



# Increasing Testing and Management in High Risk Populations

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Australia  
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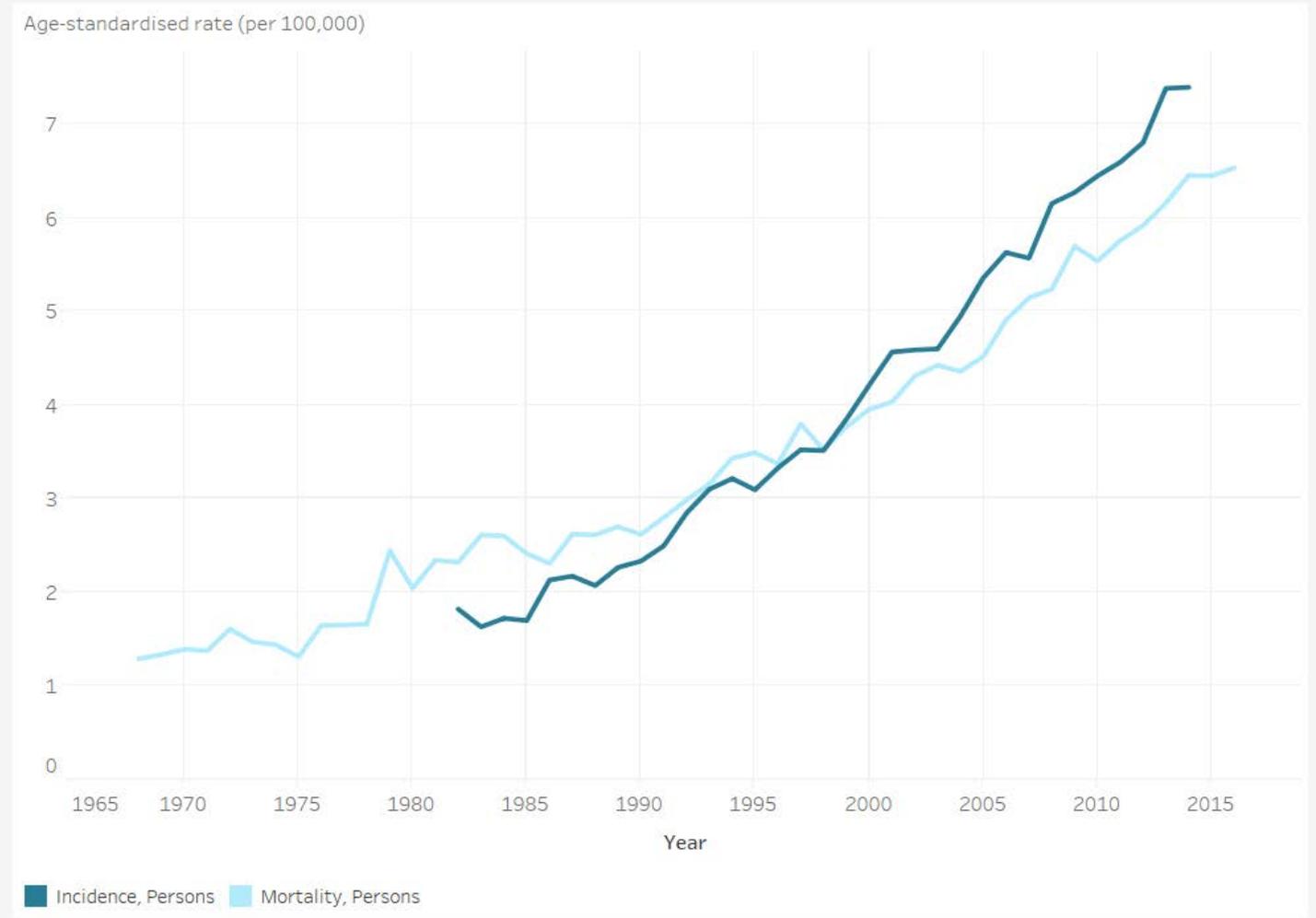
# Disclosures

No conflicts of interest to declare

# Outline

- Overview of HCC/liver cancer incidence and mortality in Australia
- Will explore the cascade of care for hepatitis B to
  - explore the barriers to treatment and care
  - provide examples of programs and systems

