



A joint venture between The University of Melbourne and The Royal Melbourne Hospital

Who is being left behind? Insights into care of individuals living with hepatitis B in Australia from linked data

Jennifer MacLachlan, Nicole Romero, Anh Nguyen,
Nicole Allard, Benjamin Cowie
WHO Collaborating Centre for Viral Hepatitis
at The Doherty Institute

jennifer.maclachlan@mh.org.au

Australasian Viral Hepatitis Conference
6th -8th August 2025

Acknowledgements



- Acknowledgement of Country
- This work is conducted as part of the National Viral Hepatitis Mapping Project, conducted in partnership with ASHM Health and supported by the Australian Government Department of Health, Disability and Ageing
- Data provided by the Australian Bureau of Statistics (ABS) via the Person-Level Integrated Data Asset (PLIDA)
- Feedback provided by our Research Advisory Group and the Annual Surveillance Reports Cascades of Care Reference Group

Background: policy context

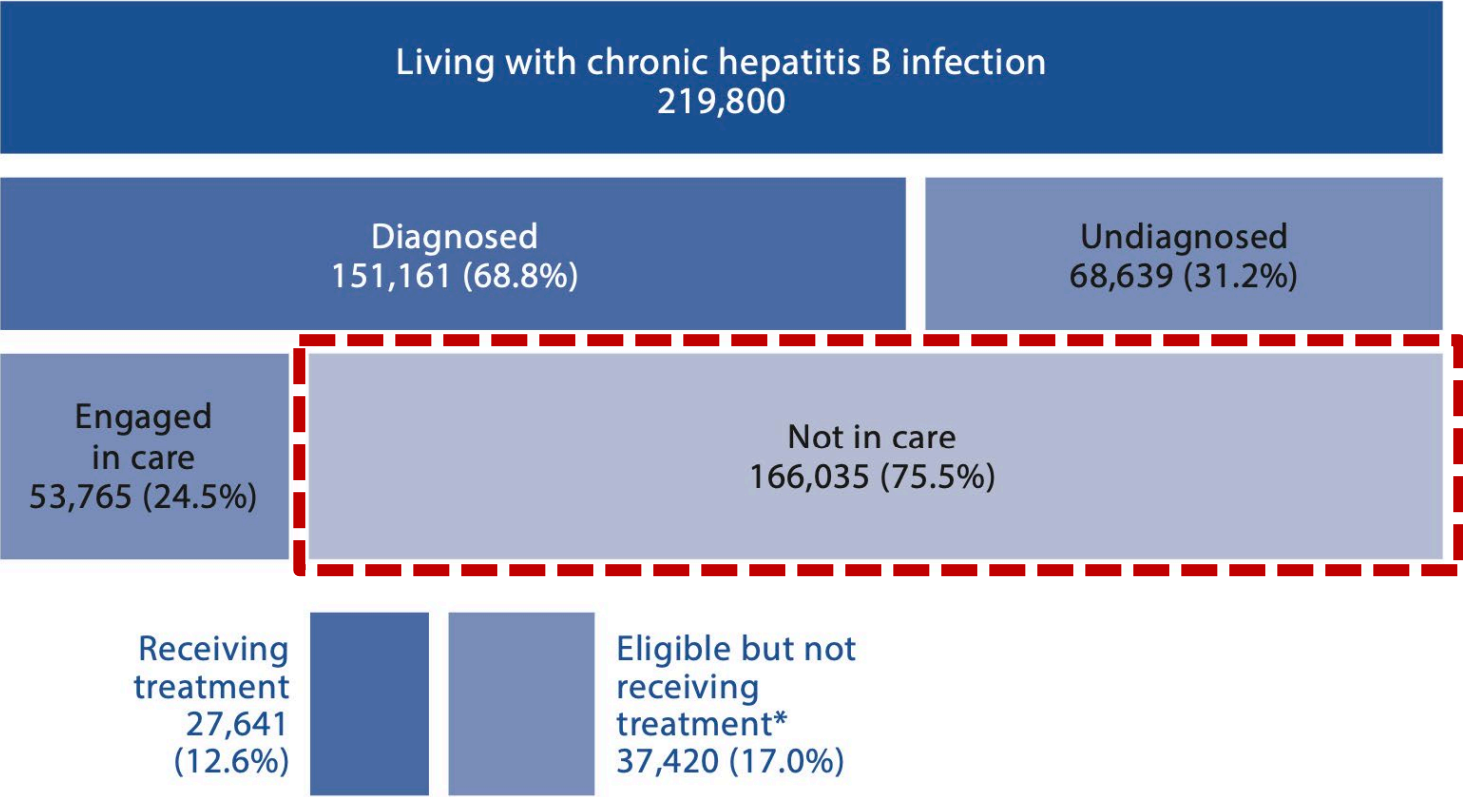


- Australia has committed to ambitious targets as part of the National Hepatitis B Strategy, including improvements in the cascade of care, where there are significant gaps

Background: policy context



- Australia has committed to ambitious targets as part of the National Hepatitis B Strategy, including improvements in the cascade of care, where there are significant gaps



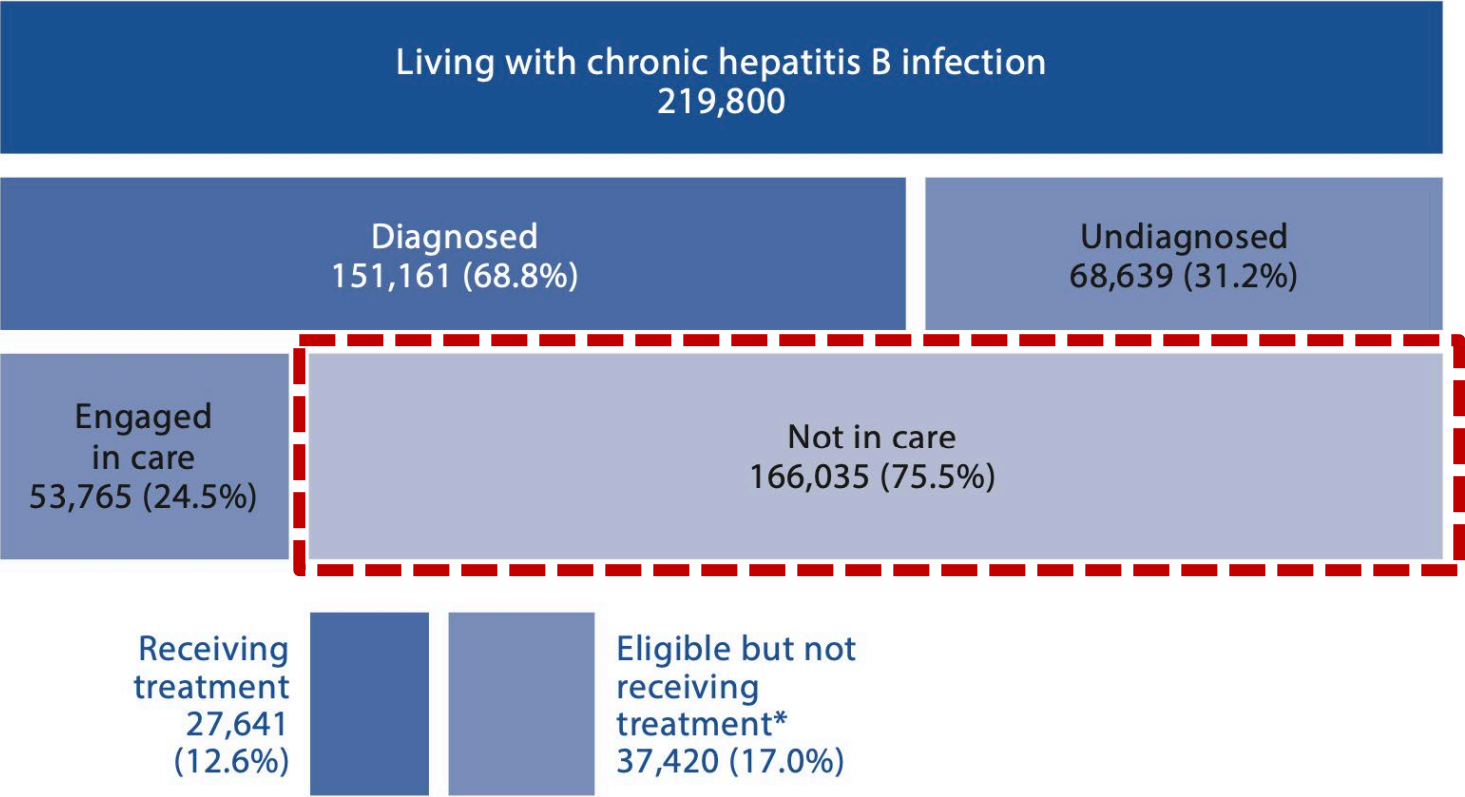
Care defined as viral load testing or treatment in the last year

Source: The Doherty Institute - National Surveillance for Hepatitis B Indicators Report 2023

Background: policy context



- Australia has committed to ambitious targets as part of the National Hepatitis B Strategy, including improvements in the cascade of care, where there are significant gaps



Care defined as viral load testing or treatment in the last year

TARGET by 2030: 80%

Source: The Doherty Institute - National Surveillance for Hepatitis B Indicators Report 2023

