# Protocol

# Monitoring the Control of Sexually Transmissible Infections and Blood-Borne Viruses: Protocol for the Australian Collaboration for Coordinated Enhanced Sentinel Surveillance (ACCESS)

Denton Callander<sup>1\*</sup>, PhD; Clarissa Moreira<sup>2\*</sup>, MSc; Carol El-Hayek<sup>2,3</sup>, MSc; Jason Asselin<sup>2</sup>, BSc (Hons), GradDipHlthPrm; Caroline van Gemert<sup>2,3</sup>, PhD; Lucy Watchirs Smith<sup>1</sup>, BA, MPH; Long Nguyen<sup>2</sup>, BCom, GradCertSc; Wayne Dimech<sup>4</sup>, BAppSci, MBA; Douglas IR Boyle<sup>5</sup>, PhD; Basil Donovan<sup>1,6</sup>, MD; Mark Stoové<sup>2,3</sup>, PhD; Margaret Hellard<sup>2,3\*</sup>, MD, PhD; Rebecca Guy<sup>1\*</sup>, PhD

#### **Corresponding Author:**

Denton Callander, PhD Kirby Institute University of New South Wales Sydney Wallace Wurth Building Sydney, 2052 Australia

Phone: 61 293859958

Email: d.callander@unsw.edu.au

# **Abstract**

**Background:** New biomedical prevention interventions make the control or elimination of some blood-borne viruses (BBVs) and sexually transmissible infections (STIs) increasingly feasible. In response, the World Health Organization and governments around the world have established elimination targets and associated timelines. To monitor progress toward such targets, enhanced systems of data collection are required. This paper describes the Australian Collaboration for Coordinated Enhanced Sentinel Surveillance (ACCESS).

**Objective:** This study aims to establish a national surveillance network designed to monitor public health outcomes and evaluate the impact of strategies aimed at controlling BBVs and STIs.

**Methods:** ACCESS is a sentinel surveillance system comprising health services (sexual health clinics, general practice clinics, drug and alcohol services, community-led testing services, and hospital outpatient clinics) and pathology laboratories in each of Australia's 8 states and territories. Scoping was undertaken in each jurisdiction to identify sites that provide a significant volume of testing or management of BBVs or STIs or to see populations with particular risks for these infections ("priority populations"). Nationally, we identified 115 health services and 24 pathology laboratories as relevant to BBVs or STIs; purposive sampling was undertaken. As of March 2018, we had recruited 92.0% (104/113) of health services and 71% (17/24) of laboratories among those identified as relevant to ACCESS. ACCESS is based on the regular and automated extraction of deidentified patient data using specialized software called GRHANITE, which creates an anonymous unique identifier from patient details. This identifier allows anonymous linkage between and within participating sites, creating a national cohort to facilitate epidemiological monitoring and the evaluation of clinical and public health interventions.

**Results:** Between 2009 and 2017, 1,171,658 individual patients attended a health service participating in ACCESS network comprising 7,992,241 consultations. Regarding those with unique BBV and STI-related health needs, ACCESS captured data on 366,441 young heterosexuals, 96,985 gay and bisexual men, and 21,598 people living with HIV.



<sup>&</sup>lt;sup>1</sup>Kirby Institute, University of New South Wales Sydney, Sydney, Australia

<sup>&</sup>lt;sup>2</sup>Burnet Institute, Melbourne, Australia

<sup>&</sup>lt;sup>3</sup>School of Public Health and Preventative Medicine, Monash University, Melbourne, Australia

<sup>&</sup>lt;sup>4</sup>National Reference Laboratory, Melbourne, Australia

<sup>&</sup>lt;sup>5</sup>Research Information Technology Unit, Health and Biomedical Information Centre, Department of General Practice, University of Melbourne, Melbourne, Australia

<sup>&</sup>lt;sup>6</sup>Sydney Sexual Health Centre, Sydney Hospital, Sydney, Australia

<sup>\*</sup>these authors contributed equally

**Conclusions:** ACCESS is a unique system with the ability to track efforts to control STIs and BBVs—including through the calculation of powerful epidemiological indicators—by identifying response gaps and facilitating the evaluation of programs and interventions. By anonymously linking patients between and within services and over time, ACCESS has exciting potential as a research and evaluation platform. Establishing a national health surveillance system requires close partnerships across the research, government, community, health, and technology sectors.

International Registered Report Identifier (IRRID): DERR1-10.2196/11028

(JMIR Res Protoc 2018;7(11):e11028) doi: 10.2196/11028

#### **KEYWORDS**

Australia; blood-borne viruses; public health; sentinel surveillance; sexually transmissible infections

# Introduction

Globally, sexually transmissible infections (STIs) and blood-borne viruses (BBVs) are associated with significant morbidity, mortality, health costs, and social stigma. Indeed, these infections represent a major public health burden. There are, for example, nearly 37 million people currently infected with HIV and >1 million associated deaths per year [1], while an estimated 70 million people live with hepatitis C, from which nearly half a million die each year [2]. Regarding hepatitis B, >250 million people live with this infection, which causes >800,000 deaths annually [3,4]. Around the world, there are >350 million new cases of curable STIs every year—chlamydia, gonorrhea, syphilis, and trichomoniasis [5]—and human papillomavirus (HPV) is responsible for nearly all cases of cervical cancer, the fourth most common malignancy worldwide [6].

In Australia, the control and elimination of some BBVs and STIs are increasingly feasible through combinations of new and existing strategies of prevention, treatment, and management. For HIV, elimination is a tantalizing possibility through regular testing in combination with pre-exposure prophylaxis among uninfected individuals and antiretroviral treatment among those living with the virus [7-9]. Achieving something as lofty as HIV elimination will, naturally, be a major challenge [10] and certainly one that requires close monitoring of biomedical prevention coverage and impact to guide the refinement of implementation strategies [11]. Similarly, curative therapy with direct-acting antivirals for hepatitis C has been made available to all infected people in Australia, representing a major advance for both individual and public health [12] but one that also requires monitoring, evaluation, and adaptation if there is any hope of reducing infection rates [13].

