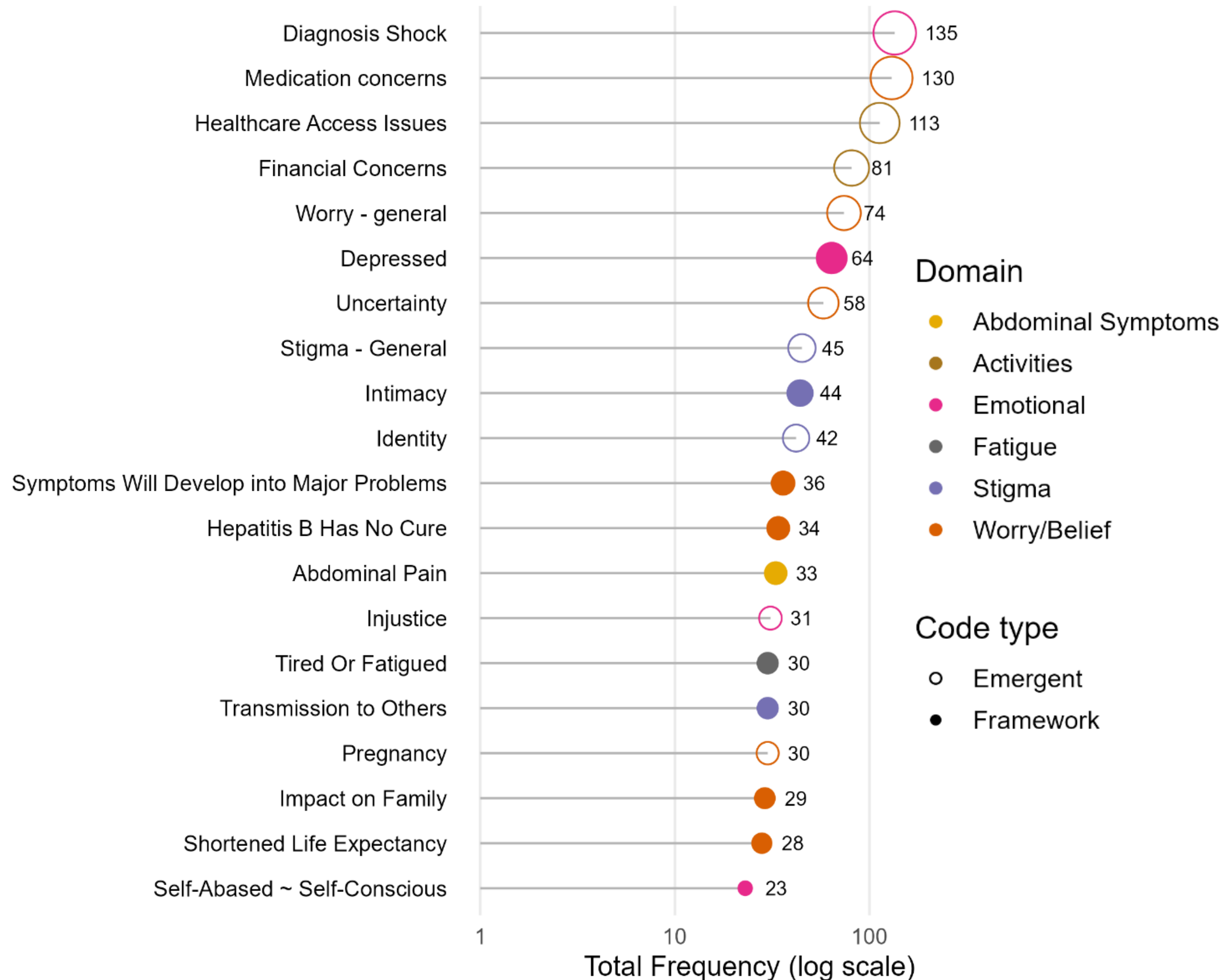
- Fit emergent items under domains
- Primarily psychosocial

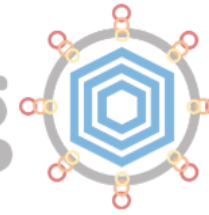


Results

- Emergent items
 - Diagnostic shock
 - Medication concerns
 - Healthcare access
 - Financial concerns
 - Uncertainty
 - Stigma
 - Identity
 - Feelings of injustice
 - Pregnancy worries

