Collecting and Analysing Testing Data to Improve the Surveillance of Sexually Transmitted Infections in the Northern Territory

by

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A thesis submitted for the degree of

Doctor of Public Health

Menzies School of Health Research

Charles Darwin University

Darwin, Northern Territory, Australia

2015

Declaration

Title of the thesis:

Collecting and analysing testing data to improve the surveillance of sexually transmitted infections in the Northern Territory

I hereby declare that this thesis, now submitted for the degree of Doctor of Public Health, is the result of my own investigations, and all references to ideas and work of other researchers have been specifically acknowledged. I hereby certify that the work embodied in this thesis has not already been accepted in substance for any degree, is not being currently submitted in candidature for any other degree, and that this thesis is less than 50,000 words in length excluding Figures, Tables and Appendices.

Three chapters of the thesis consist of research papers that have been published in peer-reviewed journals or local disease control bulletin in the Northern Territory. The initial conceptual development, planning, and data collection and analysis were performed by the candidate. Supervisors Professor John Condon and Dr Steven Skov provided guidance and advice during the process of research, and reviewed the draft papers. Their respective further contributions are described in the preface to each chapter.

Jiunn-Yih Su

Abstract

The literature has shown that surveillance data for common sexually transmitted infections (STIs) does not adequately measure disease occurrence or effectiveness of control measures because the number of notifications is strongly influenced by the amount of testing. This thesis explores how laboratory testing data could be used to improve the surveillance of STIs in the Northern Territory (NT), which has very high levels of STIs, particularly in the Aboriginal population.

Over the past 15 years, innovations using testing data to improve STI surveillance systems have occurred in several countries, and more recently in two Australian states, with differing but promising success, but most of them lacked sustainability. I therefore examined the theoretical and practical aspects of enhancing an STI surveillance system using laboratory testing data, and conducted three projects to test the feasibility and effectiveness of this approach in the NT.

The first project used testing data to investigate the sharp decrease in gonococcal cultures performed in the NT, illustrating the data's utility in monitoring testing activities at the jurisdiction level. The second project used testing data to calculate testing rates and test positivity rates to assist in the interpretation of time trends in the gonorrhoea notification rate at the district level. The third project used testing and notification data to evaluate the effectiveness of a sexual health program (that included population screening for STIs) in a group of remote communities.

The benefits of using laboratory testing data to enhance STI surveillance have been demonstrated in several countries and two Australian states. The thesis has demonstrated the feasibility of accessing and analysing such data in the NT and the benefits for STI control in a high-prevalence population. I therefore conclude by proposing a best practice model for how such an enhanced surveillance system could, and should, be implemented in the NT.

Acknowledgements

First of all, I would like to express my utmost gratitude to my supervisors Professor John Condon and Dr Steven Skov for their continuous support, guidance and advice throughout the research project. Their pain-staking effort in proof-reading my thesis drafts are greatly appreciated. Indeed, it was they who initiated me into the world of health research and accompanied me in my journey of publishing my first two papers in peer-reviewed journals, both from this research.

My sincere thanks also go to the Director of the Northern Territory Centre for Disease Control (CDC), Dr Vicki Krause, for supporting and allowing me to undertake this doctoral study while working at the Sexual Health and Blood Borne Virus Unit of the CDC. I also wish to thank Dr Kevin Sesnan, Ms Wendy Armstrong, Mr Jamie Broadfoot and Dr Nathan Ryder for supporting my research during their time working as the Section Head of my work unit at the CDC.

Last but not least, I would like to thank my parents, my wife and my sons for supporting me spiritually throughout all these years that I have been working on this research.

Dedication

I would like to dedicate this thesis to my father Zuei-Yig Su, my mother Ah-Hua Suliu, and my wife, Bor-Ling Lin, who have been the rock of my life, and who have supported and encouraged me to continue to learn and to contribute what I have learned to the world.

