Enhancing Indigenous status data in hepatitis-C notifications for greater equity and outcomes

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Background:

Improved completeness of Indigenous status in hepatitis C (HCV) data can guide strategies to address inequities in HCV outcomes, inform self-determined models of care, and address the disproportionate HCV disease burden among Indigenous people. HCV notifications data are provided to governments primarily by diagnosing laboratories, with accompanying fields that characterise notifications derived from pathology request forms. This data can help describe HCV burden over time and place and, depending on the quality of accompanying data, can be used to understand HCV burden across priority populations. We undertook desktop and systems reviews to explore Australian HCV notification systems' capacity to provide data relevant to tracking HCV elimination among Indigenous Australians.

Methods:

Between April 1 and August 30, 2024, we reviewed jurisdictional public health legislation to identify requirements for reporting Indigenous status in HCV notifications. An audit was conducted to review Indigenous status inclusion in pathology request forms from NATA-accredited pathology providers that conduct HCV testing.

Results:

Five of eight jurisdictions (NT, SA, TAS, VIC, WA) legislatively mandate inclusion of Indigenous status in disease notifications. Only six of 42 pathology provider request forms reviewed included an Indigenous status field: five public reference laboratories and one private laboratory. Of the five jurisdictions mandating Indigenous status collection for HCV notifications, only two public reference laboratories included Indigenous status fields on their pathology request forms, while no private laboratories did.

Conclusion:

Private laboratories notify the overwhelming majority of HCV cases, but only one uses a request form that includes an Indigenous status field. This oversight is inconsistent with legislation in many jurisdictions and contributes to significant underreporting of HCV diagnoses among Indigenous peoples. In addition to ensuring clinicians record Indigenous status in patient management systems, Australian governments must ensure public and private laboratories comply with legislative responsibilities to include Indigenous status in disease notifications.

Disclosure of Interest Statement:

The Burnet Institute recognise the significant intellectual contribution that our partners, namely state and territory' Departments of Health, make to Connect C's research activities. Furthermore, we recognise the need for transparency of disclosure of potential conflicts of interest through acknowledging these when sharing publicly the work of Connect C.