For some other infections—notably hepatitis B and HPV—vaccinations have proved highly effective in reducing population incidence and prevalence. There remain, however, cohorts of people not included in vaccination schedules because of their age or who have migrated to Australia from countries where prevalence is high and vaccination programs limited. For these infections, ongoing clinical screening is required to identify unvaccinated individuals, and in the case of HPV, intervene early as a precursor to cancer. In addition, for curative STIs, frequent testing and timely treatment are fundamental components of interrupting incubation and preventing unintended onward transmission [14]. For STIs and BBVs, it is clear that ongoing efforts are required to track progress against

targets, monitor population health, assess the impact of interventions, and plan into the future.

Surveillance and monitoring of BBVs and STIs are often complicated by the fact that they disproportionately affect populations defined by sexual identity, sex practice, drug use, and ethnicity [11,13,14]. Thus, their management requires a holistic and comprehensive approach to care, which in Australia and many other countries, involves sexual health clinics, targeted general practice clinics, drug and alcohol services, and hospitals. Health services like these play a vital role not only in diagnosing and managing BBVs and STIs but also in their prevention by encouraging uptake of diagnostic testing, treatment, and vaccines where available. Calculating the uptake of these initiatives, however, requires knowing the number of total attending patients—the denominator—and such information can only be sourced directly from health services. When linked between individuals' episodes of care, these data can also be used to calculate other powerful impact indicators such as incidence or the time between diagnosis and treatment.

Here, we describe ACCESS—the Australian Collaboration for Coordinated Enhanced Sentinel Surveillance—a national system of sentinel surveillance that draws upon data from several different types of health services and pathology laboratories to inform and evaluate Australia's BBV and STI control efforts.

# Methods

# **Overview and Aims**

ACCESS is a system that routinely extracts and collates line-listed, deidentified data from health services and pathology laboratories across Australia. Through anonymous patient linkage between and within services and laboratories, ACCESS produces a retrospective and prospective cohort of patients attending participating sites. Established in 2008, ACCESS began as a sentinel system for chlamydia surveillance [15] that was expanded in 2013 to include BBVs and other STIs in some Australian jurisdictions. Through funding from the Australian Department of Health in 2016, ACCESS expanded further to encompass a greater number and a more diverse selection of sites relevant to these infections in all 8 Australian states and territories.

The overall aim of ACCESS is to support the Australian response to STIs and BBVs by monitoring the testing, diagnosis, and management of these infections. In addition, ACCESS aims to operate as an evaluative platform to measure the impact and



outcomes of relevant programs and interventions. This includes attention to Australian priority populations (gay and bisexual men and other men who have sex with men, people who use drugs, Aboriginal and Torres Strait Islander people, young heterosexuals, sex workers, and people from culturally and linguistically diverse backgrounds) and to "cascades of care" (eg, HIV) [16].

#### **Infections**

ACCESS focuses on specific infections, including HIV, hepatitis B, hepatitis C, HPV, chlamydia, gonorrhea, syphilis, and trichomoniasis. The design of ACCESS, however, allows for the addition of other infections or conditions as required into the future. Already, for example, steps have been taken to begin collecting data on *Mycoplasma genitalium*, a newly identified STI.

## **Sites and Recruitment**

The ACCESS network seeks to include health services and pathology labs that best represent the prevention and management of BBVs and STIs nationally and in each state and territory. To be eligible, health services are required to use an electronic patient management system (ie, not based solely on paper files) and be willing to participate for a minimum of 2 years. Of note, we have encountered no health services still exclusively using paper files. In addition, health services have to see at least 50 individuals per year categorized as ≥1 of Australia's priority populations for BBVs and STIs or they have to represent a service designed specifically for the care and management of these infections (eg, sexual health clinics and HIV testing sites). Given differences in the overall population size between each state and territory—the largest contains >7.5 million people, while the smallest has just >200,000—we are flexible in our assessment of caseloads to allow for recruitment in smaller jurisdictions. For example, while a caseload of 50 patients with HIV might be considered small or medium in New South Wales, it would be considered large, if not the largest, in Tasmania.

Within these parameters, per jurisdiction, we have sought to include a minimum of 2 sites with large caseloads of people living with or at risk of HIV, 2 with large caseloads of people

living with or at risk of hepatitis and 2 with a large amount of STI-related testing and care. In addition, we sought to recruit 2 pathology laboratories per jurisdiction (one public and one private) that conducted testing for BBVs and STIs. While in larger states (New South Wales, Queensland, and Victoria), it was necessary to exceed these targets and recruit larger number of sites, the opposite was true in some smaller jurisdictions. In the Australian Capital Territory, for example, the vast majority of BBV-related and STI-related tests were conducted by a single pathology laboratory, making it unnecessary to recruit a second site of this kind. Details like this one highlight the need and strength for a tailored approach to recruitment, given the significant differences between each state and territory.

As noted, ACCESS has been in operation since 2008 with recruitment taking place over many years and in different iterations. Most recently, recruitment was undertaken from 2016 through 2018 to expand the network's coverage in jurisdictions beyond New South Wales and Victoria. Over time, however, methods of identifying and recruiting sites have remained consistent; to gain jurisdictionally specific information on potential sites, we consult with local stakeholders in government, health, community organizations, and research institutes. We ask them to nominate sites that either conduct a large amount of testing for or care of BBVs and STIs, or sites that provide care for concentrations of Australia's priority populations. Where available, we also review public health data on locations of BBV and STI diagnoses (by general geographic areas) to identify health services located nearby, and we review publicly available lists of doctors licensed to prescribe treatments for HIV and hepatitis C.