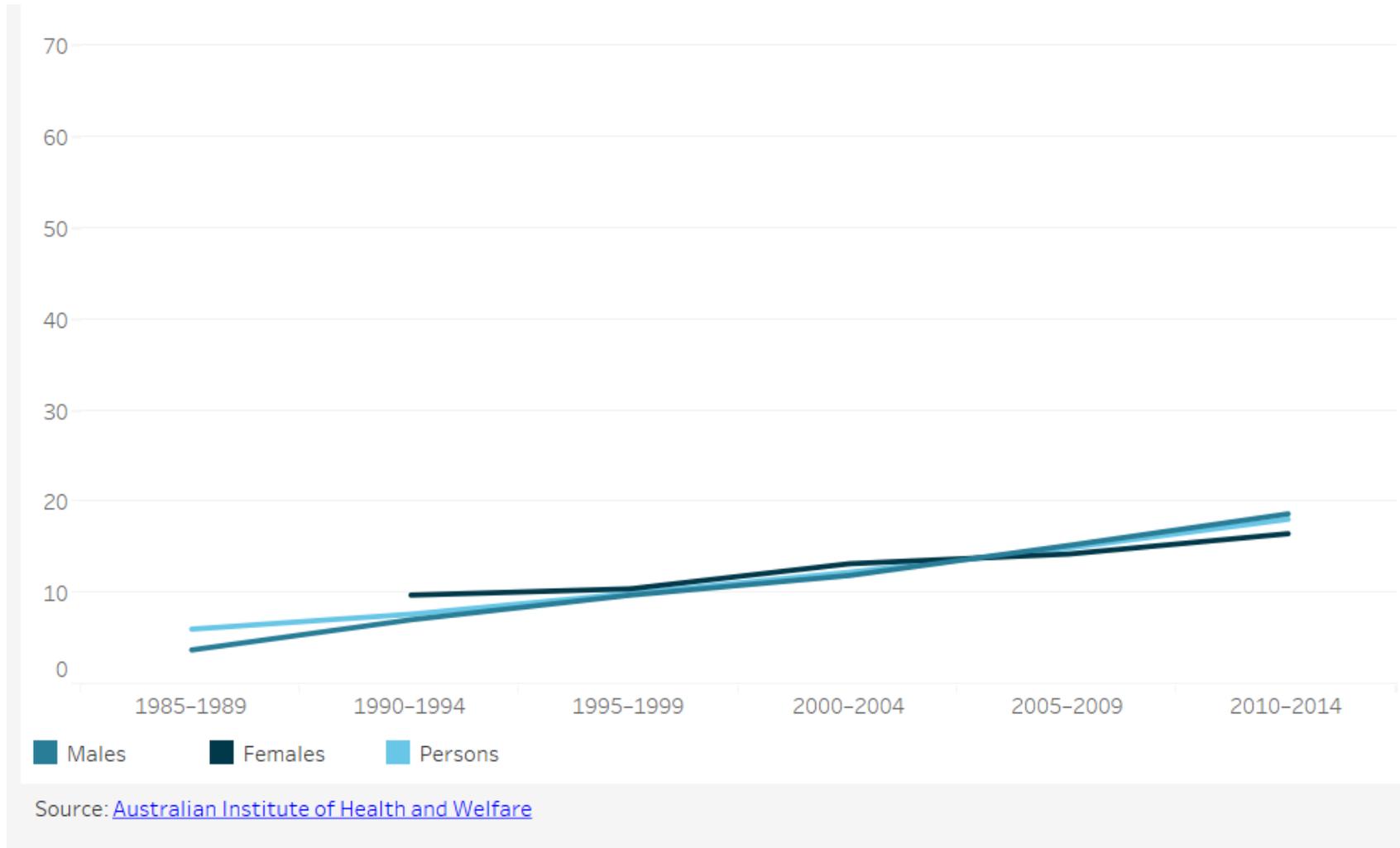
# Age standardised rates for liver cancer incidence and mortality, Australia



Source: [Australian Institute of Health and Welfare](https://www.aihw.gov.au/reports/cancer/cancer-compendium-information-trends-by-cancer/reportcontents/livercancer)



