

It's time to improve Indigenous status data for health equity in communicable diseases: Hepatitis C a case study

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At Burnet Institute, we proudly acknowledge the Wurundjeri people of the Kulin Nations as the Traditional Custodians of the land on which we meet today. We recognise their continuing connection to land, waters and community. We acknowledge Aboriginal and Torres Strait Islander peoples as Australia's First Peoples and acknowledge that sovereignty was never ceded. We pay our respect to Elders past and present, and extend that respect to all First Nations people.



A well-recognised challenge

DISPROPORTIONATE RATES OF DISEASE

Aboriginal and Torres Strait Islander people experience disproportionate burden of disease in health conditions not only for hepatitis but other notifiable diseases and other diseases such as diabetes and cancer

STIGMA

Still a lot of stigma in both ACCHO, AMS and primary care settings

Fear of community knowing, worry an aunty or others might find out, causing shame or gossip

This has been attempted many times over decades. Progress has been slow. Many organisations including NACCHO and AIHW recognise the need for 'completeness of Indigenous status in the data'.

Why is
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When the Data Isn't There

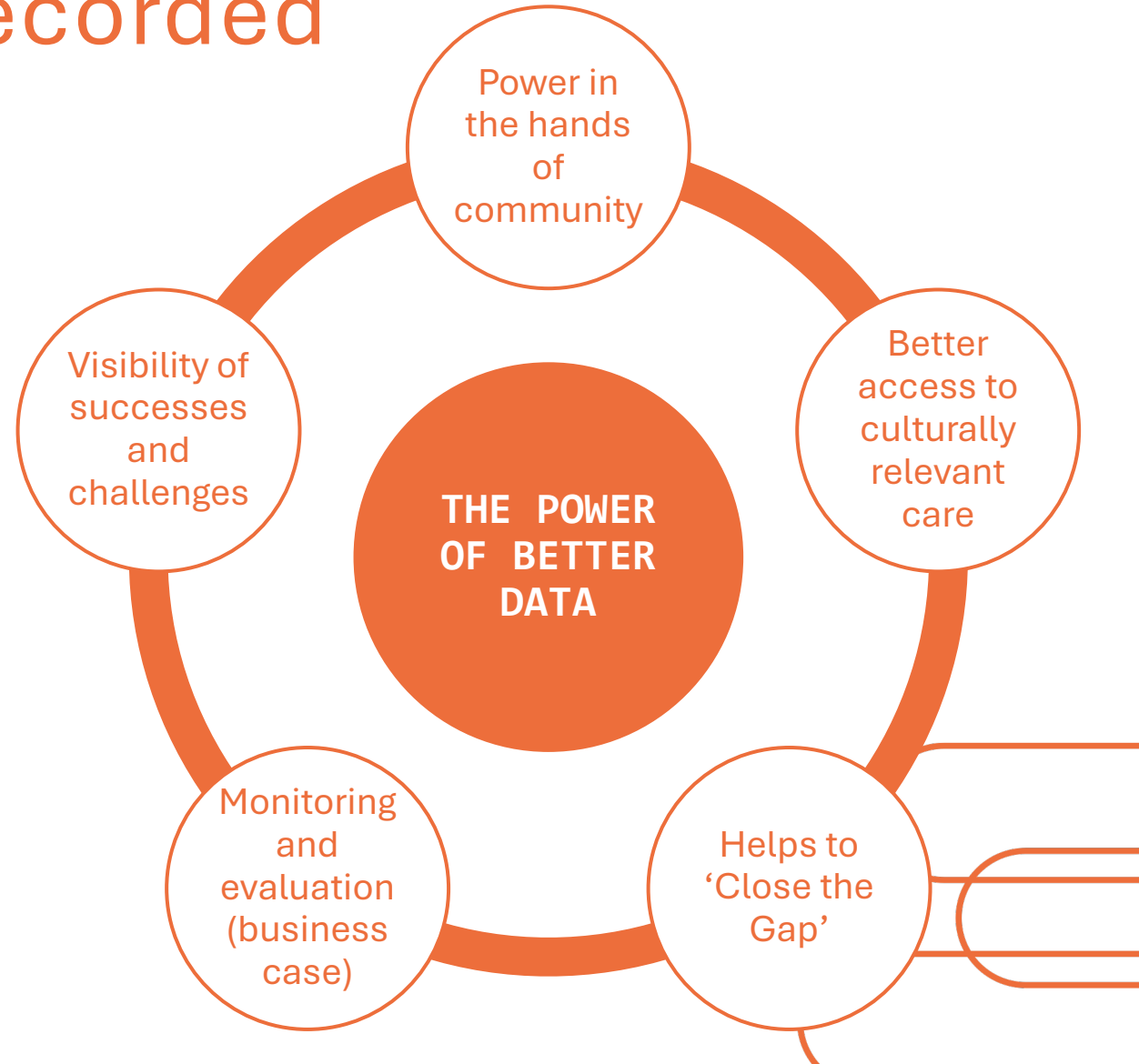
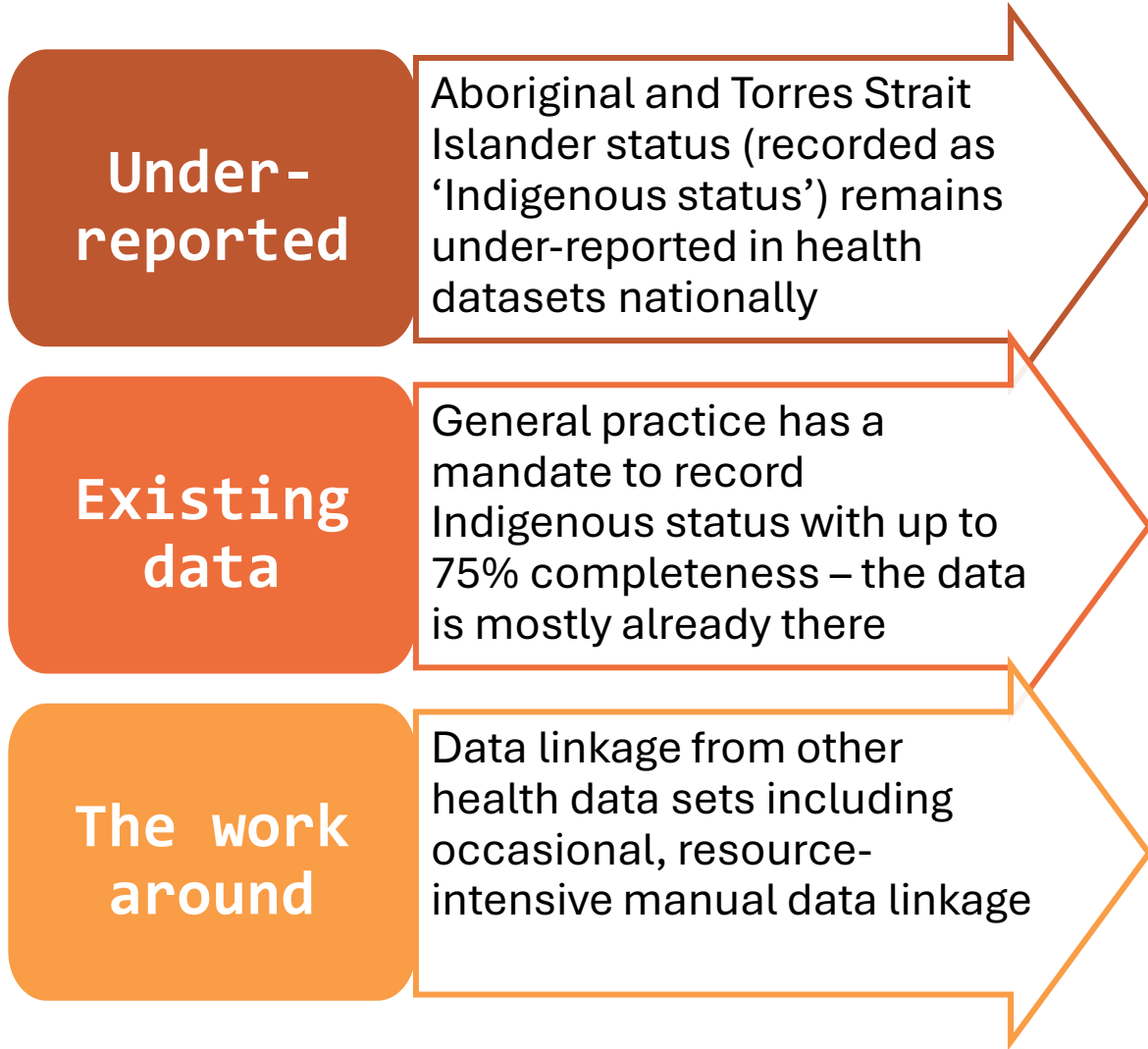
- VIC Project 2022 (in partnership with VACCHO)
- Notifications data could **not identify Aboriginal and Torres Strait Islander people**
- Unable to undertake follow up and link care pathways
- Most importantly, couldn't provide the community-led support

With better notifications data, we can reach people and allocate resources better.