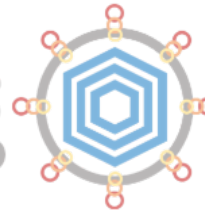
Twenty most frequently referenced impacts





Summary and future work

- Many psychosocial impacts of HBV infection are not adequately covered by existing disease-specific PROMs.
- Community-led Hep B QoL (Com-B-QoL) PROM is in development
 - Tool for research, care quality indicator, and endpoint measure for clinical trials
 - Implementation in clinics to improve care
 - Translation into priority languages

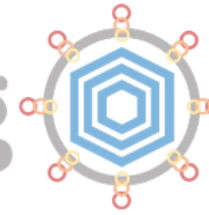


Asking: Community experiences around laboratory tests

*A needs assessment highlighting neglected
psychosocial impacts*

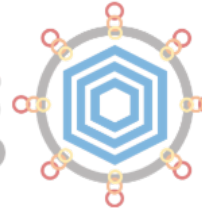
Study team: Tu T, Heriveau M, Bondezi K, Guo X, Wu A, Douglas MW, George J, Massie N, Lay K, Nguyen Dinh T, Harrold C, Cohen C, Borondy-Jenkins F, Yakubov R, Cretu D, Kabagambe K, Chanta C, Tran L.

Funding: Gilead, GSK, auDA



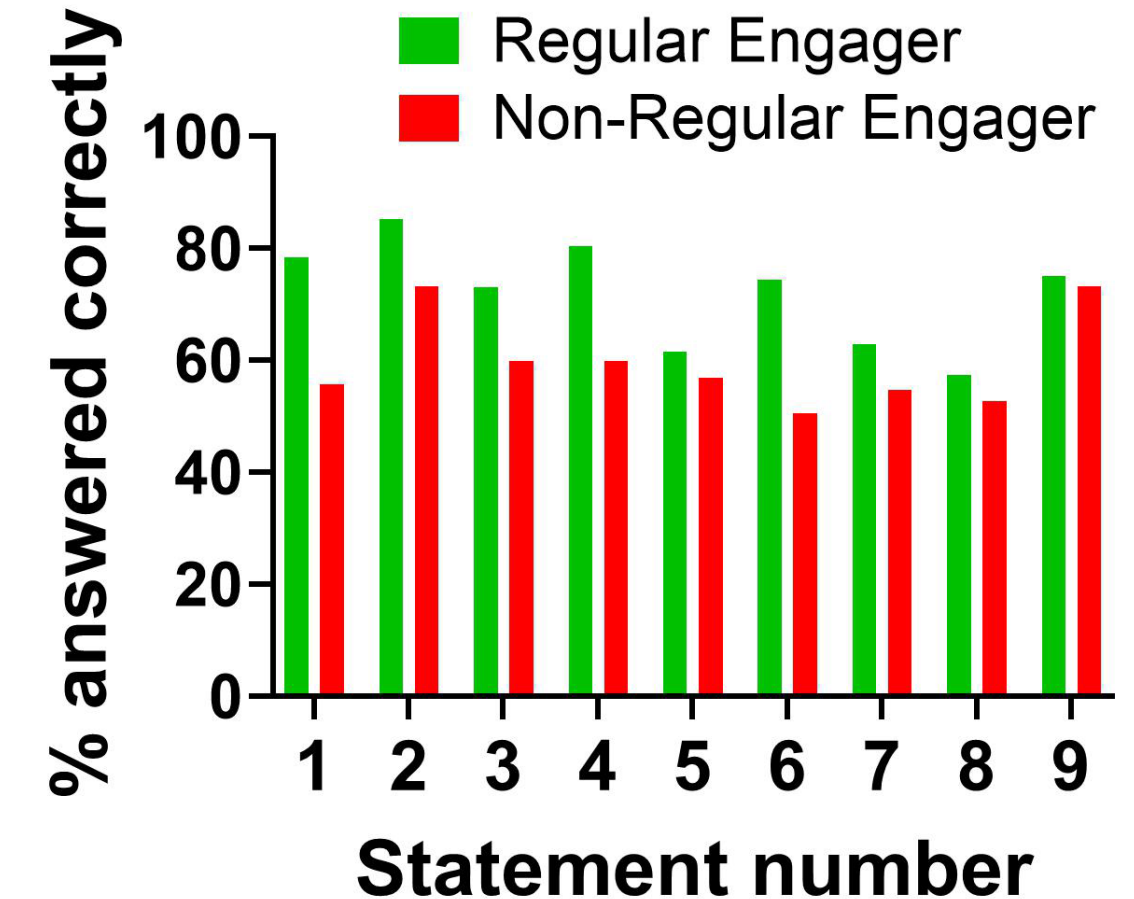
Background

- Clinicians have many resources to interpret lab results - but PLWHB do not.
- Significant demand: “lab results interpretation” thread is the most popular feature of HepBCommunity.org.
 - ~1400 posts and ~80,000 views
- Are PLWHB given enough information or explanation about their results? -> If not, this is disempowering, increases stress and damages confidence in managing their own medical care.



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

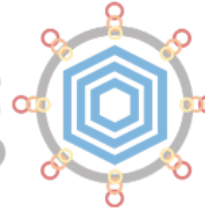




Methods Part 1:

Co-designing a survey with affected community

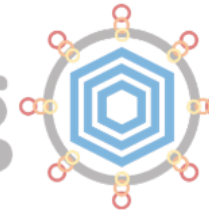
- Experiences and needs of PLWHB:
 - during diagnosis
 - during routine monitoring
- Co-designed using rounds of community review, ensuring:
 - cultural sensitivity
 - trauma-informed practice



Methods Part 2:

Surveying affected community

- 36 participants worldwide
- 20min Qualtrics survey
- Eligible: ≥ 18 years old, living with HBV, able to complete survey in English.
- Participants could opt in to receive a AUD\$150 gift card
- Questions on:
 - Diagnosis experience, including emotions and provision of information
 - information needs and sources
 - practical and emotional challenges
 - willingness to use a webtool to interpret lab results.



Results: respondents

