

“Know Your Epidemic, Know Your Response”¹: A Case Study of Quarterly Data Reports in NSW

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Purpose

This paper describes the process involved in the collection, interpretation and dissemination of quarterly HIV surveillance data in NSW. The purpose of the paper is to provide an example of a jurisdiction that is using data in an effective way to understand and respond to the local HIV epidemic. The paper highlights the value of having a regular process for building shared interpretations of data, a process that other jurisdictions in Australia may wish to adopt.

In NSW HIV surveillance data is collated and published on a quarterly and annual basis (for example see Quarter 4 & Annual 2018 Data Report)² on the NSW Health Website. The quarterly data reports include commentary to support interpretation of the data and key messages to inform policy, health promotion and service delivery. They are used to monitor progress against the goals and targets of the *NSW HIV Strategy 2016-2020*. They also allow for the timely identification of emerging issues and serve as a resource for planning new interventions and refining existing ones.

The paper is informed by consultations with members of the *NSW HIV Expert Data Advisory Group* and by the *NSW HIV Strategy 2012-2015* and the *NSW HIV Strategy 2016-2020*.

Background

Early on in the last decade, NSW, like other similar jurisdictions in Australia, Europe and USA, was observing increases in HIV diagnoses, particularly among gay men and other men who have sex with men. In this period, NSW was reliant on surveillance data with a 12-month lag, making it hard to understand and respond to HIV increases in a timely way. In 2012, against the backdrop of increases in HIV diagnoses, NSW released the *NSW HIV Strategy 2012-2015: A New Era*. For the first time this strategy included targets for prevention, testing and treatment and had an overarching aim to work towards the virtual elimination of HIV transmission in NSW by 2020³. The strategy committed to continue investment in research to understand the epidemic, and to support a high-quality surveillance system. In 2013, as part of this commitment to high-quality surveillance, the NSW Ministry of Health commenced producing quarterly data reports. These commitments were reiterated in the *NSW HIV Strategy 2016-2020*:

‘Real time’ data collection and quarterly reporting have been highly effective in stimulating discussion within the HIV sector regarding innovative strategies and new service models, improving health service quality, clinical safety, and performance. Disseminating robust data among key stakeholders supports a policy development and implementation process that is transparent, participative and responsive to emerging trends (p. 17)⁴

The Process

- The quarterly reports are compiled by the NSW Ministry of Health and include data on HIV notifications, prevention, testing, and treatment.
- The data and indicators selected for the reports are related to the goals and targets in the *NSW HIV Strategy 2016-2020*, to allow the Ministry of Health to track the goals of the strategy.

- The reports include data from a range of sources, including the Notifiable Conditions Information Management System, ACCESS Database, Sydney Gay Community Periodic Survey, public sexual health and HIV services and the Pharmaceutical Benefits Schedule Highly Specialised Drugs Programme and ACON's evaluation data.
- A data advisory group (*NSW HIV Expert Data Advisory Group*) reviews the draft data report each quarter. The data advisory group includes representatives from The Kirby Institute, UNSW; ACON; Positive Life NSW; The Centre for Social Research in Health, UNSW; and the NSW Ministry of Health.
- The data advisory group meets to discuss the draft report, and in some cases may ask for further analysis or the refining of interpretations. Ideas for new indicators and stratifications of the data may be suggested and presented at subsequent meetings.
- The data advisory group plays a key role in 'socialising' the data, in the sense that the meanings and implications of these data are discussed and debated by the data advisory group and then a set of key messages are included in the published report.
- The key messages are published in a media release by the NSW Ministry of Health at the same time as the report.
- Community partners ACON and Positive Life NSW are frequently the first contacts for the media. The close and meaningful involvement of these organisations in the development of key messages means that they 'own' the results being released and this provides for unified messages based on evidence being received by the public.
- The reports are disseminated to the Local Health Districts and used to assess local progress against the *NSW HIV Strategy 2016-2020*. The data is also presented at the Health Directors' meetings and to the Strategy Implementation Committee.

The Strengths

Quarterly reporting:

- Encourages regular scrutiny of monitoring and surveillance systems, enables modifications to the systems and the generation of new indicators. For example, the development of new measures to assess community level uptake of PrEP and TasP in the Sydney Gay Periodic Survey. The short time period between meetings means that new indicators can be evaluated relatively quickly. If they are judged to be useful, they are incorporated into routine reporting. This makes the system more responsive and informative
- supports collaborations between researchers, community organisations, and the NSW Ministry of Health
- builds capacity across the HIV sector in NSW
- supports agility around emerging issues
- acts as a catalyst for in-agency and interagency discussions
- solidifies relationships, and facilitates the identification of new targets for research, education and intervention, for example the introduction of *The Dried Blood Spot testing program* which responded to gaps in HIV testing uptake – providing a more discreet service that could be accessed by people at home and deliberately focused on infrequent testers and people from Culturally and Linguistically Diverse backgrounds
- allows the tracking of responses against the *NSW HIV Strategy 2016-2020* and ensures that those involved in health service delivery are accountable
- ensures the response to HIV is evidence-based and facilitates planning of new interventions and the realignment of existing programs
- supports work to dispel misinformation in the community and among people working in the epidemic
- supports transparency through being publicly available on the NSW Ministry of Health website
- optimises the kinds of questions asked of the data and creates opportunities for additional analysis at more granular levels
- creates opportunities for new data sets to be added when they enhance understanding, for example *Pharmaceutical Benefits Scheme* data on PrEP prescribing, to improve the overall picture of the level of PrEP use
- provides perspectives from the community and end users of services through inclusion of the annual ACON survey and the Sydney Gay Community Periodic Survey
- ensures timely data is available in a form that is meaningful and accessible to a diversity of stakeholders.

Informing Program Delivery

The availability of quarterly data, and interpretation and key messaging informed by discussions between researchers, community organisations and the Ministry of Health means that research can directly influence community-led responses. For example, ACON have an in-agency meeting to discuss and reflect on the quarterly data reports. The data reports allow ACON to keep their communities and their board aware of emerging issues and to develop responses in a timely manner [see box for example of data informed change].

The 2018 quarterly and annual data reports showed that HIV diagnoses were decreasing significantly among Australian born gay and other men who have sex with men. In contrast, reductions were not occurring among Asian born gay and other men who have sex with men. In February 2019 ACON, in partnership with Sydney Sexual Health Centre, started offering HIV and sexual health screening in Mandarin on a weekly basis at one of their Community-based Rapid HIV testing a[TEST] sites.

References

1. http://data.unaids.org/pub/manual/2007/20070306_prevention_guidelines_towards_universal_access_en.pdf
2. <https://www.health.nsw.gov.au/endinghiv/Publications/q4-2018-and-annual-hiv-data-report.pdf>
3. <https://www.health.nsw.gov.au/endinghiv/Publications/nsw-hiv-strategy-2012-15-a-new-era.pdf>
4. <https://www.health.nsw.gov.au/endinghiv/Publications/nsw-hiv-strategy-2016-2020.PDF>