# 5 year liver cancer survival rates, Australia



# Causes of liver cancer and risk groups

Leading cause in Australia and globally;

➡ Unmanaged chronic hepatitis C and hepatitis B infection

Other factors that increase risk:

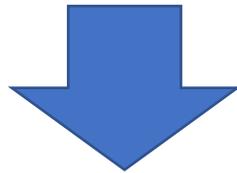
➡ liver damage, fatty liver disease or smoking, type 2 diabetes, high alcohol consumption, obesity related liver disease

- Incidence is higher for men and women born in Southern Europe, the Middle East & North Africa, and South-East and North-East Asia
- Incidence and mortality is also higher for Aboriginal people



# Cancer control has a role

- Increasing early diagnosis of viral hepatitis through screening/testing
- Increasing antiviral treatment for chronic hepatitis infection
- Increasing liver cancer surveillance for at risk population groups



Examine the barriers and enablers to identify possible interventions and strategies

# Testing and treatment barriers

## Barriers within health care services<sup>6,7,8,9,10</sup>

- Poor clinician awareness of hepatitis and the link to cancer
- Poor identification of priority groups for screening
- Uncertainty around treatment, monitoring /liver cancer screening
- Low number of general practitioners who can prescribe antivirals

# Barriers to testing and treatment in affected communities

Poor knowledge and perception of risk<sup>1,2,3,4,5</sup>

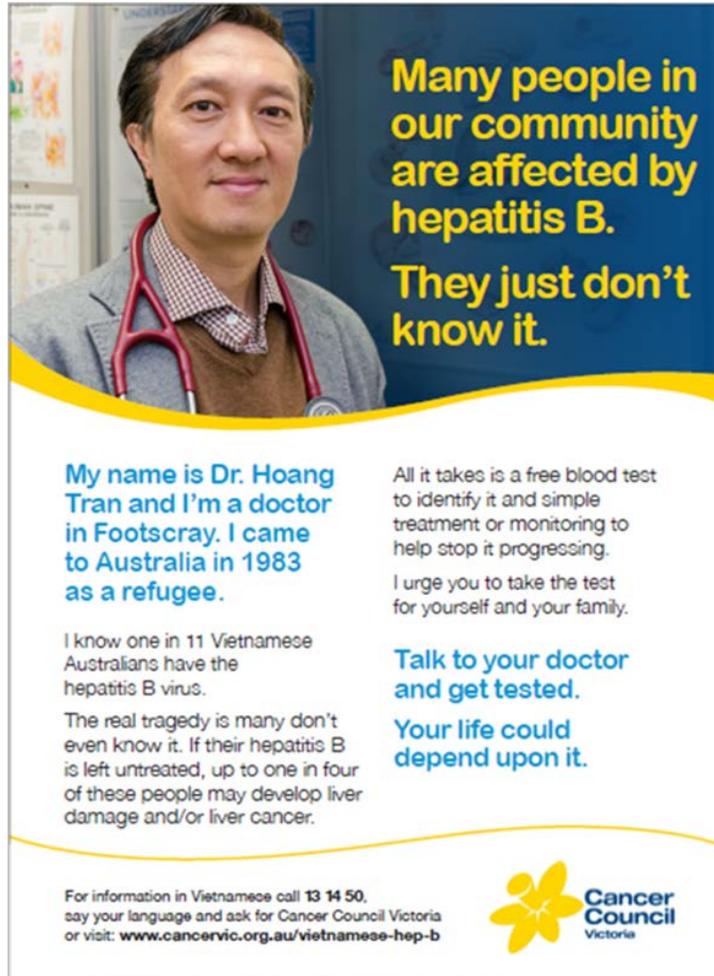
- Link between CHB and liver cancer
- Hepatitis B 'less of a problem' in Australia
- Transmission routes and risk factors
- Awareness of treatment, prevention

# Increasing diagnosis and treatment rates

## Pilot Hepatitis B Registry for Liver Cancer Prevention, Cancer Council NSW > B Positive Program

- Established antiviral treatment was more cost effective than liver cancer surveillance alone
- Piloted a screening and management program (N=1500)
- Supported general practitioners with a registry system
- Increased treatment rates to an optimal 18%

# Increasing understanding and diagnosis in affected communities



**Many people in our community are affected by hepatitis B. They just don't know it.**

**My name is Dr. Hoang Tran and I'm a doctor in Footscray. I came to Australia in 1983 as a refugee.**

I know one in 11 Vietnamese Australians have the hepatitis B virus.