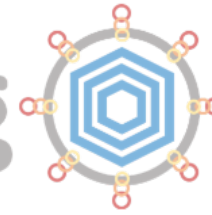
- Participants reflected a diversity of experiences and circumstances.

Country of birth	%	#
Viet Nam	26%	9
China	17%	6
Thailand	17%	6
Uganda	17%	6
<i>No answer</i>	6%	2
Australia	6%	2
India	3%	1
Cambodia	3%	1
New Zealand	3%	1
Philippines	3%	1
Total	100%	35

Language spoken at home	%	#
English	37%	13
Vietnamese	20%	7
Thai	17%	6
Chinese (Simplified)	11%	4
<i>No answer</i>	6%	2
Chinese (Traditional)	3%	1
Khmer	3%	1
Tagalog	3%	1
Total	100%	35

Results: experiences

HepBcommunity.org



73%

reported receiving
no or not enough
information at
diagnosis

(n=24/33)

47%

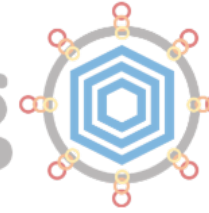
were slightly or not
at all confident
understanding their
test results

(n=15/32)

Only
42%

were confident about
managing their health
with their current hep
B knowledge

(n=13/31)



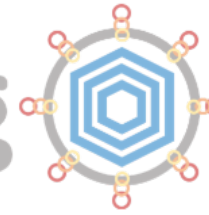
Results: support and information needs

Sources of information on lab results*

- Top support needs at diagnosis:
 - simple explanations of HBV
 - clear next steps (care, treatment, contact vaccination)
 - reassurance about living a healthy life
 - emotional support
- Any information they did receive or find was too technical, fragmented, or inaccessible.

Options	%	#
GP/healthcare specialist, nurse	44%	14
Websites	31%	10
Family	19%	6
Forum/online peer support group	16%	5
Friends or peers	16%	5
Community-based organisation	13%	4
Social media	9%	3
Printed brochures	6%	2
I don't look for information	6%	2
Medical conferences and seminars	3%	1

*multiple responses *allowed*, 32 respondents



Conclusions

- **Significant informational gaps** post-diagnosis, and during care.
- Diagnosis and care needs to address not just medical concepts but also psychological, social, and practical dimensions of living with HBV.
- Pressing need for clear, patient-centred, empathetic, multilingual, and trustworthy information.
- **Extension to survey still open!**



Empowering: HepExplain



Resources

Glossary

About

Australia/New Zealand  **HepExplain** Resources Glossary About

Can I pass Hep B to others? What is my risk of liver cancer? Should I start treatment? Should I stop treatment? **What does AFP mean?** What does my ultrasound mean?