Knowing where people are accessing care can inform better care models.

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...a, we can't
...n't build
...of care, or
even celebrate success of effective models.

Despite efforts, Indigenous status is not always recorded



Methods

PUBLIC HEALTH LEGISLATION SCAN

Notification data criteria are defined by each jurisdiction.

Reviewed relevant legislation to determine whether Indigenous status was mandated for notifications.

REVIEW OF PATHOLOGY REQUEST FORMS

Included 42 NATA-accredited pathology providers that screen for HCV.

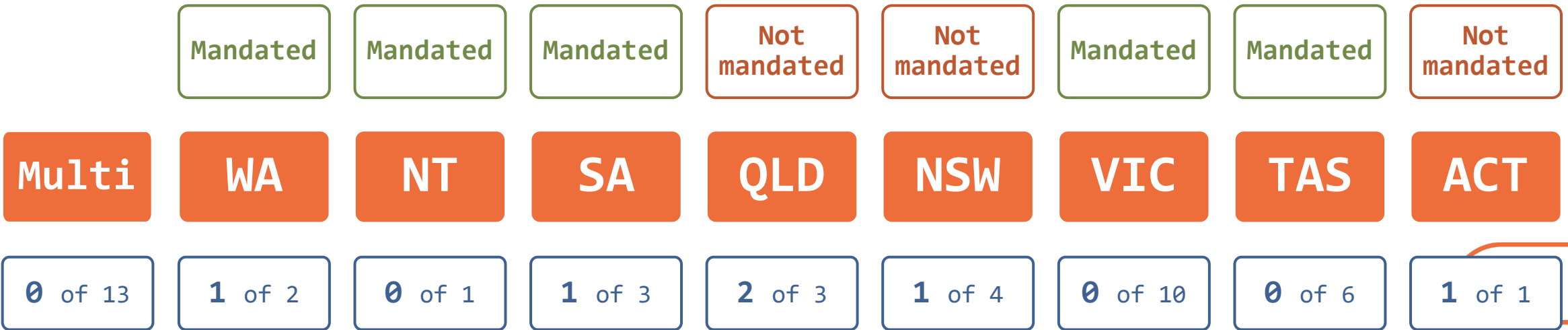
Reviewed whether their pathology request forms included a field for Indigenous status.

While this project focused on hepatitis C, the results are relevant to many notifiable diseases and other health conditions.

Results

Public health legislation mandates Indigenous status collection in 5/8 jurisdictions.

Review of 43 NATA accredited pathology providers showed that most pathology provider forms do not include Indigenous status.



Pathology request forms that include Aboriginal and Torres Straight Islander status

How we improve Indigenous status

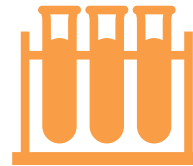
The easiest way – using the data we already have! A multi-faceted and coordinated approach



Clinicians

Primary care providers and hospitals already capture Indigenous status as part of patient records.

Ensure Indigenous status fields are consistently and accurately completed through staff education and awareness efforts.



Pathology

Pathology providers need to include an Indigenous status field on all request forms.

And include the data in notifications to health departments (e.g. via HL7)



Notifications

Notifications will include Indigenous status!

Not just hepatitis C, particular significance for vaccine preventable diseases and health registries,

Importantly, making changes to include Indigenous status fields on pathology forms doesn't require any approvals, and because it's not a mandatory completion field, it won't impact Medicare Benefits Schedule eligibility.

KEY ACTIONS & TAKEAWAYS

- Key Action 1: Standardise pathology request forms
- Key Action 2: Complete link of data sources: Clinic -> Pathology -> Notifications/Data Health Sets
- Key Action 3: Use the data to support appropriate, community-led programs to eliminate hepatitis C and support other health conditions, disproportionately impacting Aboriginal and Torres Strait Islander peoples.





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Thank you

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