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Chapter 1: Introduction

The Northern Territory (NT) has been consistently recording the highest notification rates of notifiable sexually transmitted infections among all States/Territories in Australia in the past decade.[1] However, the notification rates of these STIs are not evenly distributed across geographical areas, age groups, population groups, or between sexes as Indigenous people, younger age groups, women and those living in remote areas consistently record substantially higher rates than their counterparts.[2, 3]

Information about these high notification rates of notifiable STIs comes from the disease surveillance system operated by the Department of Health under the *Northern Territory Notifiable Disease Act*, which gives the Department of Health the statutory power to collect required personal and clinical data on positive diagnoses of notifiable diseases and conditions from medical practitioners and pathology laboratories. This disease surveillance system is usually called a passive surveillance system because it passively receives notifications on notifiable diseases and conditions from clinicians and pathology laboratories, instead of actively searching for them.

Information collected by this disease surveillance system is used to guide public health policies and interventions required for the protection of the health of the population.[4] However, the surveillance data for common STIs, such as chlamydia and gonorrhoea, as collected in passive surveillance systems is not adequate to serve the purposes mentioned above. This is because it is not possible to use surveillance data alone to effectively or confidently monitor the epidemiology of the STIs in the population. For

example, because of the high prevalence of these STIs in the population, an increase in the number of notifications can be caused by an increase in testing,[5, 6] an increase in transmission or incidence,[7, 8] the introduction of more sensitive tests,[9, 10] or a mixture of all the above. There is an obvious need to find ways to improve the surveillance system for these common STIs, especially considering their high and increasing rates in the NT in the recent decade.[1]

Dissatisfied with the limitations of traditional passive surveillance systems for STIs, both researchers and public health practitioners have been using various types of testing data to achieve a better understanding of STI epidemiology (for example, [6, 10-14]). This research aims to explore how collecting and analysing laboratory testing data can improve the surveillance system for STIs in the NT and proposes a best practice model for its implementation.

Chapter 2 presents a literature review on published papers and reports that involve using laboratory testing data for the purpose of STI surveillance and epidemiology. In Chapter 3, I examine what should be expected of a surveillance system for STIs by reviewing the original purposes of disease surveillance and its various definitions, and assessing if the current passive surveillance system for STIs both in general and in the NT is adequate to fulfil the purposes originally intended for a disease surveillance system, or those prescribed in the current definition. Chapters 4 to 6 provide real world examples of using comprehensive laboratory testing data to assist in the interpretation of surveillance data and thereby improve the current STI surveillance system to make it more capable of fulfilling the intended purposes examined in Chapter 3:

- Chapter 4 presents a short paper that has been published in the *Northern Territory Disease Control Bulletin* in 2009. It investigates the decreasing numbers of gonococcal cultures in the NT in recent years and the implications for gonococcal antimicrobial sensitivity surveillance in particular and gonorrhoea control in general. This is an example of using testing data for surveillance at the level of the whole jurisdiction.

- Chapter 5 consists of a research paper that has been published in the journal *Sexual Health* in 2012. It examines the trends in testing and notification for gonorrhoea in the Darwin Remote District of the NT and explains the reasons for the decrease in notifications during the period 2004-2008. This is an example of using testing data for surveillance of testing and disease at the regional level.

- In Chapter 6, I present a paper of program evaluation that has been published in the *Australian and New Zealand Journal of Public Health* in 2008. The paper evaluates the impacts of the Sexual Health Program implemented in the Tiwi Islands in terms of changes in notifications rates of chlamydia and gonorrhoea and uses comprehensive laboratory testing data for the communities involved to assist in the interpretation of the surveillance data. This is an example of using laboratory testing data for disease surveillance and program evaluation at the community level.

These three research projects were conducted in 2008 to 2012 and were published at that time, but the writing and submission of the thesis was delayed because due a serious family illness. However, as explained in the preface of each of these chapters, the context, comments and conclusions contained in these published papers were all current at the time of publication. Further, the primary value these papers to this thesis in illustrating the utilities of laboratory testing data to STI surveillance systems remains the same despite the passing of time. This is because the surveillance system for STIs in the NT has remained unchanged from the beginning of this research project to the time of writing of the thesis in 2015.

In the last chapter, I draw conclusions about how laboratory testing data can and should be used and analysed together with disease surveillance data to improve the surveillance system for STIs, discuss the limitations of this approach, and propose a best practice model for its implementation in the NT.