HepExplain is for people who want to understand what their lab results and scans mean, and what HepExplain was designed to help you with.

[Update results](#)

What does AFP mean?

Your AFP is higher than normal.

AFP is also called Alpha fetoprotein and is made by the liver. Most people have very low levels of AFP. Sometimes AFP can go up if the liver is stressed, healing, or if there is an unusual growth, like cancer. On its own, an AFP blood test cannot be used to diagnose cancer. It is just one piece of information that helps your doctor to understand how healthy your liver is. Your doctor will look at many things, including ultrasound, other blood tests and your medical history, to understand AFP results.

Simple Technical

This can happen for many harmless reasons. A small rise like this can happen when your liver is healing or a bit inflamed, and usually improves on its own. Regular follow-up helps catch any changes early. It is important that you keep your next appointment with your doctor and get an ultrasound if you have not had one recently. Your doctor will probably do the test again or arrange another scan to keep an eye on things.

[Continue](#)

References

The threshold of 20–100 ng/mL owned the greatest sensitivity of 61.0%, and specificity 86%.

[The threshold of alpha-fetoprotein \(AFP\) for the diagnosis of hepatocellular carcinoma: A systematic review and meta-analysis](#)

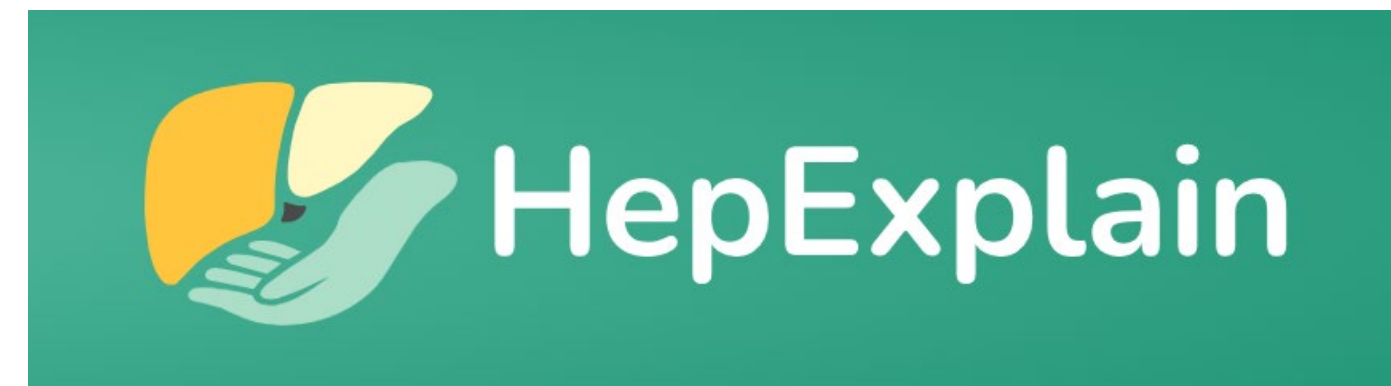
Which region?

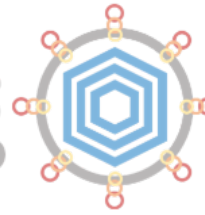
Different parts of the world have different rates of hepatitis B. Select the region you live in.

A

A co-designed webtool

- improve understanding of lab results
- best-practice recommendations
- empower PLWHB in their clinical management
- Printable report

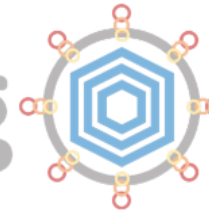




Facilitate leadership: National Consensus Community Statement on Hepatitis B Priorities

