AUSTRALIAN COLLABORATION FOR COORDINATED ENHANCED SENTINEL SURVEILLANCE (ACCESS): A PROTOCOL FOR MONITORING THE CONTROL OF SEXUALLY TRANSMISSIBLE INFECTIONS AND BLOOD BORNE VIRUSES

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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. This paper describes ACCESS (*Australian Collaboration for Coordinated Enhanced Sentinel Surveillance*), a national surveillance network designed to monitor public health and evaluate the impact of strategies aimed at controlling BBVs and STIs in Australia.

**Methods:** ACCESS is a sentinel surveillance system comprising health services and pathology laboratories in each of the eight Australian jurisdictions. Sites that provide significant testing or management of BBVs and/or STIs or see populations with particular risks for these infections ('priority populations') are included in the network. ACCESS is based on regular and automated extraction of de-identified patient data using specialised software called GRHANITE™, which creates a unique and anonymous identifier from individual patient details. This identifier allows anonymous linkage between and within participating sites, creating a national cohort that allows the evaluation of clinical and public health interventions and related research.

**Results:** As of March 2018, 104 health services (sexual health clinics, general practice clinics, drug and alcohol services, community-led testing services, and hospital outpatient clinics) and 17 pathology laboratories (private and public) were participating in ACCESS. Between 2009 and 2017, ACCESS captured data from 1,171,658 individual patients who attended a participating health service at least once, comprising a total of 7,992,241 consultations.

**Discussion:** 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.
INTRODUCTION

Globally, sexually transmissible infections (STIs) and blood borne viruses (BBVs) are associated with significant morbidity, mortality, health costs and social stigma. Globally, these infections represent a major public health burden. There are, for example, nearly 37 million people currently infected with HIV and over one million associated deaths per year[1]. Currently, an estimated 70 million people live with hepatitis C, from which nearly half a million people die each year[2], while for hepatitis B there are an estimated 250 million people living with the infection and over 800,000 associated annual deaths[3,4]. Globally, there are over 350 million new cases of curable STIs every year – chlamydia, gonorrhoea, syphilis and trichomoniasis – [5] and human papilloma viruses (HPV) are 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 is increasingly feasible through combinations of new and existing strategies of prevention, treatment and management. For HIV, elimination is a tantalising possibility through regular testing of those at risk of infection 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 in order to guide the refinement of implementation strategies. Similarly, curative therapy with direct acting antiviral therapy for hepatitis C has been made available to all infected people in Australia, representing a major advance for both individual and public health [7,11] but one that also requires monitoring, evaluation and adaptation if there is any hope of achieveing infection reduction.

For some other infections – notably hepatitis B and HPV – vaccinations have proved highly effective in lower population incidence and prevalence. There remain, however, cohorts of people who were not
included in the vaccination schedule due to their age or who have migrated to Australia from countries where prevalence is high and vaccination program 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. And for curative STIs, frequent testing and timely treatment remain fundamental towards interrupting incubation and preventing unintended onward transmission[12]. For STIs and BBVs, it is clear that ongoing monitoring is needed to track progress against targets, monitor population health, assess intervention impact and plan into the future.

Surveillance and monitoring of BBVs and STIs is often complicated by the fact that they disproportionately affect populations defined by sexual identity, sex practice, drug use, and ethnicity. Thus, their management requires a holistic and comprehensive approach to care, which in Australia and many other countries involves specialised sexual health clinics, targeted general practices, 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. From a surveillance and monitoring perspective, these service types can provide denominator data on service access and diagnostic testing to estimate the coverage of clinical care and prevention strategies. When linked between individuals’ episodes of care, these data can also be used to calculate impact indicators, such as incidence or the time between diagnosis and treatment.

Here, we describe ‘ACCESS’, 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 (Australian Collaboration for Coordinated Enhanced Sentinel Surveillance) is a system that routinely extracts and collates line-listed, de-identified 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 [13] 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 eight 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. ACCESS also aims to operate as an evaluative platform to measure the impact and outcomes of relevant programs and interventions, which includes attention to Australian priority populations (gay, bisexual and other men who have sex with men, people who use drugs, Aboriginal and Torres Strait Islander peoples, young heterosexuals, sex workers, and people from culturally and linguistically diverse backgrounds) and to ‘cascades of care’ (e.g., HIV [14]).

Infections

ACCESS focuses on specific infections including: HIV, hepatitis B, hepatitis C, HPV, chlamydia, gonorrhoea, 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

To account for differences in the structure of services and systems relevant to BBVs and STIs in each jurisdiction, consultations with government stakeholders, health workers, community organisations and other relevant experts aimed to identify key sentinel sites. This included sites that manage large caseloads of priority populations (e.g., gay and bisexual men), sites specifically providing specialist care (e.g., sexual health testing services), and those responsible for a large number of STI or BBV diagnoses. Similarly, identifying and recruiting laboratory sites relied on stakeholder input and available public health data to identify those that conducted the greatest volume of diagnostic and management testing. Complete methods for recruiting and establishing the laboratory sites are described elsewhere[15].