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Chapter 2: Using laboratory testing data for STI surveillance—a literature review

2.1 Introduction

Genital chlamydia and gonorrhoea are the most commonly notified bacterial sexually transmitted infections (STIs) in the NT.[1] Notification rates of these STIs in the NT have been by far the highest among states and territories in Australia over the last decade. For example, the NT notification rates of chlamydia (1,104.2 per 100,000 population) and gonorrhoea (722.8 per 100,000 population) in 2013, were 3.1 and 11.2 times the corresponding rates for Australia (358.7 and 64.6 per 100,000) respectively.[2]

While in the majority of patients these STIs are asymptomatic (less so for gonorrhoea in men), they can still cause serious long-term complications, including pelvic inflammatory disease (PID), tubal infertility and ectopic pregnancy in women, and infertility and epididymo-orchitis in men.[3, 4] These STIs also increase the likelihood a person might be infected with or transmit HIV infection.[3-5] Their propensity to cause serious genital and reproductive complications and their high population prevalence together make these STIs a significant public health problem.

A correct and up-to-date understanding of the epidemiology of these STIs is crucial to their control in the population. In Australia these STIs are notifiable diseases, and the

primary data source for STI epidemiology is the passive surveillance system operated by all state and territory health departments. Surveillance data collected through such passive surveillance systems have been used to monitor trends in population diagnosis rates over time, to inform the planning of public health and disease control programs, and to evaluate their effectiveness.[6]

However, the largely asymptomatic nature of these common STIs means that the diagnosed cases notified to the passive surveillance system are only a proportion of the total number of people infected.[3, 4] Given the incomplete diagnosis of prevalent cases, an increase in the notification rate may be a result of a real increase in disease prevalence (i.e. increased transmission and consequently more people infected), an increase in case-detection due to increased testing,[7-9] the introduction of more sensitive diagnostic tests,[10, 11] or a combination of all or some of these. In other words, surveillance data routinely collected by current passive surveillance systems are not an accurate measure of the true disease burden of STIs, and they do not provide a reliable indicator for monitoring trends of occurrences of disease in the population prevalence over time. This has made the interpretation of surveillance data difficult. Alternative surveillance measures or data sources are required to supplement the passive surveillance system.

Dissatisfied by the inadequacies of the passive surveillance system for STIs, public health practitioners and researchers have been trying various methods to improve surveillance for STIs, including special surveys,[12, 13] sentinel surveillance systems,[6, 14, 15] enhanced surveillance systems,[16, 17] use of hospital admission data[18, 19] and using

various types of testing data.[20-22] This literature review examines the use of testing data for the purpose of STI surveillance in the Northern Territory (NT), in other jurisdictions in Australia and in other countries.

This chapter was first written when the research commenced in 2006 to inform the conduct of the research. It has been updated and modified annually with new studies and reports to its current content. This literature review is current to end of November 2014 (the time when the writing of this chapter commenced). The Results section (section 2.3) summaries the evidence available about using testing data in surveillance systems in each country and in individual states and territories in Australia, while the Discussion section (Section 2.4) synthesises and critiques this evidence around the themes identified in Section 2.3.

2.2 Methods

2.2.1 Peer-reviewed scientific papers

The electronic database Medline was searched to identify empirical studies that involved utilising testing data to improve the understanding of STI epidemiology and the surveillance of STIs. The restrictions applied for the literature search included language being English, and papers published between January 2000 and November 2014. The reference lists of identified relevant articles were also examined for further suitable papers. Combinations of the keywords and terms used for the search included 'testing data', chlamydia, gonorrhoea, 'sexually transmitted infection', 'sexually

transmitted disease', surveillance, and epidemiology. Studies were included if they explored the collection or use of any laboratory testing data for STIs for surveillance or epidemiological purposes at the population level. Studies were excluded if they were clinic-based studies.

The objective of this part of the literature review was to examine past and current experiences of using laboratory testing data for STI surveillance in order to inform the current research for the thesis.