Study team: Joanne Carson, Marion Heriveau, Joanna Forbes



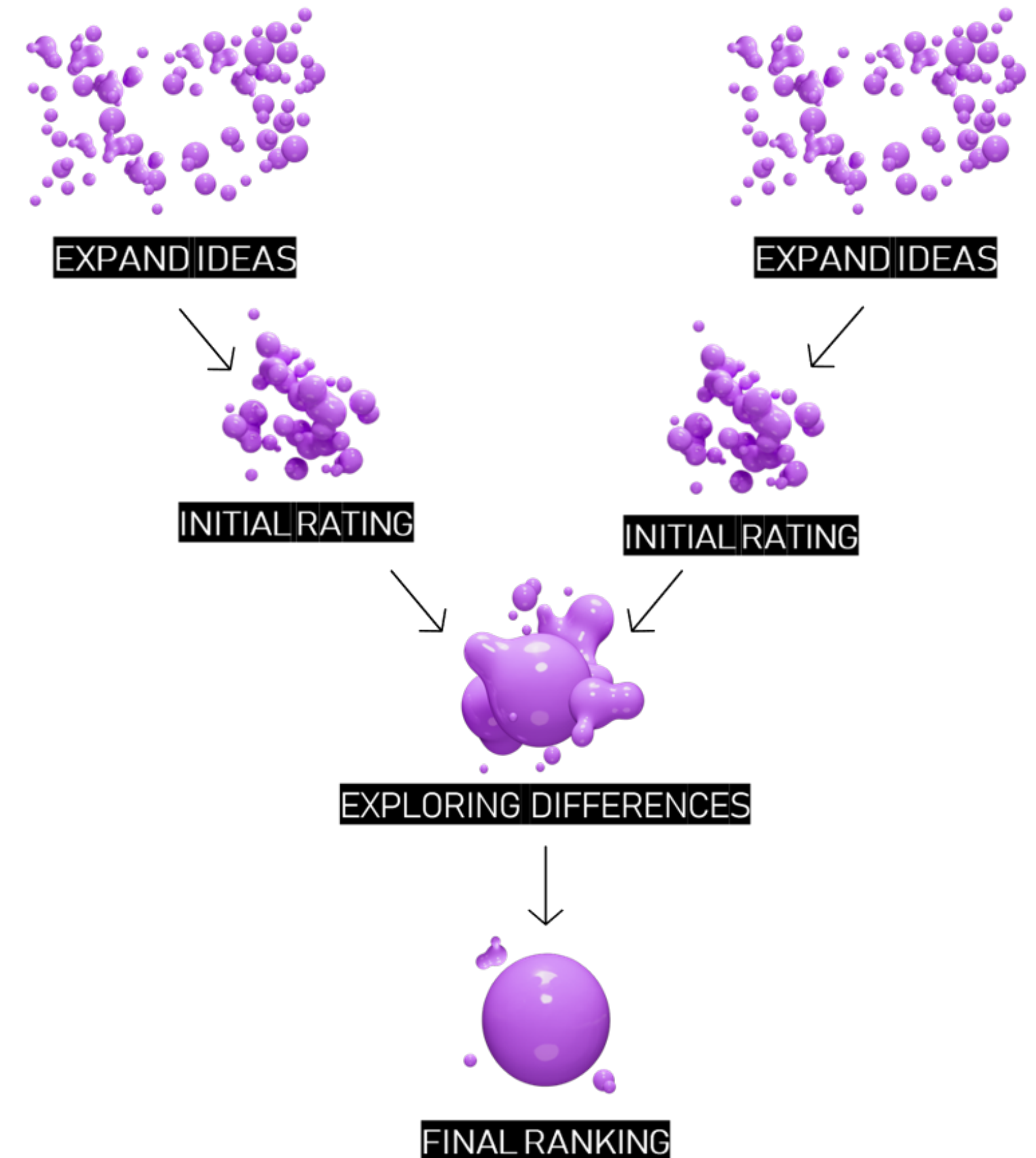


Background

- A key limitation is the **inconsistent integration of community perspectives** into decision-making.
- Hepatitis B Voices Australia is leading the development of the **first National Community Consensus Statement on Hepatitis B Priorities** centering lived experience.
- Centering people with lived experience as leaders in their own right