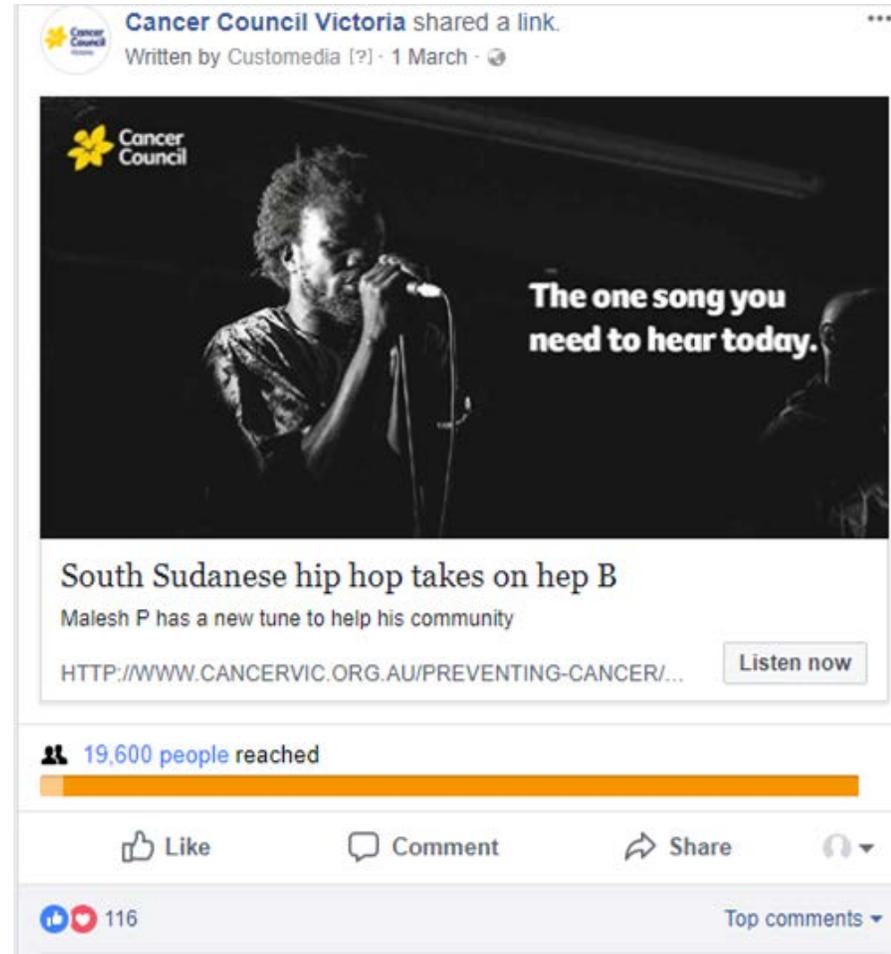
The real tragedy is many don't even know it. If their hepatitis B is left untreated, up to one in four of these people may develop liver damage and/or liver cancer.

All it takes is a free blood test to identify it and simple treatment or monitoring to help stop it progressing.

I urge you to take the test for yourself and your family.

**Talk to your doctor and get tested. Your life could depend upon it.**

For information in Vietnamese call **13 14 50**, say your language and ask for Cancer Council Victoria or visit: [www.cancervic.org.au/vietnamese-hep-b](http://www.cancervic.org.au/vietnamese-hep-b)



Cancer Council Victoria shared a link.  
Written by Customedia [?] · 1 March · 🌐



**The one song you need to hear today.**

**South Sudanese hip hop takes on hep B**  
Malesh P has a new tune to help his community

[HTTP://WWW.CANCERVIC.ORG.AU/PREVENTING-CANCER/...](http://www.cancervic.org.au/preventing-cancer/...) [Listen now](#)

👤 19,600 people reached

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👍❤️ 116    [Top comments](#)