2.2.2 Other publications

Searches were also conducted on both the search engine website Google and the websites of the health departments of all Australian states and territories for publications regarding sexually transmitted infections to determine if STI testing data have been used for STI surveillance purposes in Australia. Email enquiries were made to the officers responsible for STI surveillance in all states and territories of Australia on whether STI testing data were collected or used for surveillance purposes; if the answer was affirmative, details were obtained regarding the variables collected and the method and frequency of data collection. This information was up to date as of 30 November 2014.

The objective of this survey was to examine what had been done in relation to collecting and analysing testing data for STI surveillance purposes in Australia, which will inform the research of this thesis.

2.3 Results

This literature search found that two distinct types of testing data for STIs have been used for either surveillance or research purposes. The first type is laboratory testing data retrieved from pathology laboratories. These are usually provided as aggregate data showing numbers of tests with breakdown by demographic variables but without data on test results (for example, number of tests performed per month by age-group and gender[23]), or sometimes as test-based disaggregate data with test results (for example, individual test records with demographic data and test results[24]). The other type is administrative testing data collected for rebate claiming purposes by health insurance agencies. Testing data of this type typically contain only information on numbers of tests, but not their results. For example, in Australia, all chlamydia testing performed in health facilities other than public hospital and STI clinics is eligible for a government rebate under the Medical Benefits Schedule (MBS).[25, 62] Because there are unique item numbers in the MBS for the nucleic acid testing for chlamydia (except the period between November 2005 to May 2007 when chlamydia testing was incorporated into more general item numbers rendering it impossible to ascertain numbers of tests for chlamydia), chlamydia testing data can be retrieved from the agency responsible for collecting such data (the Health Insurance Commission, which is responsible for the universal health insurance system, Medicare) to be used as a surrogate for the total number of chlamydia tests performed in the population. However,

the caveat of this use of Medicare data is that tests performed in public hospitals and sexual health clinics are not included in this data collection and it cannot be used for other STIs.

The use of testing data for STI surveillance will now be summarised by region for New Zealand, the United Kingdom (UK) and elsewhere in Europe, the United States of America, Canada, and each state/territory of Australia.

2.3.1 New Zealand

With the exception of AIDs, STIs are not notifiable in New Zealand; therefore STI surveillance depends heavily on the voluntary provision of data from sexual health clinics, family planning clinics and pathology laboratories.[26] However, in the Waikato District (a district with an estimated resident population of 357,000 in 2008 and ~21% being indigenous Maori individuals[24]), laboratory surveillance of chlamydia and gonorrhoea testing has been incorporated into the regional STI surveillance system since 1998.[27, 28] The supply of STI testing data by the participating laboratories is voluntary, which means it may be threatened or stopped by any factors that can make the continued supply of data difficult.[29]

Morgan and colleagues have published a number of papers using these testing data.[27, 28, 30, 31] According to them, the testing data cover the whole Waikato District as they are collected from all the pathology laboratories servicing the district. The laboratories

provide data on the total number of tests undertaken on a quarterly basis, but demographic data are not provided for negative tests. For laboratory-confirmed cases of chlamydia, the data provided include age and sex, but not ethnicity. De-duplication is carried out by the laboratories to remove duplications caused by multiple tests performed on the same individual on the same day (mostly due to multiple specimen sites). It appears that ethnicity has been included in these testing data at least in recent years because their more recent papers included statistics stratified by this variable.[24, 30, 31]

Using testing data, these authors have been able to analyse and report: annual number of tests and annual number of cases; testing coverage; positivity rates for both chlamydia and gonorrhoea; and quarterly trends in the number of tests and positivity rate for chlamydia.[28] The authors have been able to use these testing statistics to attempt to explain the reasons for the considerably higher population rates of chlamydia infection in New Zealand when compared with Australia and United Kingdom (UK), and discuss whether it was caused by higher testing rates in the population or higher positivity rates or both.[27, 28, 30] This would not have been possible if data for diagnosed cases were the only data available.