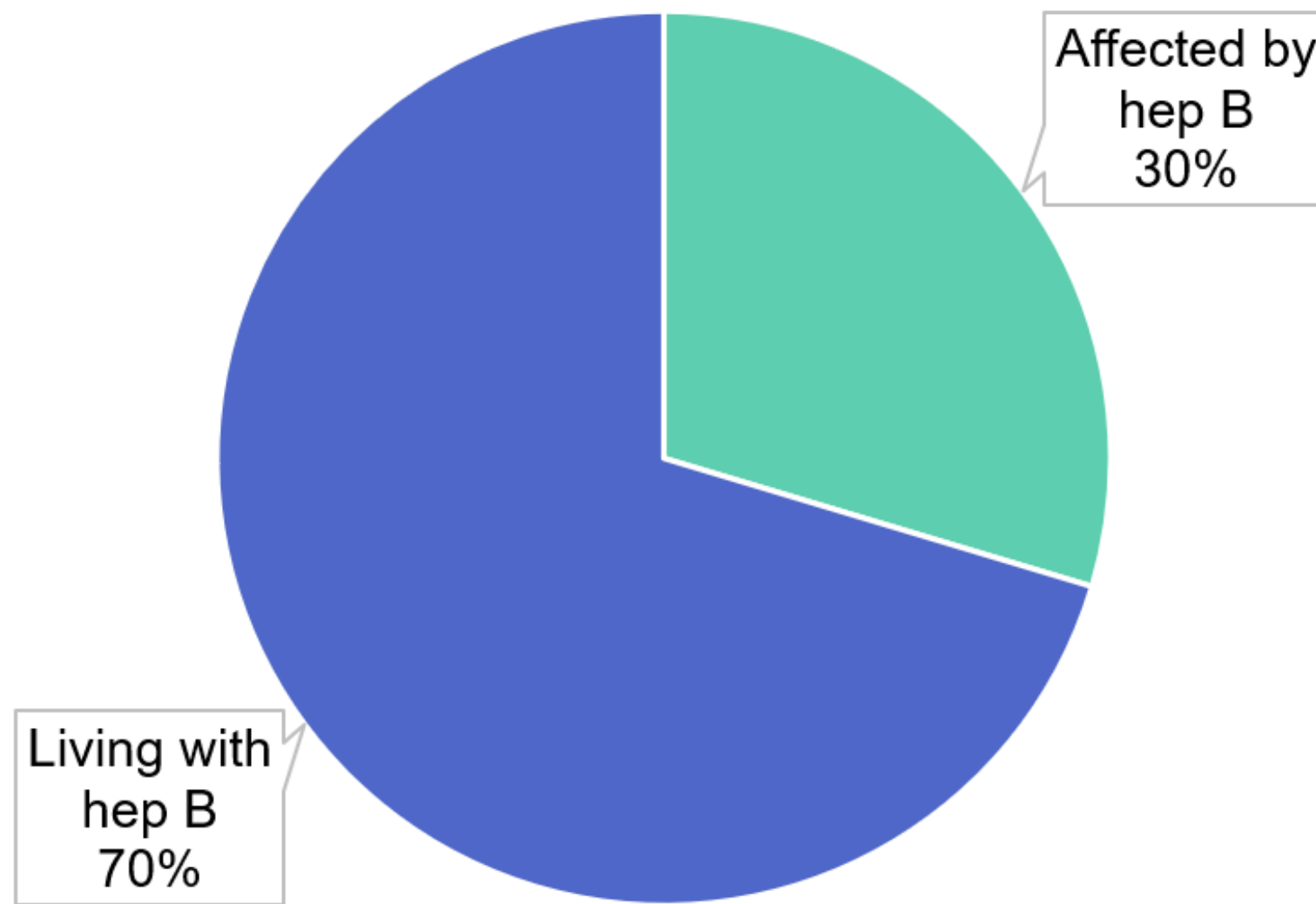
Methods: Parallel Panels

- Traditional expert-driven priority setting may reinforce existing blind spots
- **Modified Delphi design with parallel community and professions panels** provides a structured approach to integrate diverse forms of knowledge.
- Rather than suppressing disagreement this process **treats divergence as informative**, identifying tensions between priorities, feasibility, and lived realities.