Background: key evidence gaps



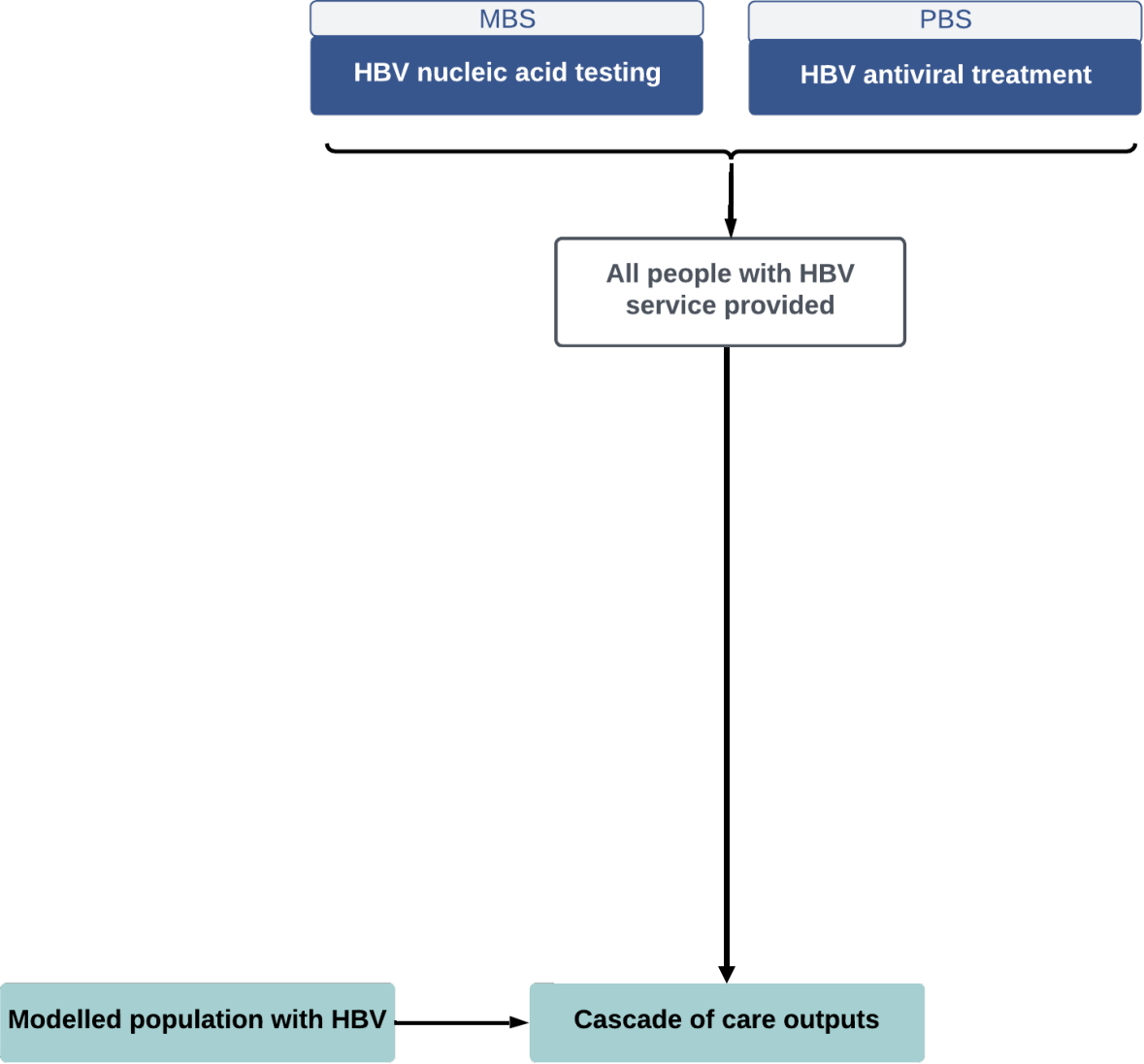
1. Do care and treatment uptake vary by priority population?
2. What is the uptake of other guideline-based care, such as HCC surveillance?
3. Are people receiving viral load testing consistently over time?
4. Are people dropping out of antiviral treatment?

Background: key evidence gaps

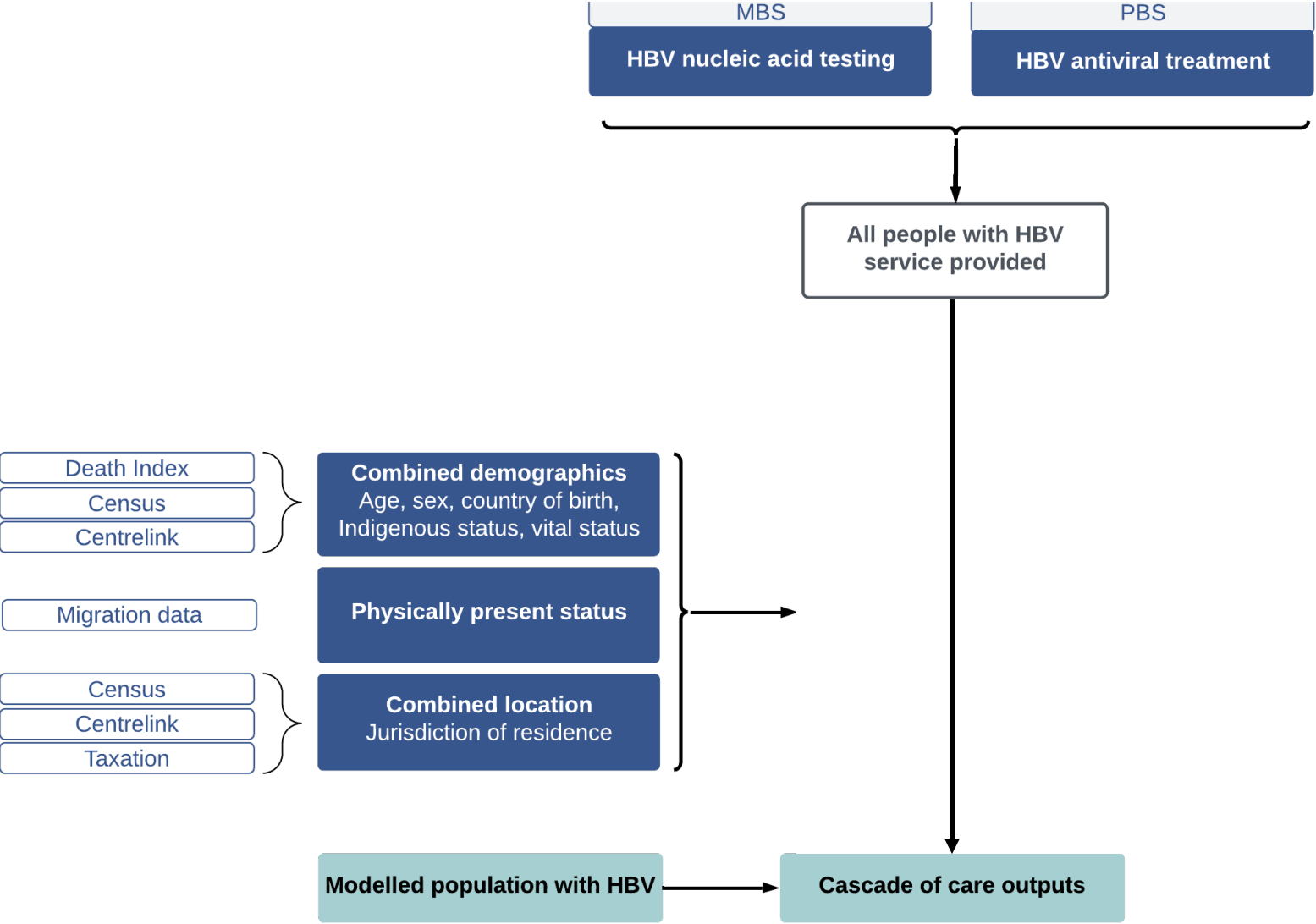


1. Do care and treatment uptake vary by priority population?
 2. What is the uptake of other guideline-based care, such as HCC surveillance?
 3. Are people receiving viral load testing consistently over time?
 4. Are people dropping out of antiviral treatment?
- Linked data provides the opportunity to assess these questions for the first time at the national level