When this process was undertaken in 2016 and 2017, we identified 115 health services and 24 pathology laboratories across Australia that met our eligibility criteria. Three-quarters of these sites were already involved with ACCESS, noting that since its inception in 2008, no site has ever withdrawn participation in the network. Of the remaining "new" sites identified through our scoping process, we undertook purposive sampling that deferred to sites with large caseloads and those that introduced diversity either through their location, patients' characteristics, or service model.

**Table 1.** Health services and pathology laboratories participating in the Australian Collaboration for Coordinated Enhanced Sentinel Surveillance network as of March 2018, by site type and jurisdiction.

| Site type                    | Total | Jurisdiction                         |                    |                       |            |                    |          |          |                      |
|------------------------------|-------|--------------------------------------|--------------------|-----------------------|------------|--------------------|----------|----------|----------------------|
|                              |       | Australian<br>Capital Territo-<br>ry | New South<br>Wales | Northern<br>Territory | Queensland | South<br>Australia | Tasmania | Victoria | Western<br>Australia |
| Sexual health clinic         | 58    | 1                                    | 38                 | 3                     | 8          | 1                  | 3        | 2        | 2                    |
| General practice clinic      | 29    | 1                                    | 10                 | 0                     | 2          | 1                  | 0        | 13       | 2                    |
| Hospital outpatient clinic   | 7     | 0                                    | 2                  | 0                     | 1          | 0                  | 1        | 2        | 1                    |
| Community-led services       | 9     | 0                                    | 4                  | 0                     | 2          | 1                  | 0        | 1        | 1                    |
| Drug and alcohol service     | 1     | 0                                    | 0                  | 0                     | 0          | 0                  | 0        | 1        | 0                    |
| Private pathology laboratory | 6     | 1                                    | 3                  | 0                     | 0          | 0                  | 1        | 1        | 0                    |
| Public pathology laboratory  | 11    | 0                                    | 5                  | 0                     | 1          | 0                  | 1        | 4        | 0                    |



A total of 31 new sites were recruited to ACCESS, resulting in 92% (104/113) of health service identified nationally and 71% (17/24) of laboratories identified nationally participating in ACCESS. Participation is being negotiated with further 11 sites, 3 refused participation altogether, and 4 were not pursued

because of small patient caseloads compared with other similar services in their jurisdiction. Table 1 provides an overview of sites contributing data to ACCESS as of March 2018, noting that these numbers will continue to change over time. Figure 1 depicts participating sites on a map of Australia.

Figure 1. Health services participating in the Australian Collaboration for Coordinated Enhanced Sentinel Surveillance network as of March 2018.

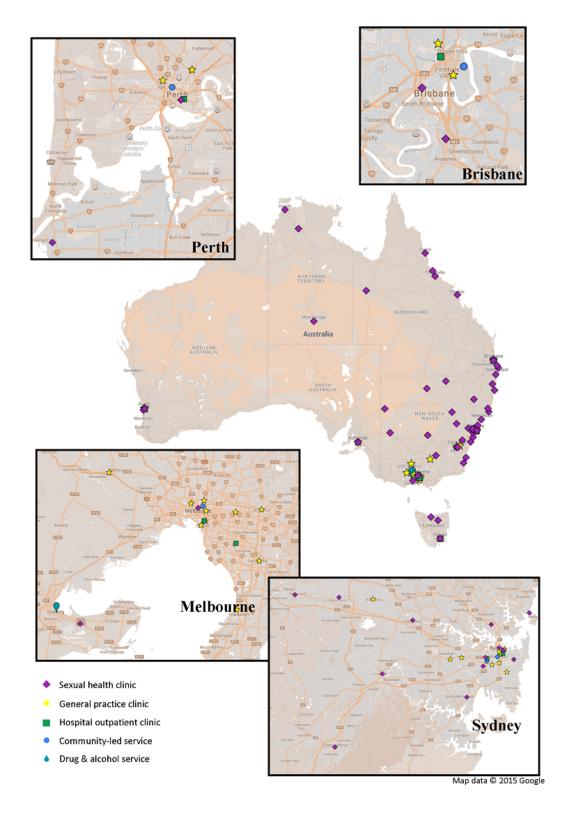




Table 2. Variables extracted (where available) from participating health services via Australian Collaboration for Coordinated Enhanced Sentinel Surveillance.

| Domain                       | Variables  |  |  |  |  |
|------------------------------|--|--|--|--|--|
| Patient information          | <ul> <li>Age</li> <li>Gender</li> <li>Home postcode</li> <li>Indigenous status</li> <li>Country of birth</li> <li>Preferred Language</li> <li>Year of arrival in Australia</li> <li>Sexual behavior</li> </ul> |  |  |  |  |
| Consultation details         | <ul> <li>Date</li> <li>Type</li> <li>Reason for attendance</li> <li>Clinical diagnosis</li> </ul>  |  |  |  |  |
| Laboratory testing           | <ul><li>Tests requested</li><li>Results</li><li>Specimen type</li><li>Anatomical site</li></ul>  |  |  |  |  |
| Treatment                    | <ul> <li>Drug name</li> <li>Start or stop dates</li> <li>Dose</li> <li>Frequency</li> <li>Route</li> </ul>   |  |  |  |  |
| Vaccination details          | <ul> <li>Vaccination history</li> <li>Vaccines administered</li> <li>Type</li> <li>Dose number</li> </ul>  |  |  |  |  |
| Behavioral: sexual practices | <ul> <li>Sexual partner gender(s)</li> <li>Sexual partner numbers</li> <li>Condom use</li> <li>Sex work</li> <li>Sex work location</li> </ul>  |  |  |  |  |
| Behavioral: drug use         | <ul> <li>Use of injecting drugs</li> <li>Shared injecting equipment</li> <li>Drugs injected</li> </ul>   |  |  |  |  |