To be eligible for participation, health services were required to use an electronic patient management system (i.e., not based solely on paper files) and be willing to participate for a minimum of two years. ACCESS was designed to be cost-neutral for participating services with support provided for all human and technical costs associated with setup and maintenance. As described later, the automated nature of data extraction helps ensure that little or no ongoing time or resources are required following initial setup.

Given differences in population size between each state and territory – the largest contains over 7.5 million people while the smallest has just over 200,000 – our assessment of caseloads and care were relative to each jurisdiction’s size. Per jurisdiction, we sought to include a minimum of two HIV-focused sites, two hepatitis-focused sites, two STI-focused sites, one private pathology laboratory and one public
pathology laboratory. Efforts were also made to recruit sites encompassing diverse service delivery models (e.g. private, public and community-led) and in geographically diverse locations. Table 1 provides an overview of sites participating in ACCESS as of March 2018.

**Table 1.** Clinical services and pathology laboratories participating in the ACCESS network (March 2018)

<table>
<thead>
<tr>
<th>Site type</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual health clinic</td>
<td>58</td>
</tr>
<tr>
<td>General practice clinic</td>
<td>30</td>
</tr>
<tr>
<td>Hospital outpatient clinic</td>
<td>7</td>
</tr>
<tr>
<td>Community-led services</td>
<td>8</td>
</tr>
<tr>
<td>Drug &amp; alcohol service</td>
<td>1</td>
</tr>
<tr>
<td>Private pathology laboratory</td>
<td>6</td>
</tr>
<tr>
<td>Public pathology laboratory</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>121</strong></td>
</tr>
</tbody>
</table>

**Data extraction and management**

Data are extracted from participating sites using software known as GRHANITE™, which was designed specifically for the secure collection of de-identified health data. GRHANITE™ works by being installed on a local system at each participating site and, on an at least monthly basis, the software queries the site's database or accesses files extracted from the database by employing schemas customised to ACCESS's requirements and the structure of each database or file. Schemas are entirely customisable, enabling ACCESS to harness the flexibility of GRHANITE™ in order to work across diverse systems and databases that range from established commercial platforms to unique systems built-for-purpose by individual services. Details of GRHANITE™ have been published previously [16,17]. Data extracted for ACCESS, where available, are listed in Table 2. In some sites, behavioural data collected from clients at each episode of care are also extracted.
Table 2. Data extracted (where available) from participating health services

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

As part of the extraction process, GRHANITE™ removes any data that could potentially identify a patient. Whilst still working within a participating site, GRHANITE™ generates probabilistic record linkage keys (or signatures) called 'hashes' for the purposes of record linkage. These signatures are derived from but do not contain personal information, utilising, for example, patient surname and given name. Additional
techniques protect these hashes against dictionary attack or any form of replication outside approved installations of GRHANITE™ for ACCESS. With these hashes, probabilistic linkage can be safely conducted between and within participating ACCESS sites, which 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 pathology testing would be unrelated to BBVs or STIs and it would place a high technical burden on systems to fully extract these data. Thus, filters are employed and regularly reviewed to ensure accuracy and completeness.

ACCESS data are processed using code that organises pathology testing, treatment and patient details into standardised 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 employed to identify test names, dates and results and then organise that information into consistent categories. This code is regularly reviewed for accuracy and, as required, adapted over time. A similar process is employed to identify patients that form part of Australia’s priority populations, which involves drawing upon numerous pieces of information (e.g., demographic, behavioural details, pathology tests) in order to properly categorise patients. For example, previous research has found that sexual orientation is not well-recorded among men attending Australian general practice clinics[18]. To address this issue, we use history of rectal swabs for STI testing as a proximal
marker, which has previously been found an effective way to identify members of this population[19]. Definitions for organising pathology tests and categorising 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 in order 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 each 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.

Beyond completeness, we also attend carefully to the accuracy of ACCESS data. This involves what is extracted but also how we process extracted data, which is to say how variables are organised into distinct and consistent categories. Wherever possible, ACCESS data are triangulated with other sources in order 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 test results align. Comparing data in this way has allowed us to refine pathology filters and our processes for organising results. In the past, ACCESS data have also been assessed for accuracy against passive surveillance data. For example, we previously
requested information on HIV and STI notifications in New South Wales just for those sexual health clinics participating in the ACCESS network, which was used to calibrate our systems for processing diagnoses in these clinics [20].