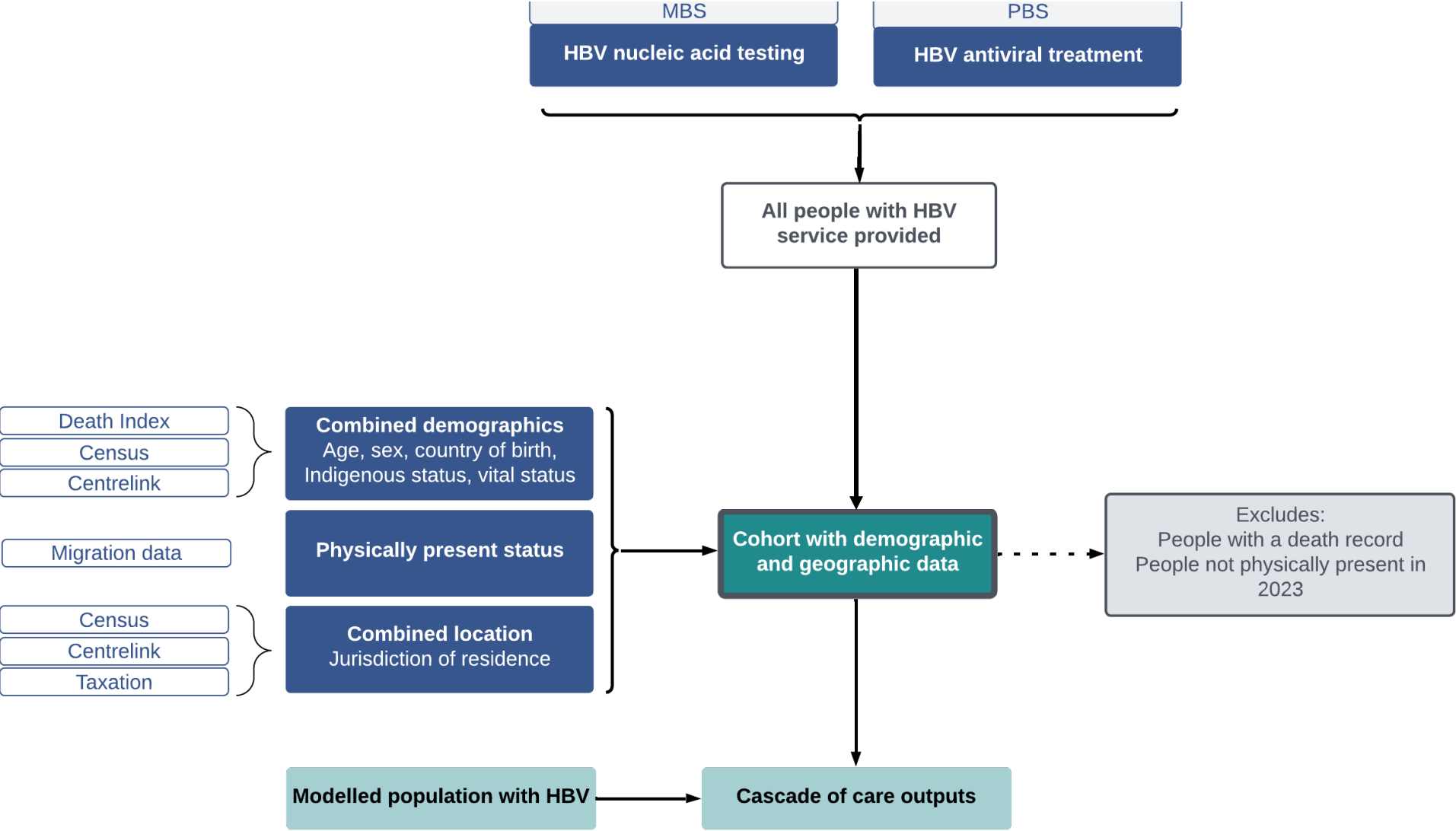
Data sources: previous evidence



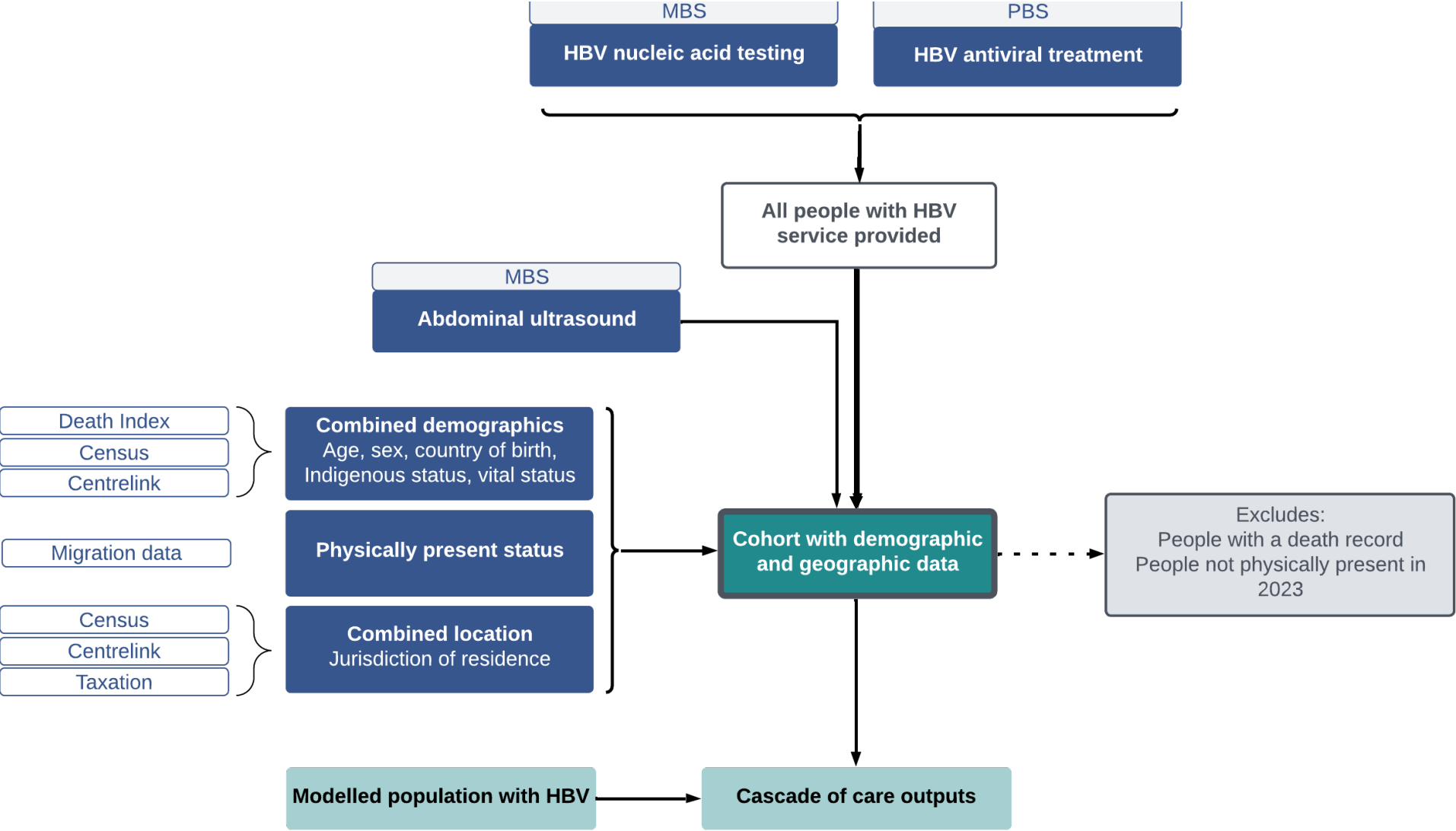
Data sources: what linked data adds



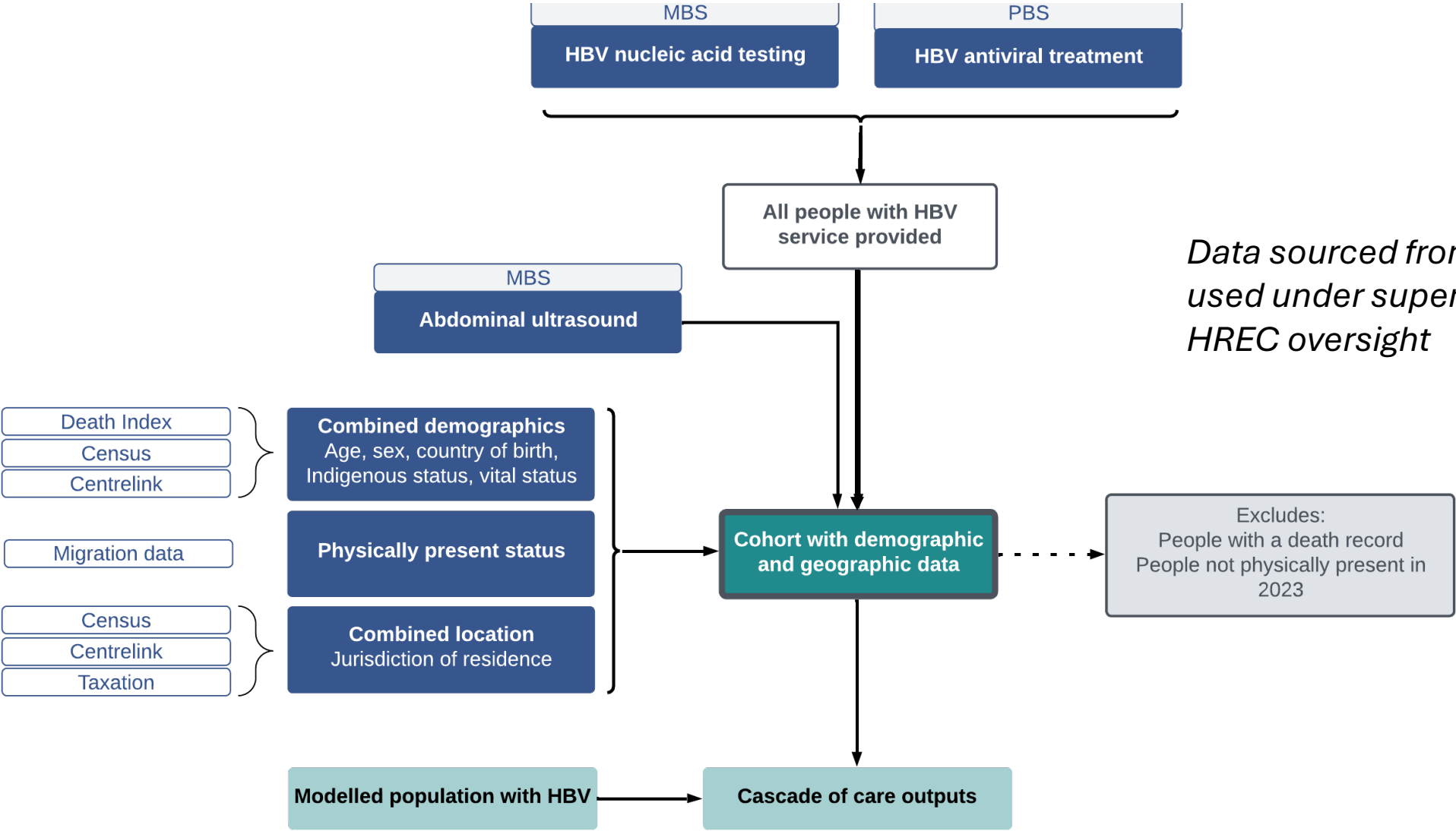
Data sources: what linked data adds



Data sources: what linked data adds



Data sources: what linked data adds



Data sourced from ABS PLIDA data, used under supervision and with HREC oversight

Outcome definitions: care uptake by priority population



- *Outcome 1: Does care and treatment uptake vary by priority population?*

Treatment uptake and care uptake (treatment or viral load testing) during 2023, measured against total estimated population with CHB

Country of birth and Indigenous status sourced from other linked datasets

Denominator generated using mathematical modelling and population-specific prevalence

Outcome definitions: HCC surveillance



- *Outcome 2: what is the uptake of other guideline-based care, such as HCC surveillance?*

Eligibility based on age group and country of birth and Indigenous status

Table 17. Populations with chronic hepatitis B in whom surveillance for HCC should be performed

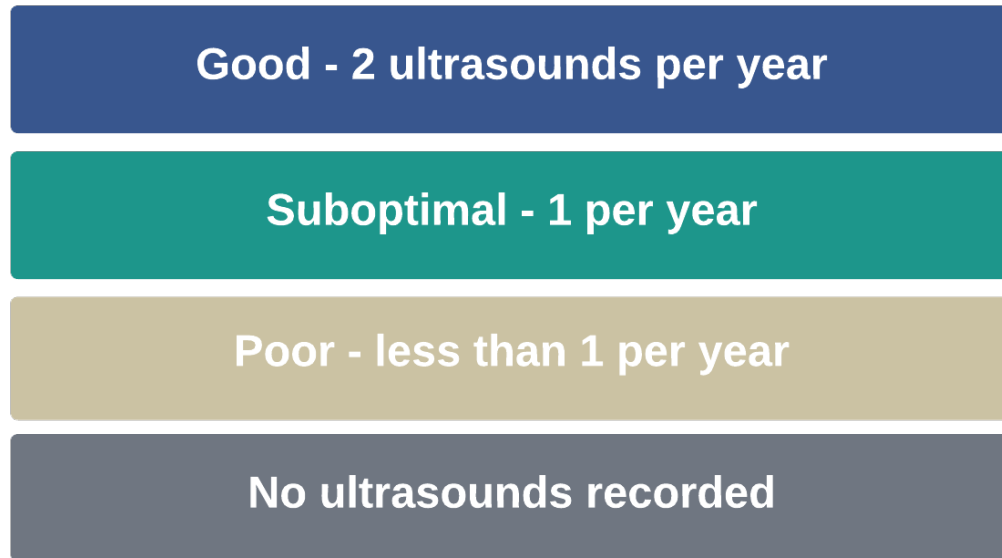
Population
• People with cirrhosis
• People <i>without</i> cirrhosis:
▶ Asian men older than 40 years
▶ Asian women older than 50 years
▶ Sub-Saharan Africans older than 20 years*
▶ Aboriginal and Torres Strait Islander people older than 50 years [†]
▶ With coinfection with hepatitis delta virus
▶ With family history of HCC (first-degree relative)
▶ Observed HBsAg loss with prior indications for HCC surveillance
• Other high-risk groups in whom surveillance can be considered:
▶ People from other racial groups, according to risk scores (e.g. PAGE-B)