# Increasing liver cancer surveillance – major gap in supporting structures

Current Australian recommendations for liver cancer surveillance for people with chronic hepatitis B infection

All people with cirrhosis

Those with a first-degree family history of HCC

Asian men aged >40 years, and Asian women aged >50 years

African people aged >20 years

Aboriginal or Torres Strait Islander people aged >50 years

# Increasing liver cancer surveillance for people with hepatitis B

- Liver cancer audit at a community health center
- Hospital based nurse supported surveillance
  - 67 participants; 27% came every 7 months (good adherence);
  - 43% had less than 2 scans in 14<sup>th</sup> months (sub optimal adherence)
  - 30% had less than one scan every 14 months (poor adherence)
- Concluded, adherence is difficult even with extra support

# Conclusions

- In Australia, diagnosis and management in primary care needs to improve for the reduction of liver cancer
- Liver cancer screening needs further investigation and improvement
- Any major program or system change needs collaboration between hepatitis sector, cancer organisations and the affected communities



**Thank you.**  
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# Effective public policy and addressing the lived experience

Jack Wallace, Senior Research Officer

## Role of Public Policy

- Aims to establish a context to increase access of people with viral hepatitis to health services
- **Global**
  - WHO “expert committee” on viral hepatitis (1953)
  - Immunisation programs (1984 – onwards)
  - World Health Assembly resolution on viral hepatitis (2010)
  - *Global Health Sector Strategy on Viral Hepatitis 2016-2021*
  - *Guidelines for the prevention, care and treatment of persons with chronic hepatitis B infection* (2015)
  - *Guidelines on hepatitis B and C testing* (2017)

# Lived experience - public policy development

- Australian National Hepatitis C Strategy
  - People affected were included in development
  - Broad community consultation for development of first strategy
  - Social research was available to use - needs assessment, with community consultation providing validation

# Social Research - public policy development

- Provide alternative to clinical perspective
- Recognises that viral hepatitis occurs in a social context
- Highlights that social implications of infection essentially affect health care access

# Hepatitis B Testing

- Objectives
  - Inform a person with hepatitis B that they have the infection
  - Identify the clinical state of the infection within an individual patient
  - Provide data to the health system.
  - For a person with hepatitis B, their diagnosis becomes the first part of a life-long journey and is a point where their life, and the lives of many of their families, are essentially transformed.



# Hepatitis B Testing: the lived experience

*I didn't have an understanding of it, either in my own culture and language (or) in English. And when he first saw me, he's like, "Sorry, you've got hepatitis B." But, I wasn't expecting it so there was ... no discussion about it and what that meant for me. ... It was a bit of a shock, but I really didn't understand it (mid-20s African-born woman, Melbourne).*

*There was (a test) before going to high school, during which I was found to be a hepatitis B carrier... the teacher posted the health check results on the classroom wall ... so individual students could go and check what sort of problems they had, for example, short-sightedness. (25-30yo woman, Shanghai)*

*In grade 3, 9 years old ... 15-18 of us were invited into another room, and said that "yes, you guys are hepatitis B carriers" (35-year-old man, Guangzhou)*

## Testing: the lived experience

*My parents have it, my relatives on my mother's side have it, two of my mother's siblings. My mother's younger sister and younger brother and younger brother's daughter have it. My father died of liver cancer when I was around 16 years old (25-30yo man, Guangzhou).*

*At first it was my daughter who got sick with hepatitis B, and ... the professor (at the hospital) told me: "Your daughter has hepatitis B, it's better for the parents to have a check-up as well." ... So, both me and my wife had a check-up ... and were diagnosed with hepatitis B. I had hepatitis B E-positive, my wife had E-negative, my daughter was also E-positive (35 year-old man, Guangzhou)*

# Testing:

- No consent
- Lack of confidentiality
- Cost
- Asymptomatic
- Lack of routine screening
- Poor response to ante-natal testing
- Poor access to health services
- Lack of awareness of health services
- **How does a person make sense of hepatitis B?**

# Testing: the policy response

- Global
  - Focus on infrastructure/experience of hepatitis C/individual experience
  - Little qualitative information
- Australia
  - Who uses them?
  - Testing policy developed + not implemented
- **Who benefits from testing?**