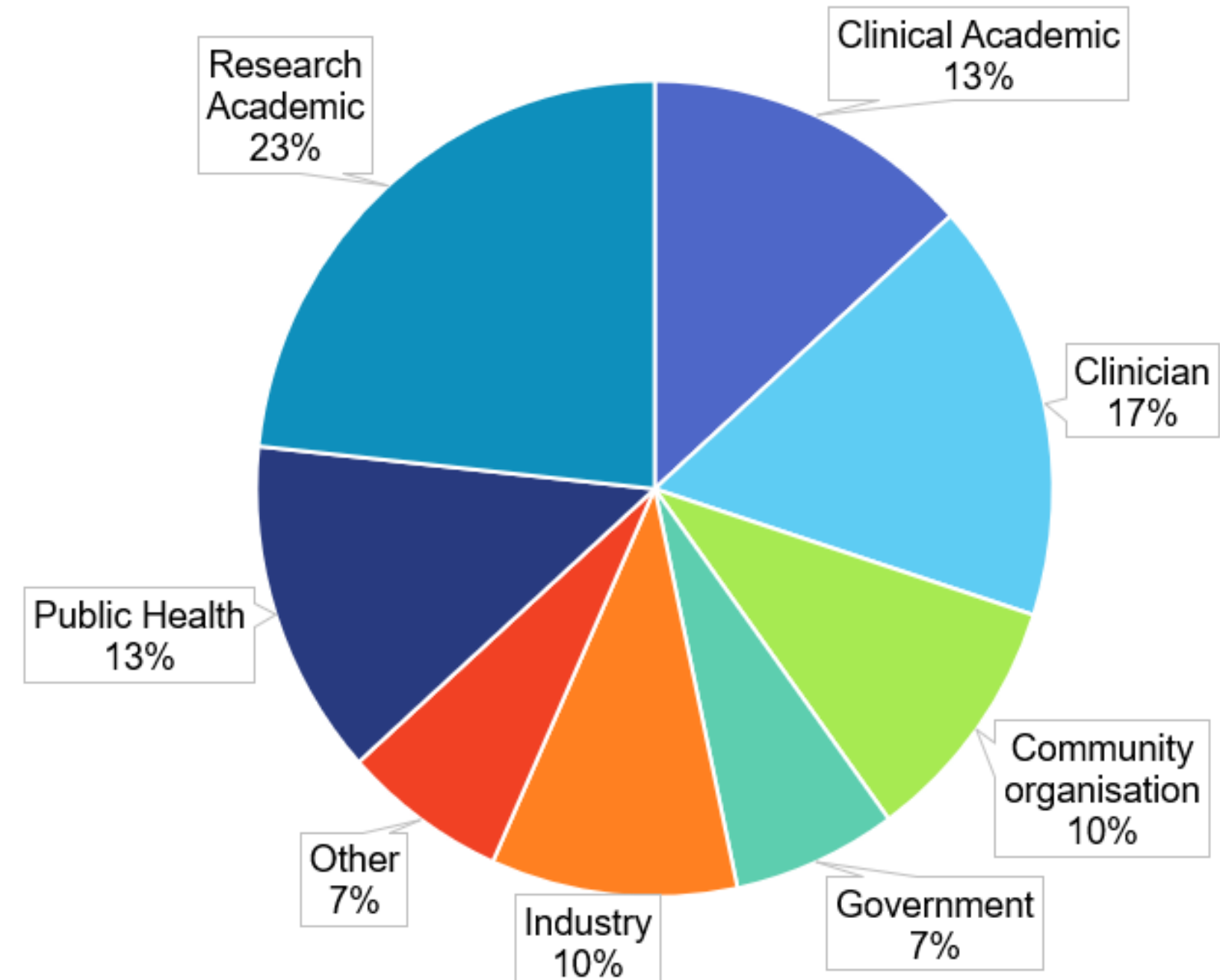




Methods: Panel composition



Community Panel (n=28)