▶ Māori and Pacific Islander men older than 40 years and women older than 50 years*

Outcome definitions: HCC surveillance



- *Outcome 2: What is the uptake of other guideline-based care, such as HCC surveillance?*

Number of ultrasounds per year on average during time eligible, categorised using existing framework¹:

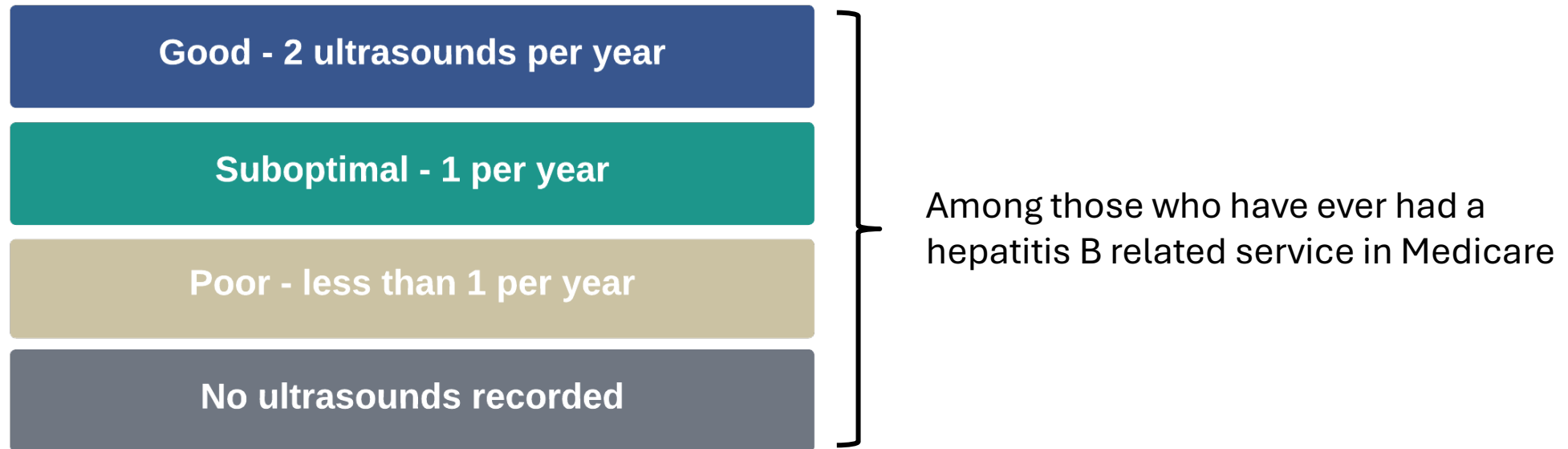


Outcome definitions: HCC surveillance



- *Outcome 2: What is the uptake of other guideline-based care, such as HCC surveillance?*

Number of ultrasounds per year on average during time eligible, categorised using existing framework¹:



Outcome definitions: care consistency and uptake



- *Outcome 3: Are people receiving viral load testing consistently over time?*

Among people who received a viral load test but not treatment during 2014-2023

Divided into categories by time period:

Viral load test during:		
2014-2016	2017-2019	2020-2023

Consistently received viral load testing

Started receiving viral load testing

Stopped a then started receiving viral load testing

Receiving viral load testing then stopped

Outcome definitions: care consistency and uptake



- *Outcome 4: Are people dropping out of antiviral treatment?*

Population: People who received antiviral treatment for 2+ years during 2014-2023

Assessed against 80% threshold for sufficient viral suppression

Consistently received antiviral treatment

Received antiviral treatment but then stopped

Received inconsistent / non-adherent antiviral
treatment

Outcome definitions: care consistency and uptake



- *Outcome 4: Are people dropping out of antiviral treatment?*

Population: People who received antiviral treatment for 2+ years during 2014-2023