#### **Data Extraction and Management**

Data are extracted from participating sites using software known as GRHANITE, which was designed specifically for the secure collection of deidentified health data. GRHANITE works by being installed on a local system at each participating site. Technical and financial costs associated with calibrating and installing GRHANITE are borne by ACCESS, making it a cost-neutral enterprise for sites. On an at least monthly basis, querying the site's database or accessing files already extracted from the database is performed. The nature of these queries is guided by schemas customized to meet the requirements and structures of each database. Because of their flexibility, GRHANITE's schemas can be deployed for use with almost any database structure to work across diverse systems ranging from established commercial platforms to unique systems built-for-purpose by individual services. Details of GRHANITE have been published previously [17,18]. Table 2 lists variables extracted for ACCESS, where available. Some sites routinely

collect behavioral information from patients, and where available, these data are also extracted.

As part of the extraction process, GRHANITE removes any data that could potentially identify a patient. While still working within a participating site, GRHANITE generates probabilistic record linkage keys (or signatures) called "hashes." These signatures are derived from, but do not contain, personal information, which means that probabilistic linkage can be safely conducted between and within participating ACCESS sites. This process makes it possible to monitor patient movement between services in a way that is anonymous and ensures that no identifiable patient details are ever transmitted beyond participating sites. Following extraction, GRHANITE encrypts the data and transmits it to a central, secure server.

Data are extracted for all patients and consultations, but pathology and treatment data are only extracted when there is evidence of testing or treatment for an STI or BBV. This approach helps limit the size of the ACCESS database by focusing on the most relevant pathology testing. In general



practice clinics, notably, the majority of testing would be unrelated to these infections, which would place an unnecessarily high technical burden on systems to fully extract all data. Thus, filters are used and regularly reviewed to ensure accuracy and completeness.

ACCESS data are processed using code that organizes pathology testing, treatment, and patient details into standardized formats. This step also involves unifying the structure of data received from different systems. Notably, because many patient management systems store pathology results as free text, computational parsing is used to identify test names, dates, and results to organize that information into consistent categories. This code is regularly reviewed for accuracy and adapted over time, as required. A similar process is used to identify patients that form part of Australia's priority populations, which involves drawing upon numerous pieces of information (eg, demographics, behavioral details, and pathology tests) to properly categorize patient files. For example, previous research has found that sexual orientation is not well recorded among men attending Australian general practice clinics [19]. To address this issue, we use history of rectal swabs for STI testing as a proximal marker indicating anal sex, which has previously been found to be effective for identifying gay and bisexual men and other men who have sex with men [20]. Definitions for organizing pathology tests and categorizing patients into priority populations were constructed in close consultation with relevant clinical and laboratory experts, as well as community representatives.

# **Data Quality**

The quality of ACCESS data is ensured through a number of processes. Data extracted from new services are validated through a consultative process with site investigators, which includes sharing preliminary outputs to gauge the degree to which they converge (or diverge) from clinical experience. This feedback is then used to improve data processing and address gaps or errors in the extraction process. For example, to ensure data completeness, we might ask clinic staff to estimate the number of HIV-positive patients they see each year or the number of chlamydia tests they conduct in an average week, which can then be compared against extracted and processed data. This process has previously identified components missing from extracts, including pathology test names, drugs types, and demographic variables, and then used to adapt and correct extraction processes.

Beyond completeness, we also carefully attend to the accuracy of ACCESS data. This involves what is extracted as well as how we process extracted data, which is to say how variables are organized into distinct and consistent categories. Wherever possible, ACCESS data are triangulated with other sources to improve accuracy. This process includes comparing extracted health service data to that from pathology laboratories; because some participating laboratories serve participating health services, we can assess the degree to which the number of tests and results align. Comparing data in this way has allowed us to refine pathology filters and our processes for organizing results. In the past, ACCESS data have also been assessed for accuracy against passive surveillance information. For example, we

previously requested information on HIV and STI notifications among sexual health clinic attendees in New South Wales to calibrate our systems for processing diagnoses in these clinics [21].

Routine data quality checks are also conducted on a quarterly basis, which focus on assessing if there are significant changes in test frequencies over time to generate alerts for significant deviations. For example, if the number of tests extracted for chlamydia doubled from one period to the next, this would be used as a point of investigation. Investigations include reviewing data processing, checking raw data, and consulting with site investigators. This kind of quality assurance is done on the dataset as a whole, by health service type and to the level of individual sites.

#### **Dissemination and Use**

ACCESS data are used for diverse purposes. Data extracted via ACCESS can be used to generate a number of powerful indicators relevant to BBVs and STIs, most commonly those related to diagnostic testing (test uptake, test frequency, test comprehensiveness, and retesting), treatment (treatment uptake and treatment success), infections (test yield, test positivity, incidence, and reinfection), and vaccinations (coverage of vaccine-acquired immunity). Indeed, indicators like these form part of ACCESS's contributions to the national surveillance of BBVs and STIs [22] and their surveillance by individual states and territories, including as stand-alone reports or as part of existing reporting mechanisms [23]. In reports such as these, ACCESS has been used to improve estimates of treatment uptake and success, which supports more accurate "cascades of care" for HIV and other infections. The automated nature of data extraction and processing facilitates timely production of reports, which in some cases are published as early as 4 weeks from the end of a reporting period. Furthermore, site-specific ACCESS data are routinely reported back to participating sites, which can include analyses of testing uptake, test positivity, and diagnosis frequency.