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 and generate flags if these changes exceed two standard deviations from the mean. For example, if the number of tests extracted for chlamydia increased significantly 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. Indicators generated using ACCESS data contribute to national surveillance of BBVs and STIs [17] and to their surveillance by individual states and territories, including as stand-alone reports or as part of existing reporting mechanisms e.g.,[21]). The automated nature of data extraction and processing facilitates timely production of reports, which in some cases are published as early as four weeks from the end of a reporting period. Site-specific ACCESS data are also 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 [22,23] and an analysis of HCV testing and
diagnoses among people living with HIV [24]. ACCESS data have also been used to assess the impact of clinical practice interventions around syphilis testing [25]. Beyond this work, ACCESS is being used increasingly to support other research and evaluation, which includes a large-scale study of HIV treatment-as-prevention[26], several PrEP implementation trials[27,28], an evaluation of HIV control in New South Wales[29], and an evaluation of Victoria's hepatitis C elimination response[30]. Through these projects, ACCESS demonstrates it capacity to support diverse research on STIs and BBVs, extending beyond the realms of surveillance and monitoring.

Ethics and governance

Ethical approval was granted by the lead human research ethics committee at the 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. Ethical reviews were also provided by organisations representing key populations, notably gay and bisexual men, people living with HIV, sex workers and Aboriginal and Torres Strait Islander people.

An advisory committee was established comprising representatives from government organisations, 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

As of March 2018, the ACCESS network included a total of 121 sites in every state and territory, including 63 in New South Wales, 24 in Victoria, 12 in Queensland, six in Tasmania, six in Western Australia, four in South Australia, three in the Australian Capital Territory, and three in the Northern Territory (Figure 1).
Since its inception, no ACCESS sites have ever withdrawn from participation. Table 1 provides an overview of sites in the ACCESS network, noting that these figures are likely to change over time.

Details on data captured by ACCESS laboratory sites are outlined elsewhere[15]. Across health services, from 2009 up until the end of 2017 data were collected in ACCESS from a total of 1,171,658 individual patients who attended a participating health service at least once, comprising 7,992,241 clinical consults. Although some sites were able to provide electronic data going back as far as the 1980s, data quality and completeness across the network is best from 2009 onwards when all services had replaced paper files with some form of electronic record. Patient gender was evenly represented between men (51%) and women (49%) and records were extracted from a total of 1,116 transgender patients: 34% trans men, 32% trans women and 34% of unspecified gender.

Specific to Australia’s priority populations, from 2009 to 2017 ACCESS captured data on 366,441 young heterosexuals aged 16 to 29 years old. The network also includes data from 96,985 men identified as gay or bisexual, which included those recorded as such, those who reported same-sex partners, and men with a history of rectal swabs for STI testing. 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/or Torres Strait Islander patients attended an ACCESS health service between 2009 and 2017, noting that this variable was not complete for 74% of patients attending general practice clinics and 50% of patients attending other services. Even though Australian guidelines recommend collecting Indigenous status from all patients[31], in many cases it seems that this indicator is not included in patient records.
Figure 1. Clinical services participating in the ACCESS network as of March 2018

- Sexual health clinic
- General practice clinic
- Hospital outpatient clinic
- Community-led service
- Drug & alcohol service
As noted, sexual health clinics in Australia routinely collect enhanced behavioural 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, ACCESS health services saw 12,111 people who reported injecting drug use at least once in the 12 months prior to consultation and 21,205 men and women who reported recent sex work. As noted it is not possible to identify these people in settings other than sexual health and community-lead clinics, which is due to a lack of standardised methods for collecting and recording behavioural data. Work is ongoing to support the implementation of behavioural surveys in some general practice clinics and to develop algorithms for recognising 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 aims to complement 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. It is also a project rooted in collaboration, which involves 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 overall trajectory and the time it takes to move from diagnosis to viral suppression or cure. Further, 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 (e.g., 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 not only between Australian jurisdictions but also between different types of service models, such as community-based testing services, sexual health clinics or hospitals. These comparisons are important for identifying gaps, comparing the utility of different ways for providing care and for providing nuanced information on how BBVs and STIs are diagnosed and managed. Further, by attending to 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 and priority populations seen anywhere in the world.

The automated nature of ACCESS significantly reduces the resources and time required to report surveillance data, benefits which are already being realised through quarterly reporting to state health departments. Although initial enrolment of new sites to ACCESS requires some time, maintenance is minimal once established, which helps ensure the system’s ongoing sustainability. Participating sites also realise benefits through 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. Also, it is not possible for ACCESS 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 of the potential they will also 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 making use of this information in a confidential manner. 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 now underway 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 capitalise on the network’s potential. In the future, it is imagined that ACCESS will exist as a readily-accessible resource for diverse stakeholders that seek to make of it as a unique, national database.

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