Assessed against 80% threshold for sufficient viral suppression

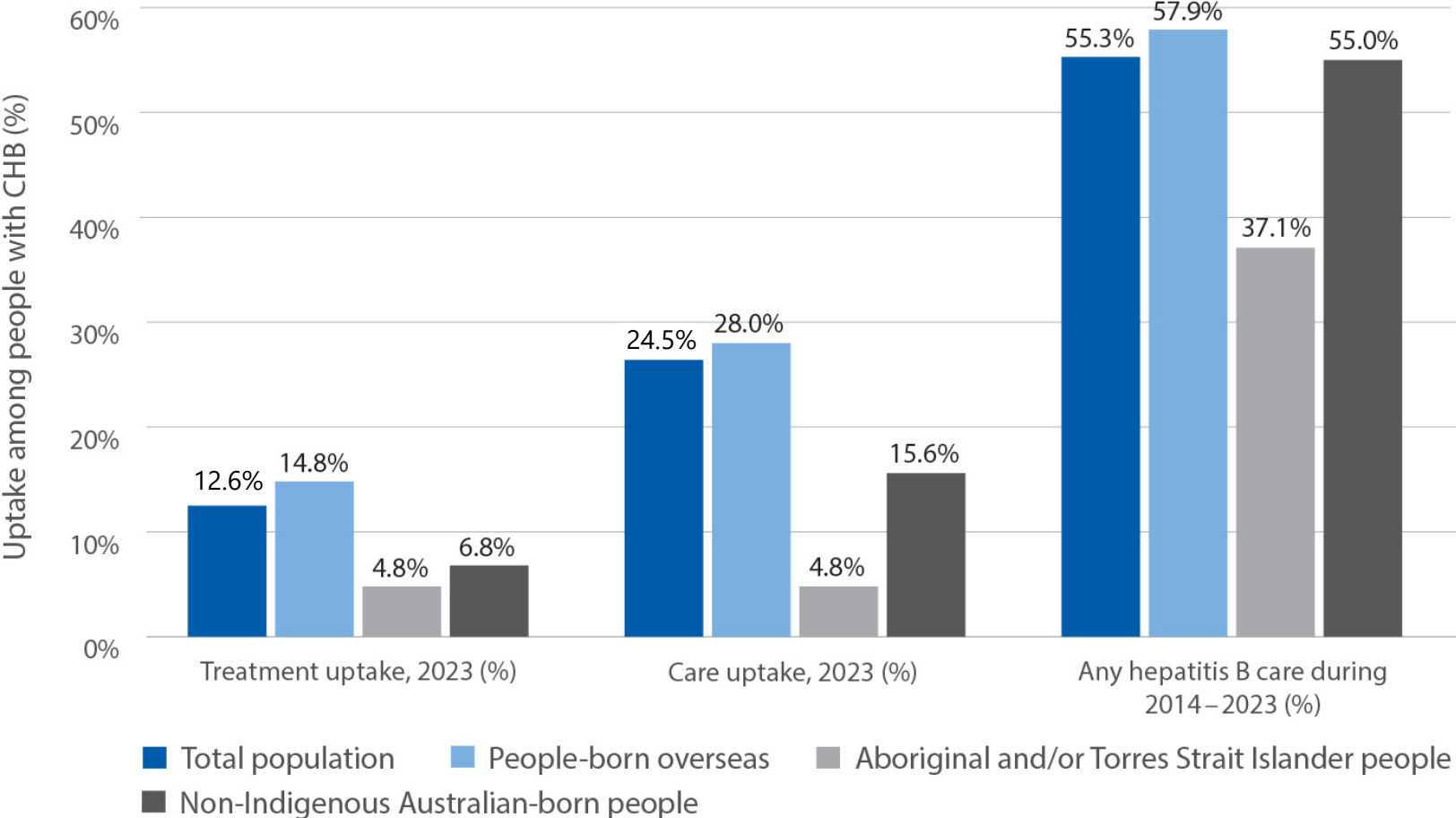
Consistently received antiviral treatment

Received antiviral treatment but then stopped

Received inconsistent / non-adherent antiviral treatment

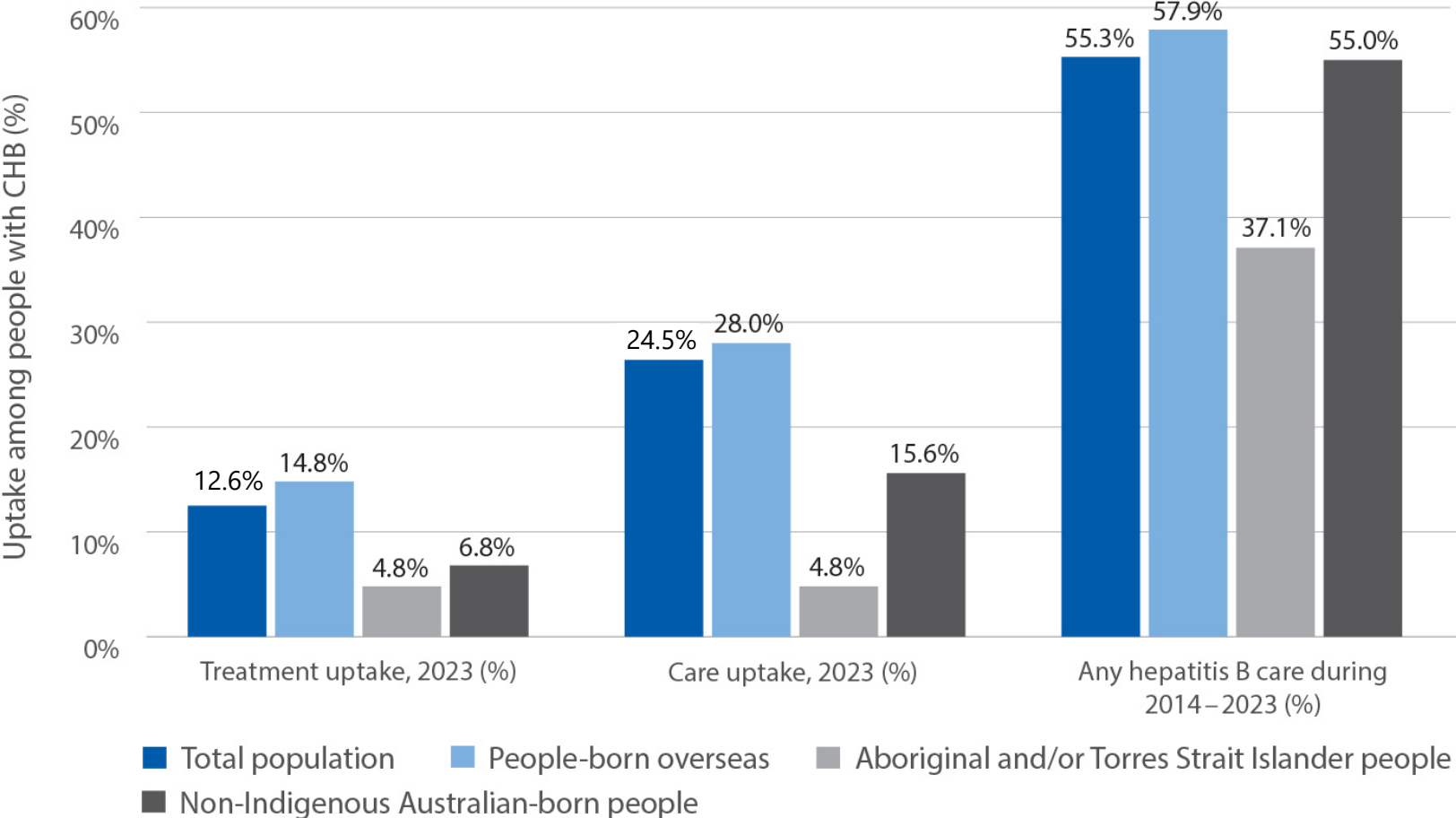
Proportion who had follow up serology or viral load

Outcome 1: Treatment and care by priority population



Source: Person Level Integrated Data Asset (PLIDA), incorporating combined demographics, combined location, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, and physically present status. Accessed via ABS DataLab. Findings based on use of PLIDA data.

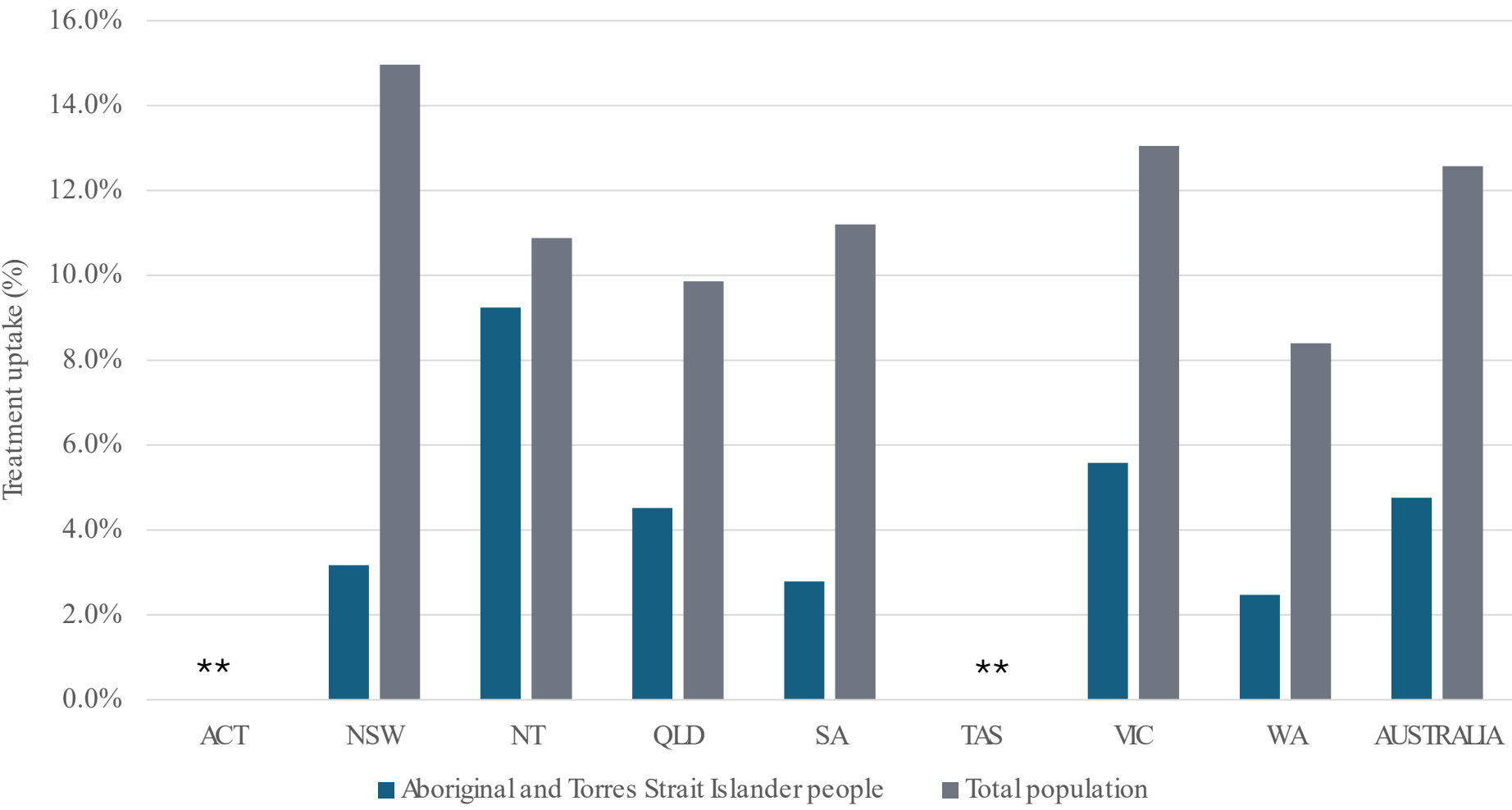
Outcome 1: Treatment and care by priority population