In addition to routine surveillance reporting, ACCESS data are used for a number of other related projects. Notably, ACCESS data have been used in stand-alone analyses of population health, for example, in studies of HIV and STIs among sex workers in Australia [24,25] and an analysis of hepatitis C testing and diagnoses among people living with HIV [26]. Moreover, ACCESS data have been used to assess the impact of syphilis testing interventions [27]. Beyond this work, ACCESS is being used increasingly to support other forms of research and evaluation. In some projects, ACCESS provides line-listed and deidentified datasets, which are and have been used to conduct a large-scale study of HIV treatment-as-prevention [28], evaluate pre-exposure prophylaxis implementation trials [29,30], and study Victoria's hepatitis C elimination response [31]. In other cases, as in the evaluation of HIV control in New South Wales [32], ACCESS has routinely provided specifically designed indicators (eg, HIV testing uptake and rates of viral suppression) to monitor and evaluate various aspects of BBV prevention and management. In many of these examples, ACCESS fills an important role by providing the kinds of data and indicators that are required for research of this kind to be conducted. Through



these projects, ACCESS demonstrates its capacity to support diverse research on STIs and BBVs, which extends beyond the realms of surveillance and monitoring.

#### **Ethics and Governance**

Ethical approval was granted by the lead human research ethics committee of Alfred Hospital in Melbourne (248/17), University of Tasmania (H0010220), and the Menzies School of Health Research (08/047). All ethics committees waived the need for consent to be collected from individual patients. Furthermore, ethical reviews were provided by organizations representing key populations, notably gay and bisexual men, people living with HIV, sex workers, and Aboriginal and Torres Strait Islander people.

To protect the identities of individual patients, access to the line-listed database is restricted to a small and select group of researchers. Where data are shared with others, potentially identifying details (eg, patient postcode) are replaced with broad categories (eg, urban/nonurban), which is a similar approach taken in any reporting of ACCESS data. Furthermore, analyses that produce cell counts of <5 individuals are suppressed.

An advisory committee was established comprising representatives from government organizations, community groups, health services and laboratories, and research institutes. This committee provides advice on the project's development and conduct; promotes its aims and objectives; and contributes to analysis, interpretation, and dissemination.

# Results

Although some sites were able to provide electronic data going back as far as the 1980s, data quality and completeness tends to diminish further back in time when health services were less familiar with technologies of electronic health that dominate today. To examine a more recent period, we note that ACCESS captured data from a total of 1,171,658 individual patients who attended a participating health service at least once in the recent past between 1 January 2009 and 31 December 2017. These patients attended for a total of 7,992,241 clinical consultations or an average of 0.8 consultations per patient per year. Patient gender was evenly represented between men (597,545/1,171,658, 51%) and women (574,112/1,171,658, 49%), and records were extracted from a total of 1116 transgender patients (380/1116, 34% transgender men; 356/1116, 32% transgender women, and 380/1116, 34% unspecified gender).

Specific to Australia's priority populations, from 2009 to 2017, ACCESS captured data of 366,441 young heterosexuals aged 16-29 years. In addition, the network includes data from 96,985 gay and bisexual men and other men who have sex with men. Data were also captured from 21,598 people living with HIV, drawing upon recorded HIV diagnoses, confirmed HIV pathology results, viral load testing, and clinical attendance for "HIV management." In total, 22,089 Aboriginal and Torres Strait Islander patients attended an ACCESS health service during this period, noting that this variable was incomplete for 74% (576,219/778,674) of patients attending general practice clinics and 50% (196,490/392,984) of patients attending other services. Even though Australian guidelines recommend

collecting indigenous status from all patients [33], it seems that this indicator is still not routinely collected.

As noted, sexual health clinics in Australia routinely collect enhanced behavioral data on factors associated with BBVs and STIs. This information is used by ACCESS to further identify members of priority populations. From 2009 to 2017, for example, it is possible to identify 12,111 people who attended an ACCESS site and reported injecting drug use at least once in the 12 months prior to consultation, as it is possible to identify 21,205 men and women who reported sex work in the previous 12 months. As noted, identifying members of these priority populations is not possible in settings other than sexual health and community-lead clinics, which is attributed to a lack of standardized methods for collecting and recording behavioral data. Work is ongoing to support the implementation of behavioral surveys in some general practice clinics and to develop algorithms for recognizing these populations through other means, such as through certain types and patterns of pathology tests and testing.

# Discussion

In this paper, we described the methods used to establish a national sentinel surveillance system for BBVs and STIs. ACCESS seeks to complement the existing passive surveillance by tracking the uptake and impact of strategies aimed at controlling these infections. The system is highly flexible and can be adapted for use in a multitude of health contexts and evolve over time to address emerging surveillance needs. In addition, it is a project deeply rooted in collaboration, involving government, researchers, community, and clinicians from every corner of Australia. ACCESS is a unique national resource and a model with potential relevance for other countries.

A key strength of ACCESS is its ability to anonymously link patients between services and over time. In some ways, this feature makes ACCESS akin to a national retrospective and prospective cohort, which has exciting possibilities in a number of areas. ACCESS allows scrutiny of the ways that individuals move through different pathways of care, including the overall trajectory and the time it takes to move from diagnosis to viral suppression or cure. Furthermore, this linkage facilitates the calculation of powerful epidemiological markers, like incidence and test frequency and also allows for examinations of compliance with clinical guidelines associated with testing (eg, chlamydia testing among young people presenting to clinics or following past positive tests). ACCESS also makes possible detailed, individual, and large-scale evaluations of public health policy, interventions, and other strategies aimed at controlling BBVs and STIs.

Another key strength of ACCESS relates to its coverage. Specifically, the network of health services in every state and territory enables comparison between not only Australian jurisdictions but also different types of service models, such as community-based testing services, sexual health clinics, and hospitals. These comparisons are important for identifying gaps, comparing the utility of different ways for providing care and nuanced information on how BBVs and STIs are diagnosed and managed. Furthermore, by attending to the geographic



concentrations of Australia's priority populations and working with community groups and health experts, ACCESS has collated some of the largest samples of "high-risk" priority populations seen anywhere in the world.