Testing data have also been used to evaluate health system policy and program effectiveness in relation to STI control:

- to assess the impact (in selected districts) of the implementation of a national chlamydia management guideline aimed at optimising testing and treatment for chlamydia;[31]

- to evaluate the impact of general practice funding to improve the provision of primary care based sexual health services to adolescents;[32] and

- to examine testing and diagnosis trends for chlamydia and gonorrhoea in Waikato District and their temporal relationship with noteworthy local and national interventions, such as the introduction of the more sensitive nucleic acid testing for *Chlamydia trachomatis* in 1998, reduction of the legal drinking age from 20 to 18 years in 1999, the availability of free sexual and reproductive consultations for under 25-year-olds in 2003-2004, and a national chlamydia awareness media campaign conducted in 2004.[28]

A recent study[24] that used laboratory testing data to investigate the testing behaviour revealed high repeat chlamydia testing rates in the population of the Waikato District. The authors concluded that using the crude statistics for the number of tests to calculate the population testing coverage will yield overestimates, if repeat tests are not excluded. The study was able to calculate the amount of repeat testing because the testing data were provided with a unique identifier, the National Health Index code, which is assigned to every individual eligible for accessing public health services in New Zealand. This study used data for each test (rather than aggregate data that had

been used in other studies), which enabled the researchers to use time-to-event ('survival') analysis at the individual person level to estimate the amount of repeat testing. As a result of the availability of the New Zealand unique health identifier, temporal trends for the rate of repeat testing could be estimated and analysed using survival analysis.

2.3.2 United Kingdom

In the United Kingdom (UK), the first passive surveillance system for STIs was established in 1917 to regularly collect data on STI diagnoses from all genitourinary medicine (GUM) clinics.[33, 34] Every quarter, GUM clinics used the 'KC60 form' to submit aggregate data to the national Centre for Infections of the Health Protection Agency (HPA) for analysis and reporting; hence the system was called the KC60 System. This aggregate data consisted of the total number of STI diagnosis episodes with breakdowns by age-group and sex; it also included the number of cases diagnosed heterosexually or through male to male sexual contact. A supplementary laboratory-based system named CoSurv was established later, which collects data on STI diagnoses from pathology laboratories that have agreed to provide data.[34] Both the KC60 system and the CoSurv system only reported diagnosed cases of STIs and did not include any denominator data regarding the amount of testing. It is worth noting that the HPA has been replaced by Public Health England in 2013 and the paper-based KC60 System ceased in 2008 and was replaced by an electronic surveillance system, the Genitourinary Medicine Clinic Activity Dataset (GUMCADv2).

In their paper evaluating STI surveillance systems in England,[34] Ihekweazu et al. revealed the inadequacies of these passive surveillance systems. Firstly, as it collects data from GUM clinics only, its representativeness is limited: compared with the number of STI diagnoses reported with the comprehensive laboratory data collected for the Avon area, the KC60 System only captured 31% of genital chlamydia and 64% of gonorrhoea diagnoses in 2002. Secondly, as the data submission only occurs quarterly, and regional data have to be relayed from the national data centre with further delay involved, timeliness can be a major problem. Thirdly, many variables that are important for public health intervention programs are not collected by these systems, such as risk factors, ethnicity and occupations. Lastly, the rigid aggregate data format does not allow any further data manipulation that may be required to answer specific epidemiological inquiries. The authors concluded that these systems cannot provide adequate surveillance data for public health actions against STIs.

In recent years, attempts have been made to collect and use laboratory testing data in the UK to improve the existing surveillance systems by addressing some of the above mentioned limitations and problems. The Avon System for Surveillance of Sexually Transmitted Infections (ASSIST) was one of the earliest population-level surveillance systems for STIs established in the UK that collected comprehensive and disaggregate person-based and episode-based data about all STI tests and their results across all healthcare settings.[33] It operated as a funded research project in the Avon area of the South West region of England between 2000 and 2004, and was also implemented later in the Brent area between 2003 and 2006.[35] In addition to the test-specific variables, the system also collected other variables, including the name of

infection, diagnostic setting, age, sex and area of residence. Because of the collection of these variables, especially the denominator data about the testing amount, health authorities were able to monitor the testing and diagnostic trends and thereby interpret the number of positive chlamydia tests in relation to testing patterns. Furthermore, the statistics derived from such testing data could also be used to examine the inequalities in terms of geographical distribution of STIs and testing, assess the difference in the provision of sexual health services by different providers, plan local sexual health services and interventions and monitor their implementation and effectiveness.