45% of people with hepatitis B had no record of hepatitis B treatment or viral load via Medicare during 2014-2023

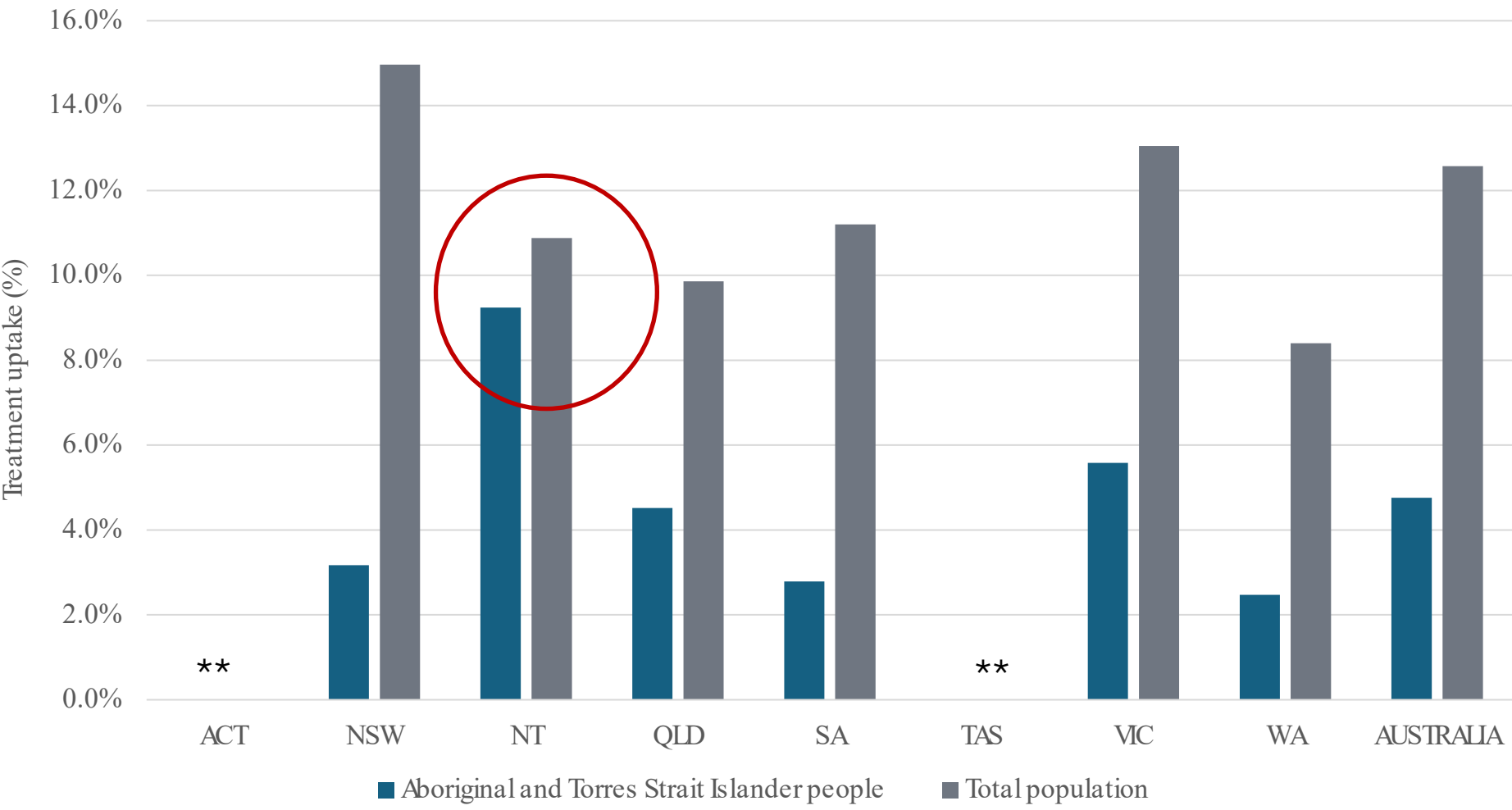
Source: Person Level Integrated Data Asset (PLIDA), incorporating combined demographics, combined location, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, and physically present status. Accessed via ABS DataLab. Findings based on use of PLIDA data.

Outcome 1: Treatment by Indigenous status and jurisdiction



Source: Person Level Integrated Data Asset (PLIDA), incorporating combined demographics, combined location, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, and physically present status. Accessed via ABS DataLab. Findings based on use of PLIDA data. ****Data not available due to low number of individuals with HBV.**

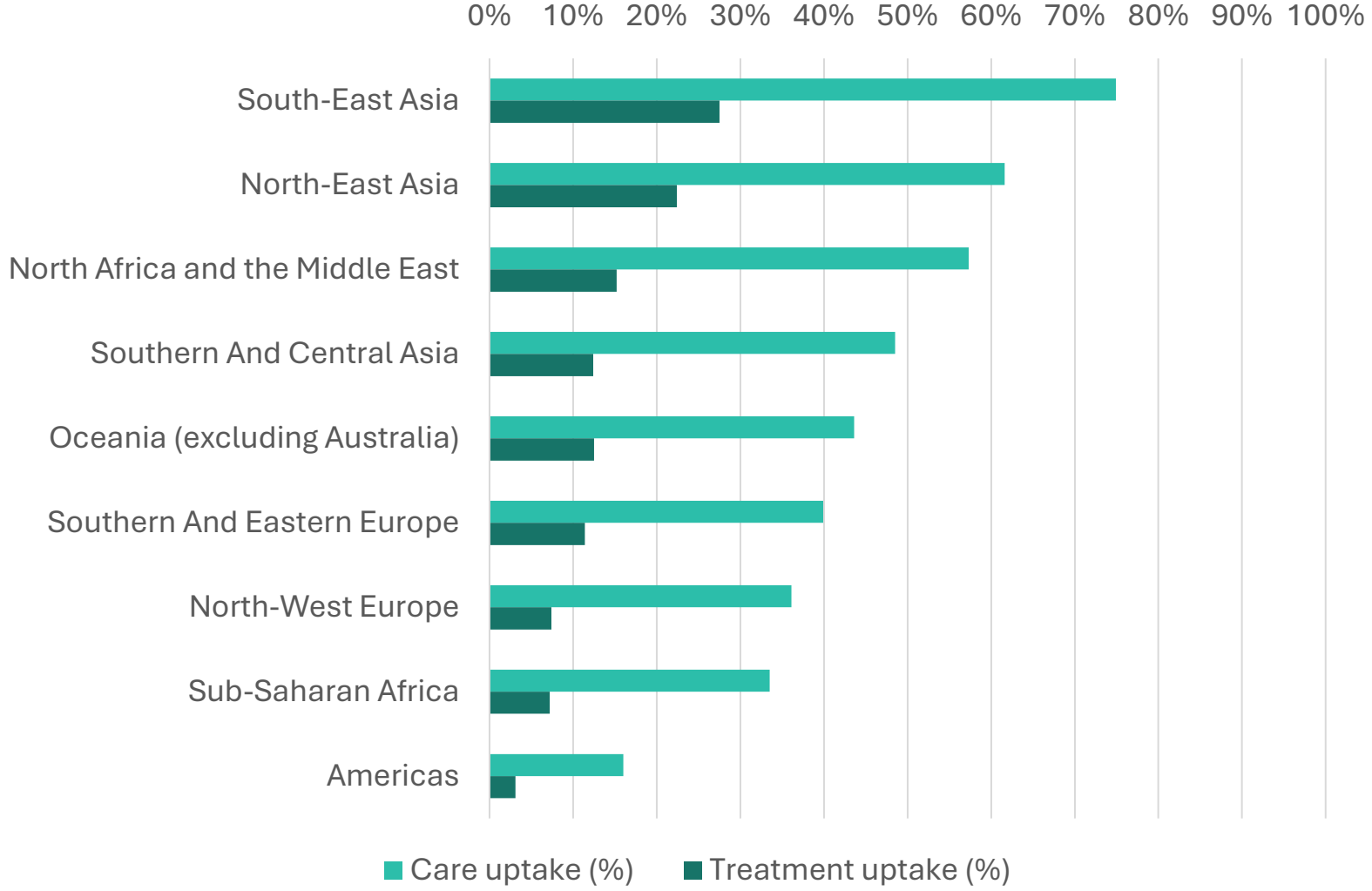
Outcome 1: Treatment by Indigenous status and jurisdiction