The automated nature of ACCESS significantly reduces the resources and time required to report surveillance data, benefits that are already being realized through quarterly reporting to state health departments. Although initial enrollment of new sites to ACCESS requires some time, maintenance is minimal once established, which helps ensure the system's ongoing sustainability. Moreover, participating sites realize benefits through the publication of scientific research and the ability to more readily access their own data, including through tailored site reports that can include comparisons with aggregated data from similar sites. These strengths are reflected in the observation that in a decade of operation, no site has yet chosen to withdraw from ACCESS.

There are some limitations of the system that warrant consideration. As a surveillance network, ACCESS does not capture all new diagnoses and is, therefore, not a replacement for passive surveillance. Although we have described the process for anonymously linking patients between ACCESS sites, gaps arise when patients attend health services outside of the network. These gaps can be partly overcome through data from participating laboratories but they are inherent in the network's

"sentinel" nature. Another limitation is ACCESS's inability to collect all clinical information, in particular, the free text detail contained within patient notes. Patient notes contain a wealth of details that would likely be relevant to BBVs and STIs but are not accessed by this system because they can potentially contain identifying information. Options for identifying and extracting relevant details through the use of text-recognition software are currently being assessed as a potential means of using this information confidentially. Finally, ACCESS is entirely reliant on routinely recorded health information; the quality and completeness of these details can vary between and within sites. This limitation, however, can be overcome in some cases with ACCESS's capacity for anonymous patient linkage by pooling information from multiple services and laboratories to construct a more complete picture.

ACCESS represents a new way of conducting sentinel surveillance, which adds value for government, research, clinical, and community partners. With data extraction under way across the country, over the coming years, the project will focus on new ways of providing regular feedback to health service and laboratory sites as a way to improve service delivery, sustain interest, and capitalize on the network's potential. In the future, it is imagined that ACCESS will continue to develop as a readily accessible resource for diverse stakeholders that seek to make use of it as a unique, national database.

#### Acknowledgments

The ACCESS team gratefully acknowledges the site investigators and database managers who make this project possible, including Cheryle Abela, Afrizal, Debbie Allen, Eugene Athan, Craig Atkinson, David Baker, Deborah Bateson, Charlotte Bell, Mark Bloch, Annie Braendler-Phillips, Rebecca Bowman, Katherine Brown, Michael Burke, Christopher Carmody, Andrew Carr, Jo Chew, Kim Ching, Stephen Davies, Nicholas Doong, Jane Estoesta, Christopher Fairley, Robert Finlayson, Brad Forssman, Manoji Gunathilake, Philip Habel, Krispin Hajkowicz, Shane Hewitt, Eva Jackson, Bill Kefalas, Susan Kennett, Julian Langton-Lockton, Frederick Lee, Jane Leighton, David Lewis, Sharon Lewis, Peter Locke, Heng Lui, Josephine Lusk, Justin Manuel, Lewis Marshall, Sarah Martin, Jenny McCloskey, Anna McNulty, Maggie McPherson, Arun Menon, Graham Neilsen, Alison Nikitas, David Nolan, Leanne Oberin, Catherine O'Connor, Maree O'Sullivan, Louise Owen, Cheryn Palmer, Goran Pervan, Phillip Read, Mark Roberts, Wendell Rosevear, Norm Roth, Sally Rowell, Darren Russell, Nathan Ryder, Desiree Schild, Andrew Small, David Smith, Tuck Meng Soo, Carmel Swiggs, BK Tee, David Templeton, Karlie Tucker, Catherine Turnbull, David Townson, Emanuel Vhalkis, Adrian Waldock, Cheryl Walker, Alison Ward, Mark Wilson, and Jeff Wilcox.

In addition, ACCESS is supported by an Advisory Group, which includes the following representatives: Scott McGill, Stella Pendle, Ben Wilcock, Melanie Walker, Scott Bowden, Deborah Bateson, Helen Tyrrell, Aaron Cogle, Christine Selvey, Jules Kim, Mark Boyd, Jane Hocking, Michael West, Nicola Stephens, and Lisa Bastian. ACCESS acknowledges the data management support from Tobias Vickers, Gijo Thomas, and Victoria Polkinghorne. The Burnet Institute gratefully acknowledges support from the Victorian Operational Infrastructure Support Program.

ACCESS is funded by the Australian Department of Health. MH, RG, MS, and BD are supported by fellowships from the National Health and Medical Research Council.

## **Conflicts of Interest**

None declared.

# References

- 1. UNAIDS. 2015 World AIDS Day report: Fact Sheet 2015 URL: <a href="http://www.unaids.org/en/resources/fact-sheet">http://www.unaids.org/en/resources/fact-sheet</a> [accessed 2018-05-10] [WebCite Cache ID 6zIbRRapQ]
- 2. Stanaway JD, Flaxman AD, Naghavi M, Fitzmaurice C, Vos T, Abubakar I, et al. The global burden of viral hepatitis from 1990 to 2013: findings from the Global Burden of Disease Study 2013. Lancet 2016 Sep 10;388(10049):1081-1088 [FREE Full text] [doi: 10.1016/S0140-6736(16)30579-7] [Medline: 27394647]



