

DATA, RESEARCH AND EVALUATION

Unlock access to big data

OBJECTIVES

To strengthen the national evidence base underpinning HIV prevention, testing and treatment initiatives.

CURRENT ISSUES

- There is a range of critical data that can inform HIV prevention, testing and treatment efforts across Australia including Pharmaceutical Benefits Scheme and the Medicare Benefits Scheme data;
- At present, access to this data has been through the efforts of jurisdictions rather than

a uniform national effort to generate analytics and insights to inform the national response;

- Improved access to this data, and regular linkage of that data to existing jurisdictional data sets (including, for example, hospitalisation data) would generate actionable, population-level insights into

current trends in HIV treatment coverage and retention in care across Australia. This would include insights into access to testing, treatment and care among 'hidden populations' such as Aboriginal and Torres Strait Islander people with HIV and overseas-born populations.

PROPOSED ACTIVITIES

- Convene a national roundtable on HIV-related data linkage to create dialogue and agreement regarding privacy protections, protocols and controls acceptable to people with HIV and affected communities;
- The Australian Government to make a determination that all data held by its agencies that could usefully inform the HIV response be made available to states and territories and to the community-led response. This should

be done in such a way as to maintain strict protections for individuals' privacy;

- Commit to providing de-identified line-listed PBS data on a quarterly basis (100% sample) for HIV treatment and Pre-Exposure Prophylaxis, including demographics, provider type, dispensing location and jurisdiction;
- Undertake regular data linkages as a quality assurance (as opposed to research) activity, linking national HIV notification data with

Pharmaceutical Benefits Scheme, Medicare Benefits Scheme and hospital datasets;

- Include data linkages with hospital morbidity datasets to determine Aboriginal and Torres Strait Islander status, and processes to conduct more timely linkages in the future. During this process, determine Aboriginal and Torres Strait Islander status from hospital morbidity datasets and establish processes for more timely linkages in the future.

IMPACT

Strengthening data systems and data architecture will produce more accurate, complete and timely data, that in turn will improve the capacity of the workforce to deliver tailored and impactful interventions.

COST-BENEFIT

A more tailored response will increase the impact of HIV prevention efforts and result in an increase in testing and retention in care.

ADDITIONAL INVESTMENT

\$0.