- Similar for care uptake - NT is the only jurisdiction with higher uptake among Aboriginal and Torres Strait Islander people

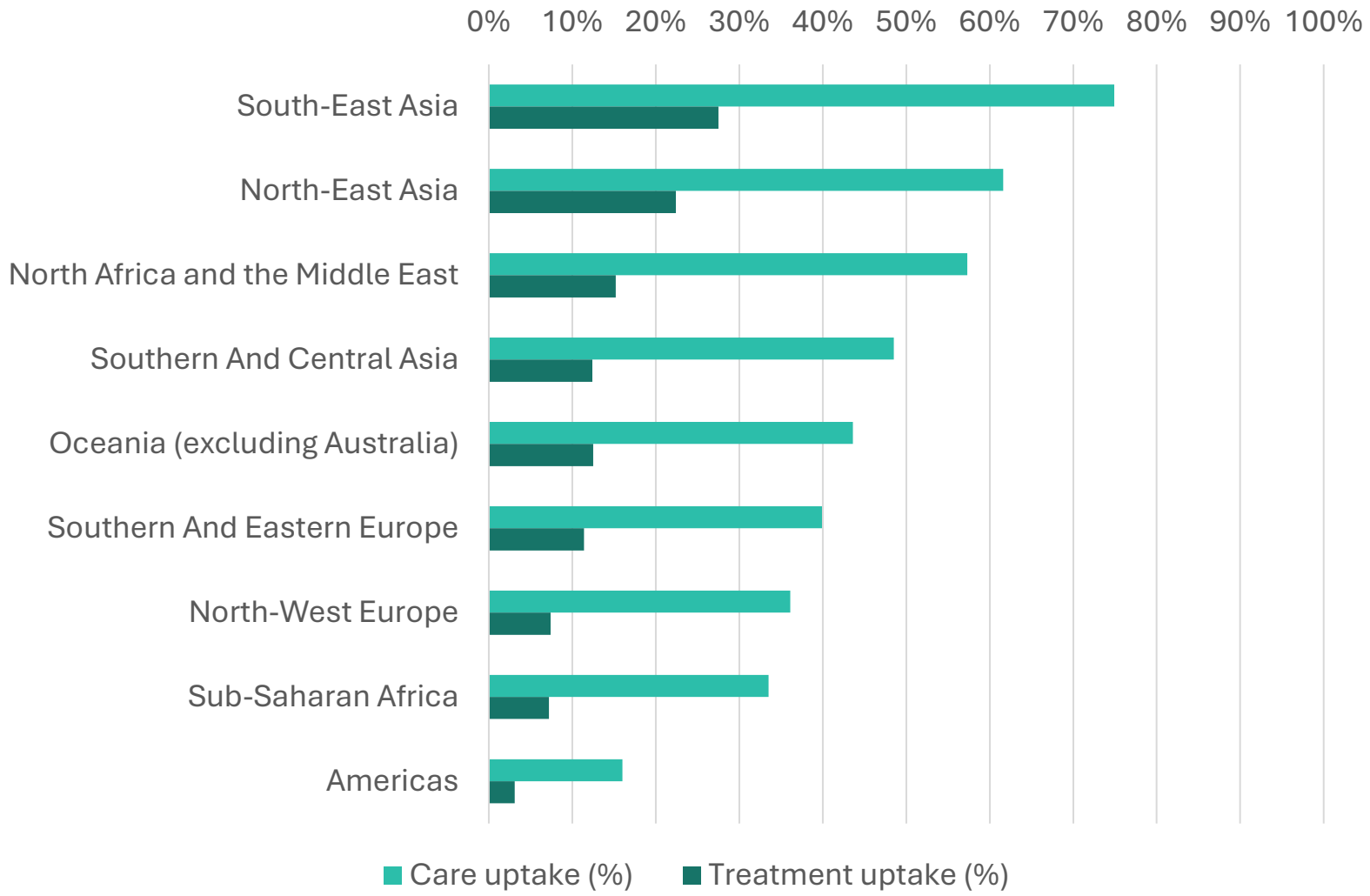
Source: Person Level Integrated Data Asset (PLIDA), incorporating combined demographics, combined location, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, and physically present status. Accessed via ABS DataLab. Findings based on use of PLIDA data. ****Data not available due to low number of individuals with HBV.**

Outcome 1: Treatment and care by region of birth



Source: Person Level Integrated Data Asset (PLIDA), incorporating combined demographics, combined location, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, and physically present status. Accessed via ABS DataLab. Findings based on use of PLIDA data.

Outcome 1: Treatment and care by region of birth



- South-East Asia (12,500 people) and North-East Asia (19,900 people) largest groups not in care
- None exceed treatment and care targets

Source: Person Level Integrated Data Asset (PLIDA), incorporating combined demographics, combined location, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, and physically present status. Accessed via ABS DataLab. Findings based on use of PLIDA data.

Outcome 2: HCC surveillance among all eligible people



2014 **2023**

Good - 2 per year (8%)

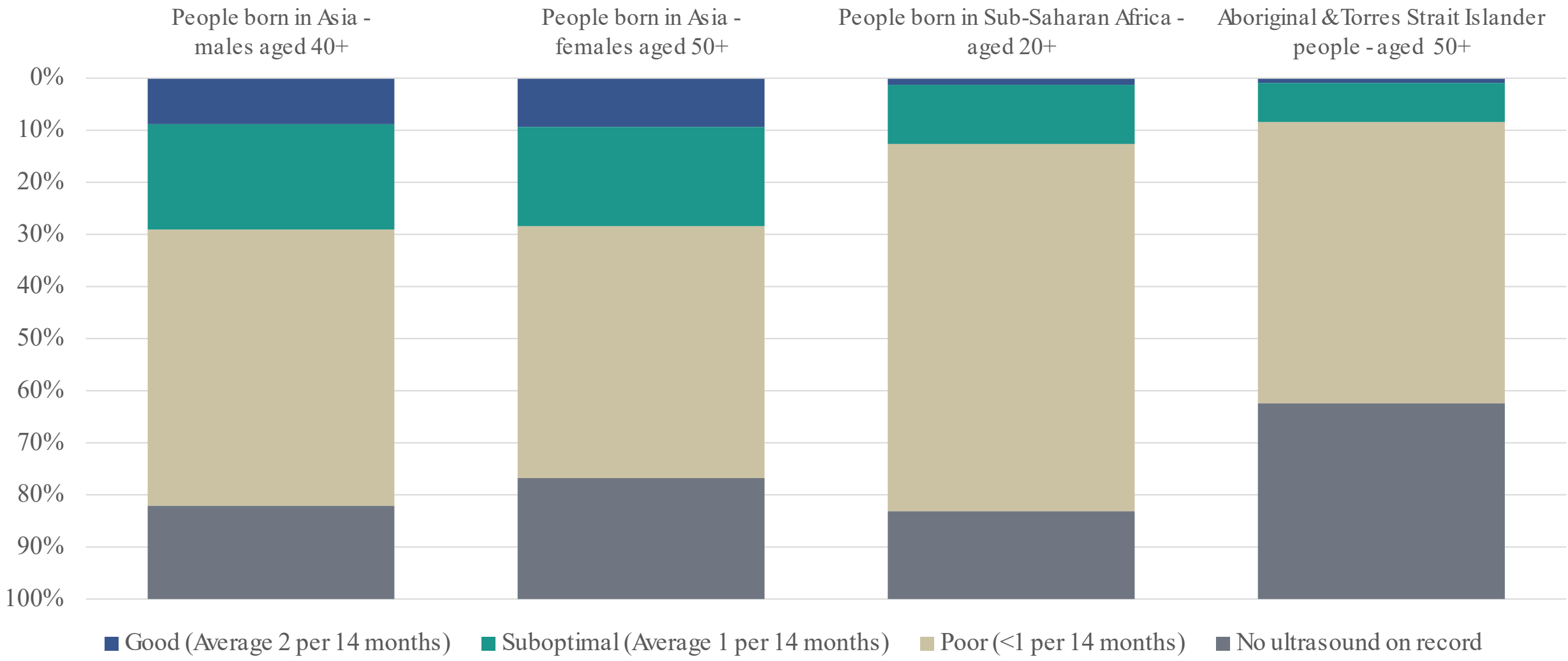
Suboptimal - 1 per year (18.5%)

Poor - less than 1 per year (52.8%)

No ultrasounds recorded (20.7%)