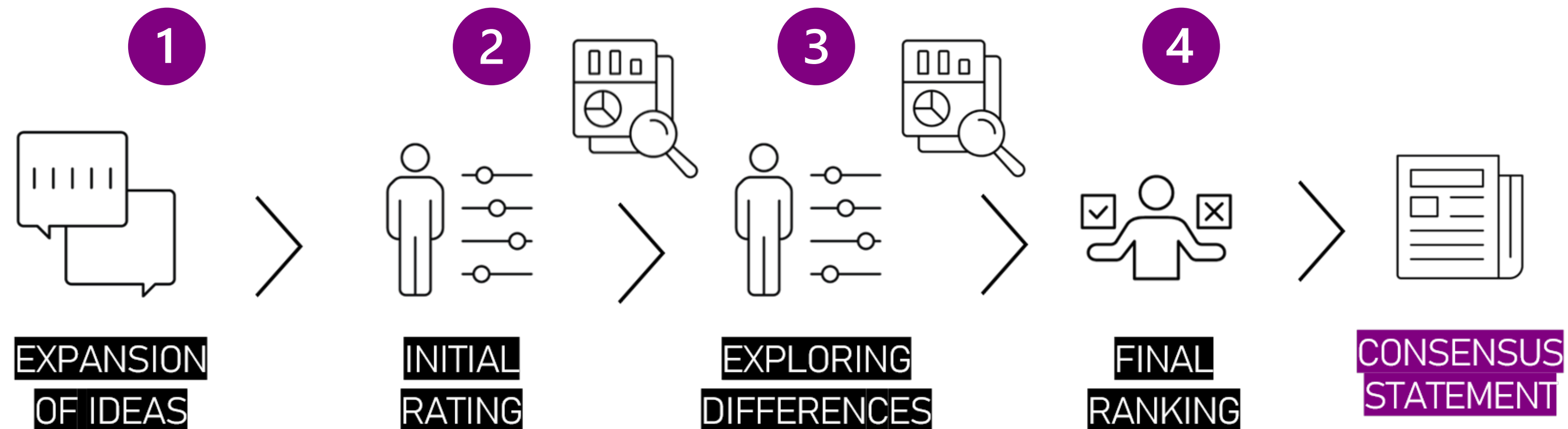


Professions Panel (n=29)



Methods: process stages

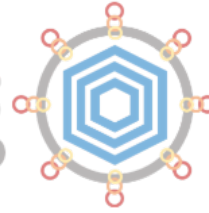
Round 3: priorities are consolidated, classified as shared or panel-specific, and re-rated after cross-panel reflection.



Rounds 1-2: panels independently generate and rate priorities in 4 domains: clinical care; research; community engagement; and policy and law.

Round 4: priorities get consolidated and ranked. Professions Panel: applies feasibility lens. Community Panel: determines final priorities.

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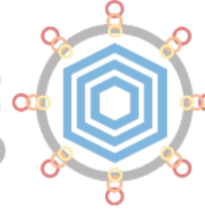
Results

*Speedy on
next year!*



Summary

This project establishes **the first community-led hep B priority framework** that aligns care, research, and policy with the priorities of people impacted by hep B.



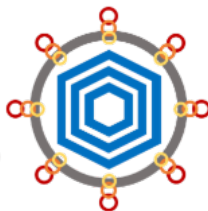
Conclusions

- Community engagement is **critical** for effective elimination efforts
- Lived experience is expertise
- Lived experience needs respect and support

Acknowledgements

**past members*

HepBcommunity.org



Leadership

Su Wang

Chari Cohen

Jessica Hicks

Paul Hartmann

Bright Ansah

Marion Heriveau (project manager)

Joanna Forbes (project manager)

*Joan Block**

Sumaya Mozumder (project manager)*

Mylisa Vu (project manager)*

Contributors/supporters

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John Tavis (ICE-HBV)

Andrew Vaillant (Replicor)

Tim Block (HBF)

Mark Douglas (SLC)

Carla Treloar (CSRH)

Loren Brener (CSRH)

David Carter (UNSW)

Simone Strasser (RPAH)

Eleonora Feletto (CCNSW)



Leadership

Thomas Tu

Nafisa Yussf

Lien Tran

Kim Ngo

Uyen Vo*

*Aye Aye Kiang**

Ambassadors

Ben Cowie

Lester Mascarenhas

Su Wang

Rob Moodie

Staff and support

Ha Ngyuen

Zhenni Jiang

Marion Heriveau

Joanna Forbes

Adi Mondell

All of our volunteers

*Mylisa Vu**

Sumaya Mozumder*

Jay Shivanna*

Financially supported and co-ordinated by:



Endorsed by:



Research



Kiri Lay



Loren Brener

Robyn Horwitz

Sylvester Okeke



Nicholas Massie

Mark Douglas

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Keshni Sharma

Allen Wu



UNSW
SYDNEY

Dr Joanne Carson

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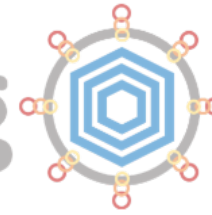
Gilead Sciences

.au domain admin

Commonwealth DoH

CC Vic

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Thank you!

Questions?