# Clinical management

- Incurable
- Long-term monitoring
- Anti-virals: entecavir, tenofovir, lamivudine, adefovir, and telbivudine
- Specialist services

# Clinical management: the lived experience

*My body is normal, there's nothing different about it so I don't have any treatment...there are no physical manifestations...people say that your skin must be yellow, your eyes must be yellow (45-year old Vietnamese-born woman, Melbourne)*

*If I become sick, then they call it the C virus don't they? It's like I have the B virus [now] and if I become sick, if [the virus] is not sleeping, then I will be sick and it's called C... (44-year old Vietnamese woman, Melbourne).*

# Clinical monitoring: the lived experience

*I said, "you should give me some medication because I have liver disease and if I don't take any medication then later on, the virus will wake up and it will eat my liver. Then I will have cancer and die". They didn't give me any medication... They need to give me medication! (52-year old Chinese born man, Melbourne)*

*I need to compare the price, especially when I need to choose between long-term medication and short-term medication, but on the other hand, I need to find out whether expensive medication is more effective than cheaper ones.  
(30-year old man, Beijing)*

# Clinical management: the challenges

- Asymptomatic incurable infection
- Limited awareness that treatment is available
- Impact of marginalisation on access
- Policies are developed by, and for specialists
- Cost of treatments (in Asia)
- Lack of specialists
- **Are hepatitis B clinical models human, viral or liver centred?**

# Social Implications

*Recently I have been looking to start a relationship. I have met four or five boys but because of this disease, I was rejected by them all  
(25-30yo woman, Shanghai).*

*Most of the time people with hep B are like a vampire movie – we cannot go into the sunshine, and you cannot let people know who you really are. There is always some wall between you and others (20-25yo woman, Beijing).*

# Discrimination

*I am an intern, and my company is planning to arrange an internal group health check for hepatitis in July... I am very worried that if the results showed that I had it, the company may ask me to leave or something... I heard that there's a medication which can temporarily turn the result from positive into negative. ... There seems to be no other way (20-25yo woman, Guangzhou).*

*I was forced to work in the small (factory), because large factories conduct health checks ... To enter big factories, I might need to bribe the staff by giving them a couple thousand RMB (35-40yo man, Guangzhou).*