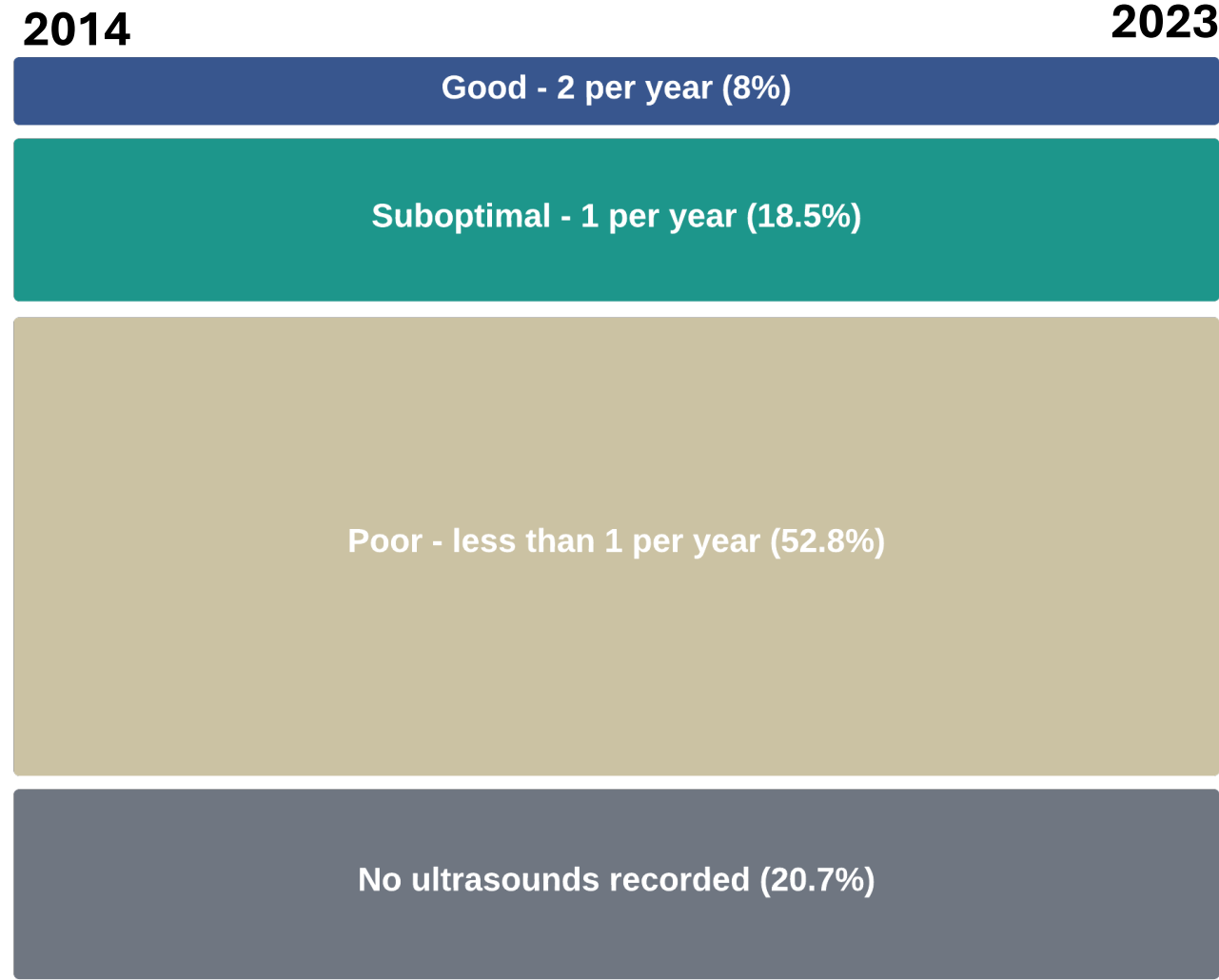
Source: Person Level Integrated Data Asset (PLIDA), incorporating combined demographics, combined location, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, and physically present status. Accessed via ABS DataLab. Findings based on use of PLIDA data.

Outcome 2: HCC surveillance by population



Source: Person Level Integrated Data Asset (PLIDA), incorporating combined demographics, combined location, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, and physically present status. Accessed via ABS DataLab. Findings based on use of PLIDA data.

Outcome 2: HCC surveillance overview



- Consistent with other baseline data from specialist clinic cohort - 10% had twice yearly ultrasounds²
- No demographic group had >25% uptake of good surveillance, nor did those receiving regular viral load tests
- Even among those on continuous treatment, only 40% had good surveillance

Outcome 3: consistency of care engagement (viral load testing)



2014

2023

Consistently received viral load testing (21.3%)

Started receiving viral load testing (39.7%)

Stopped and then started receiving viral load testing (3.9%)

Receiving viral load testing then stopped (35.2%)

Outcome 3: consistency of care engagement (viral load testing)



2014

2023

Consistently received viral load testing (21.3%)

Started receiving viral load testing (39.7%)

Stopped and then started receiving viral load testing (3.9%)

Receiving viral load testing then stopped (35.2%)

- This cohort excludes people who migrated away from Australia and those who are now deceased
- Some people may spontaneously clear HBV - but only ~1% a year
- Represents over 28,000 people lost to follow up
- Additional 120,000 people with no evidence of care at all

Outcome 4: consistency of care engagement (treatment)



2014

2023

Consistently received antiviral treatment (71.3%)

Received antiviral treatment but then ceased (9.1%)

Received inconsistent / non-adherent antiviral treatment (19.6%)

Outcome 4: consistency of care engagement (treatment)



2014

2023

Consistently received antiviral treatment (71.3%)

Received antiviral treatment but then ceased (9.1%)

Received inconsistent / non-adherent antiviral treatment (19.6%)

- Of those who ceased treatment, 64.5% had a viral load or serology test after their last script
- Similar findings (80% adherence) in large cohort of people on treatment in specialist care³

3. Allard 2017 doi: [10.1111/jvh.12582](https://doi.org/10.1111/jvh.12582)

Source: Person Level Integrated Data Asset (PLIDA), incorporating combined demographics, combined location, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, and physically present status. Accessed via ABS DataLab. Findings based on use of PLIDA data.

Summary of findings



1. Do care and treatment uptake vary by priority population?

- Uptake is higher among those born overseas and varies widely by jurisdiction for Aboriginal and Torres Strait Islander people
- No population is meeting the target nationally and nearly half of all people had no evidence of care

2. What is the uptake of other guideline-based care, such as HCC surveillance?

- HCC surveillance coverage is universally suboptimal

3. Are people receiving viral load testing consistently over time?

- Consistent testing was uncommon, and one-third dropped out of monitoring

4. Are people dropping out of antiviral treatment?

- Most people who commence treatment continue, had monitoring after they stopped

KEY ACTIONS & TAKEAWAYS

- Key Action 1: Accept
- Key Action 2: Understand & intervene
- Key Action 3: Evaluate & expand





Amelia Savage

Anh Nguyen

Beth Hamilton

Irene Guan

Jennifer MacLachlan

Lien Tran

Mielle Abbott

Nicole Allard

Nicole Romero

Roisin McColl

Tepy Hoeung

Additional slides



Additional slides - prevalence in Aboriginal and Torres Strait Islander people



Supplementary Table 1: Estimated prevalence of CHB in 2023 among Aboriginal and Torres Strait Islander people, by remoteness area and state/territory

State/territory	Major cities	Inner regional	Outer regional	Remote	Very remote	TOTAL
ACT	0.7%	n.a.	n.a.	n.a.	n.a.	0.7%
NSW	0.7%	0.7%	1.6%	6.4%	10.1%	1.0%
NT	n.a.	n.a.	2.0%	4.5%	4.9%	4.1%
Qld	1.7%	0.7%	2.6%	0.9%	3.8%	1.8%
SA	1.5%	1.2%	2.2%	0.6%	4.7%	1.9%
Tas.		0.7%	0.8%	0.8%	1.1%	0.7%
Vic.	0.7%	0.05%	0.1%	n.a.	n.a.	0.4%
WA	1.1%	1.0%	2.8%	5.9%	6.9%	3.0%

ABS, Australian Bureau of Statistics. CHB, chronic hepatitis B. n.a., not applicable (no regions with this level of remoteness exist in the jurisdiction).

Data source: CHB prevalence estimates based on mathematical modelling incorporating population-specific prevalence and ABS population data. Data specific to Aboriginal and Torres Strait Islander people derived from antenatal prevalence studies supplemented with notifications data.

Notes: Remoteness category based on designations by the ABS.³

Disclaimer regarding the use of ABS PLIDA data



A joint venture between The University of Melbourne and The Royal Melbourne Hospital

The results of these studies are based, in part, on data supplied to the ABS under the Taxation Administration Act 1953, A New Tax System (Australian Business Number) Act 1999, Australian Border Force Act 2015, Social Security (Administration) Act 1999, A New Tax System (Family Assistance) (Administration) Act 1999, Paid Parental Leave Act 2010 and/or the Student Assistance Act 1973. Such data may only be used for the purpose of administering the Census and Statistics Act 1905 or performance of functions of the ABS as set out in section 6 of the Australian Bureau of Statistics Act 1975. No individual information collected under the Census and Statistics Act 1905 is provided back to custodians for administrative or regulatory purposes. Any discussion of data limitations or weaknesses is in the context of using the data for statistical purposes and is not related to the ability of the data to support the Australian Taxation Office, Australian Business Register, Department of Social Services and/or Department of Home Affairs' core operational requirements.

Legislative requirements to ensure privacy and secrecy of these data have been followed. For access to PLIDA and/or BLADE data under Section 16A of the ABS Act 1975 or enabled by section 15 of the Census and Statistics (Information Release and Access) Determination 2018, source data are de-identified and so data about specific individuals has not been viewed in conducting this analysis. In accordance with the Census and Statistics Act 1905, results have been treated where necessary to ensure that they are not likely to enable identification of a particular person or organisation.