- 3. Ott JJ, Stevens GA, Groeger J, Wiersma ST. Global epidemiology of hepatitis B virus infection: new estimates of age-specific HBsAg seroprevalence and endemicity. Vaccine 2012 Mar 09;30(12):2212-2219 [FREE Full text] [doi: 10.1016/j.vaccine.2011.12.116] [Medline: 22273662]
- 4. Goldstein ST, Zhou F, Hadler SC, Bell BP, Mast EE, Margolis HS. A mathematical model to estimate global hepatitis B disease burden and vaccination impact. Int J Epidemiol 2005 Dec;34(6):1329-1339. [doi: 10.1093/ije/dyi206] [Medline: 16249217]
- 5. Newman L, Rowley J, Vander HS, Wijesooriya NS, Unemo M, Low N, et al. Global Estimates of the Prevalence and Incidence of Four Curable Sexually Transmitted Infections in 2012 Based on Systematic Review and Global Reporting. PLoS One 2015;10(12):e0143304 [FREE Full text] [doi: 10.1371/journal.pone.0143304] [Medline: 26646541]
- 6. World Health Organization. Cervical cancer estimated incidence, mortality and prevalence worldwide in 2012 URL: <a href="http://globocan.iarc.fr/old/FactSheets/cancers/cervix-new.asp">http://globocan.iarc.fr/old/FactSheets/cancers/cervix-new.asp</a> [accessed 2018-05-10] [WebCite Cache ID 6zIbaJC1q]
- 7. World Health Organization. Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a public health approach. 2nd edition. Geneva, Switzerland: World Health Organization; 2016.
- 8. Cohen MS, Chen YQ, McCauley M, Gamble T, Hosseinipour MC, Kumarasamy N, et al. Prevention of HIV-1 infection with early antiretroviral therapy. N Engl J Med 2011 Aug 11;365(6):493-505 [FREE Full text] [doi: 10.1056/NEJMoa1105243] [Medline: 21767103]
- 9. UNAIDS. 90-90-90 An ambitious treatment target to help end the AIDS epidemic. 2014. URL: <a href="http://www.unaids.org/sites/default/files/media\_asset/90-90-90\_en.pdf">http://www.unaids.org/sites/default/files/media\_asset/90-90-90\_en.pdf</a> [accessed 2018-05-10] [WebCite Cache ID 6zIbpaaJS]
- 10. Scott N, Stoové M, Kelly SL, Wilson DP, Hellard ME. Achieving 90-90-90 Human Immunodeficiency Virus (HIV) Targets Will Not Be Enough to Achieve the HIV Incidence Reduction Target in Australia. Clin Infect Dis 2018 Mar 19:66(7):1019-1023. [doi: 10.1093/cid/cix939] [Medline: 29099920]
- 11. Australian Government Department of Health. Seventh National HIV Strategy 2014-2017. Canberra, ACT, Australia: Commonwealth of Australia; 2014. URL: <a href="http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-bbvs-hiv">http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-bbvs-hiv</a> [accessed 2018-05-10] [WebCite Cache ID 711SZUe0c]
- 12. Dore GJ, Feld JJ. Hepatitis C virus therapeutic development: in pursuit of "perfectovir". Clin Infect Dis 2015 Jun 15;60(12):1829-1836. [doi: 10.1093/cid/civ197] [Medline: 25761867]
- 13. Australian Government Department of Health. Fourth National Heptatits C Strategy 2014-2017. Canberra, ACT, Australia: Commonwealth of Australia; 2014. URL: <a href="http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-bbvs-hepc">http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-bbvs-hepc</a> [accessed 2018-05-10] [WebCite Cache ID 711SgrY6l]
- 14. Australian Government Department of Health. Third National Sexually Transmissible Infections Strategy 2014-2017. Canberra, ACT, Australia: Commonwealth of Australia; 2014. URL: <a href="http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-bbvs-sti">http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-bbvs-sti</a> [accessed 2018-05-10] [WebCite Cache ID 6zIbkDhK6]
- 15. Guy RJ, Kong F, Goller J, Franklin N, Bergeri I, Dimech W, et al. A new national Chlamydia Sentinel Surveillance System in Australia: evaluation of the first stage of implementation. Commun Dis Intell Q Rep 2010 Sep;34(3):319-328. [Medline: 21090187]
- 16. Medland NA, McMahon JH, Chow EPF, Elliott JH, Hoy JF, Fairley CK. The HIV care cascade: a systematic review of data sources, methodology and comparability. J Int AIDS Soc 2015;18:20634 [FREE Full text] [Medline: 26626715]
- 17. Boyle DIR. Middleware Supporting Next Generation Data Analytics in Australia. Stud Health Technol Inform 2015;216:1019. [Medline: 26262320]
- 18. Boyle D, Kong F. A Systematic mechanism for the collectioninterpretation of display format pathology test results from Australian primary care records. Electronic Journal of Health Informatics 2011;6(2):7.
- 19. Callander D, Bourne C, Pell C, Finlayson R, Forssman B, Baker D, et al. Recording the sexual orientation of male patients attending general practice. Fam Pract 2015 Feb;32(1):35-40. [doi: 10.1093/fampra/cmu061] [Medline: 25236604]
- 20. Ampt FH, El-Hayek C, Agius PA, Bowring AL, Bartnik N, Fairley CK, et al. Anorectal swabs as a marker of male-to-male sexual exposure in STI surveillance systems. Epidemiol Infect 2017 Dec;145(12):2530-2535. [doi: 10.1017/S095026881700098X] [Medline: 28528588]
- 21. Bourne C, Lam M, Selvey C, Guy R, Callander D. Changing pattern of sexually transmissible infections and HIV diagnosed in public sexual health services compared with other locations in New South Wales, 2010-14. Sex Health 2018 Jul 16. [doi: 10.1071/SH17183] [Medline: 30008288]
- 22. The Kirby Institute. HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report. Sydney, NSW: The Kirby Institute, UNSW; 2017. URL: <a href="https://kirby.unsw.edu.au/report/">https://kirby.unsw.edu.au/report/</a> annual-surveillance-report-hiv-viral-hepatitis-stis-2016 [accessed 2018-10-22] [WebCite Cache ID 73N9fJh1i]
- 23. The NSW Ministry of Health. NSW HIV Strategy 2016-2020: April-June 2017 Data Report. 2017. URL: <a href="http://www.health.nsw.gov.au/endinghiv/Publications/q2-2017-nsw-hiv-data-report.pdf">http://www.health.nsw.gov.au/endinghiv/Publications/q2-2017-nsw-hiv-data-report.pdf</a> [accessed 2018-10-10] [WebCite Cache ID 6zIc6Sweg]
- 24. Callander D, McManus H, Guy R, Hellard M, O'Connor CC, Fairley CK, et al. Rising Chlamydia and Gonorrhoea Incidence and Associated Risk Factors Among Female Sex Workers in Australia: A Retrospective Cohort Study. Sex Transm Dis 2018 Mar;45(3):199-206. [doi: 10.1097/OLQ.00000000000000114] [Medline: 29420449]