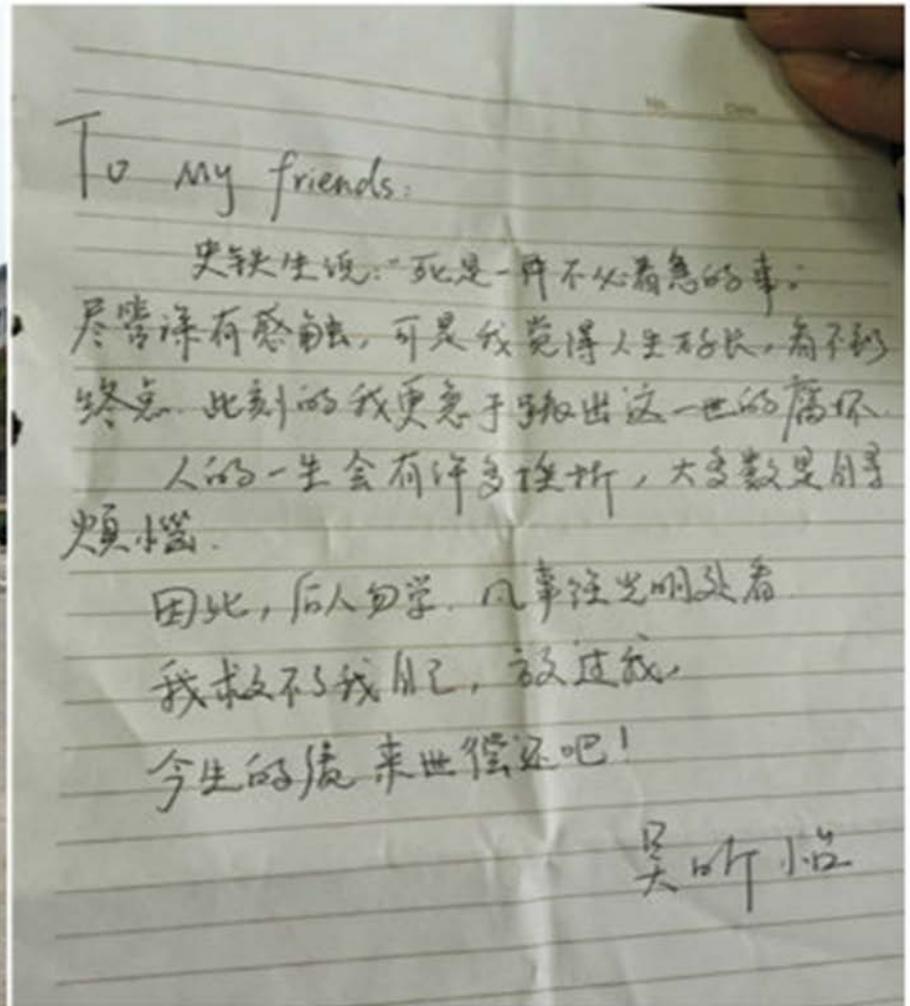
# Literature interest

Infection + stigma	No of articles
HIV	3589
AIDS	2482
Hepatitis C	104
Hepatitis B	49

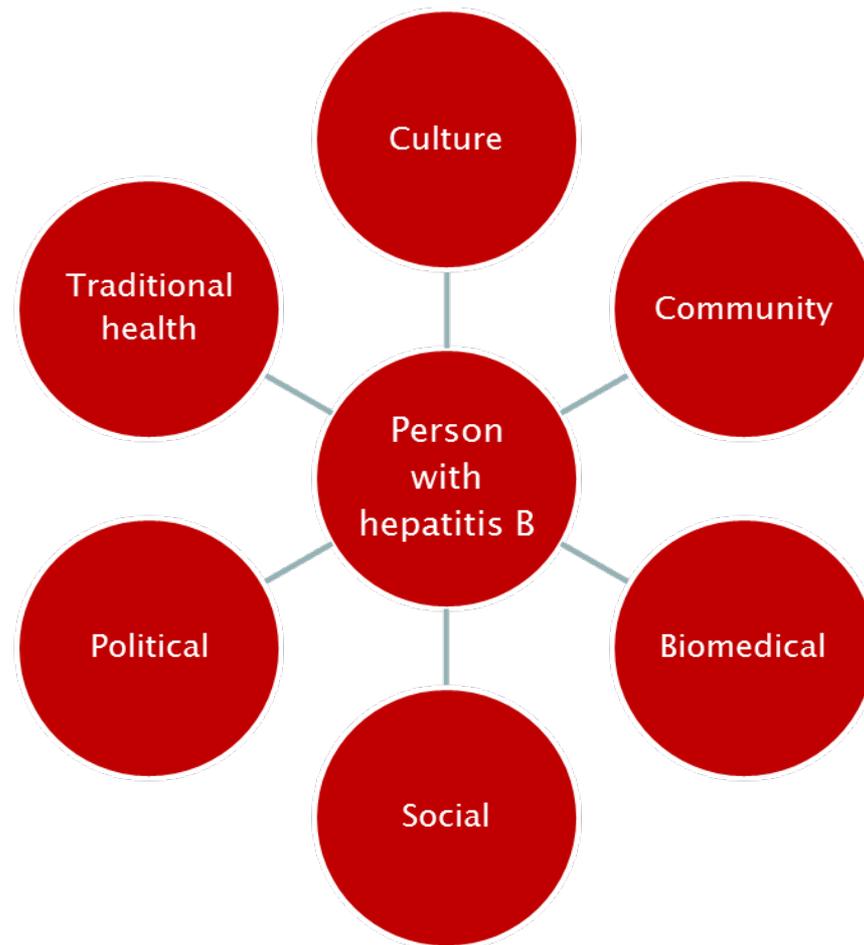
# Stigma, discrimination and marginalisation

- Different experience in different countries/within countries
- Different sources in different countries
- Neglects regulations marginalising people
  - No discussion of cross border impact
  - Immigration/work visa
- Regular and ignored calls for awareness campaigns
- Is health seeking influenced by marginalisation of people with hepatitis B in their country of origin?
- **Who wins from stigma?**

# Hepatitis B: A social disease



# A comprehensive response:



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