- Callander D, Read P, Prestage G, Minichiello V, Chow EPF, Lewis DA, et al. A cross-sectional study of HIV and STIs among male sex workers attending Australian sexual health clinics. Sex Transm Infect 2017 Jun;93(4):299-302. [doi: 10.1136/sextrans-2016-052578] [Medline: 27591189]
- 26. Boettiger DC, Law MG, Dore GJ, Guy R, Callander D, Donovan B, et al. Hepatitis C testing and re-testing among people attending sexual health services in Australia, and hepatitis C incidence among people with human immunodeficiency virus: analysis of national sentinel surveillance data. BMC Infect Dis 2017 Dec 01;17(1):740 [FREE Full text] [doi: 10.1186/s12879-017-2848-0] [Medline: 29191154]
- 27. Chow EPF, Callander D, Fairley CK, Zhang L, Donovan B, Guy R, ACCESS collaboration. Increased Syphilis Testing of Men Who Have Sex With Men: Greater Detection of Asymptomatic Early Syphilis and Relative Reduction in Secondary Syphilis. Clin Infect Dis 2017 Aug 01;65(3):389-395. [doi: 10.1093/cid/cix326] [Medline: 28419198]
- 28. Callander D, Stoové M, Carr A, Hoy JF, Petoumenos K, Hellard M, et al. A longitudinal cohort study of HIV 'treatment as prevention' in gay, bisexual and other men who have sex with men: the Treatment with Antiretrovirals and their Impact on Positive And Negative men (TAIPAN) study protocol. BMC Infect Dis 2016 Dec 12;16(1):752 [FREE Full text] [doi: 10.1186/s12879-016-2073-2] [Medline: 27955627]
- 29. Ryan K, Lockwood J, Asselin J, Mak A, Price B, Murphy D, et al. Health systems and study design features permitting rapid enrolment of individuals at high-risk of HIV acquisition into a pre-exposure prophylaxis study in Melbourne, Victoria, Australia. 2017 Presented at: International AIDS Conference on HIV Science; 2017; Paris, France.
- 30. Zablotska IB, Selvey C, Guy R, Price K, Holden J, Schmidt H, EPIC-NSW study group. Expanded HIV pre-exposure prophylaxis (PrEP) implementation in communities in New South Wales, Australia (EPIC-NSW): design of an open label, single arm implementation trial. BMC Public Health 2018 Dec 02;18(1):210 [FREE Full text] [doi: 10.1186/s12889-017-5018-9] [Medline: 29394918]
- 31. Pedrana A. Implementing an Elimination program for Hepatitis C: A partnership approach in Australia. Implementing an Elimination program for Hepatitis C: A partnership approach in Australia. International Symposium on Hepatitis Care in Substance Users. New Jersey. USA; 2017 Presented at: International Symposium on Hepatitis Care in Substance Users; 2017; New Jersey, USA.
- 32. Keen P, Selvey C, Grulich A. The HIV prevention revolution: measuring outcomes maximising effectiveness in NSW. HIV Australia 2016;14(2):35-37 [FREE Full text]
- 33. Australian Institute of Health and Welfare. National best practice guidelines for collecting Indigenous status in health data sets. Canberra, Australia; 2010 Apr 08. URL: <a href="https://www.aihw.gov.au/reports/indigenous-australians/national-guidelines-collecting-health-data-sets/contents/table-of-contents">https://www.aihw.gov.au/reports/indigenous-australians/national-guidelines-collecting-health-data-sets/contents/table-of-contents</a> [accessed 2018-10-10] [WebCite Cache ID 6zIcHKdOP]

#### **Abbreviations**

ACCESS: Australian Collaboration for Coordinated Enhanced Sentinel Surveillance

**BBV:** blood-borne virus **HPV:** human papillomavirus

STI: sexually transmissible infection

Edited by G Eysenbach, N Kuter; submitted 11.05.18; peer-reviewed by J Constantin, J Donnelly; comments to author 12.07.18; revised version received 19.07.18; accepted 23.08.18; published 20.11.18

#### Please cite as:

Callander D, Moreira C, El-Hayek C, Asselin J, van Gemert C, Watchirs Smith L, Nguyen L, Dimech W, Boyle DIR, Donovan B, Stoové M, Hellard M, Guy R

Monitoring the Control of Sexually Transmissible Infections and Blood-Borne Viruses: Protocol for the Australian Collaboration for Coordinated Enhanced Sentinel Surveillance (ACCESS)

JMIR Res Protoc 2018;7(11):e11028

URL: http://www.researchprotocols.org/2018/11/e11028/

doi: <u>10.2196/11028</u> PMID: <u>30459142</u>

©Denton Callander, Clarissa Moreira, Carol El-Hayek, Jason Asselin, Caroline van Gemert, Lucy Watchirs Smith, Long Nguyen, Wayne Dimech, Douglas IR Boyle, Basil Donovan, Mark Stoové, Margaret Hellard, Rebecca Guy. Originally published in JMIR Research Protocols (http://www.researchprotocols.org), 20.11.2018. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Research Protocols, is properly



# JMIR RESEARCH PROTOCOLS

Callander et al

cited. The complete bibliographic information, a link to the original publication on http://www.researchprotocols.org, as well as this copyright and license information must be included.