However, the ASSIST model did have its limitations. First of all, it was established as a research project. As such, the funding was limited and the system was not integrated into the regular STI surveillance system. As the funding ran out, its operation stopped. The data collection only occurred once a year. For it to be sustainable and have good timeliness, it needs to be integrated into the regular STI surveillance system. Secondly, as it collects data from multiple health care settings, de-duplicating data about tests performed for the same person in different settings and linking geographical data could become problematic.

The National Chlamydia Screening Programme (NCSP) in England started in September 2002,[36] and was implemented in three phases.[37] It promotes chlamydia screening in young people aged 15-24 years who attend health care facilities outside of the GUM clinics, including contraceptive clinics, general practices, young people's services, antenatal services, colposcopy and infertility units, and termination of pregnancy clinics. As part of the programme, there is also comprehensive testing data

collection. All screening sites submit standard core data items in disaggregate form to the Health Protection Agency on a quarterly basis. The core data set consists of 12 variables: clinic code, patient number, gender, date of birth, postcode of patient residence, ethnicity, attendance date, reason for test, specimen type, presence of a new sex partner in last 3 months, presence of 2 or more sex partners in last 12 months, type of laboratory test, and test result.[37] The model of laboratory testing data collection would be very useful for the surveillance of chlamydia if the testing coverage of the targeted population was adequately high, given the variables collected and the identifiable and disaggregate nature of the data (allowing de-duplication). However, as reported by Simms et al. after the three phases were all implemented,[37] testing coverage was low (4.9%). Given the low coverage and that the individuals tested were not a random sample of the general population, the data may not be representative of the target population (15-24 year olds) at greatest risk of genital chlamydia infection.

Another regional attempt to collect comprehensive testing data for a region in the UK was a project implemented in the East of England between April 2008 and March 2010 reported by Jennison et al.[38] The project set out to collect community-based chlamydia testing data from pathology laboratories servicing the East of England. These chlamydia tests were performed outside of GUM clinics, and therefore were not included in the KC60 System mentioned above. They were not performed as part of the NCSP either, and therefore were not included in the regular testing data collection via the NCSP. These chlamydia tests were primarily performed in general practices, abortion clinics, prisons and military settings and other health services not commissioned by the NCSP. The project used the minimum data collection,

processing and reporting requirements set out by the NCSP national team to develop a data specification for laboratories, and thereby collected the specified disaggregate chlamydia testing data on a quarterly basis. The variables collected included demography of the client (including names, sex, date of birth and postcode of residence), postcode information of the requesting GP and the laboratory, and test-specific variables. Data submitted by the laboratories were imported into and processed in a purpose-built Structured Query Language (SQL) database, where de-duplication was carried out using patient name, date of birth, and a range of healthcare setting codes. According to the authors, although the non-GUM non-NSCP data collected with this centralised method of data collection only represented a small proportion of all chlamydia tests undertaken in the region, they can be combined with existing chlamydia testing data (NCSP and GUM clinic activity data set) to produce the most complete data set for chlamydia testing providing many great opportunities for epidemiological analyses.

2.3.3 Other European Countries

In Denmark, all pathology laboratories are required to report the results on tests for gonorrhoea and chlamydia to Statens Serum Institut (SSI) in Copenhagen.[39] Reporting by laboratories is done on a quarterly basis, which includes total number of tests and the number of positive results. For positive results, further information is also reported, including sex and age of the patient and the type of specimen, date of specimen, and place of test (hospital or general practice). Similar reporting of denominator data is also implemented in Norway and Sweden (and in Greece for

gonorrhoea).[40] The reporting frequency varies from continuously, weekly, monthly, quarterly to 6-monthly.

2.3.4 United States of America and Canada

The literature search did not find any published paper fitting the search criteria.

2.3.5 Current surveillance practices in Australia

In Australia, the surveillance for communicable diseases (including STIs) is conducted by the health departments of states and territories. There is no dedicated central surveillance agency for communicable diseases in the federal government equivalent to the Centre for Disease Control and Prevention in the US. The co-ordination of national surveillance programs for communicable diseases is managed by the Communicable Diseases Network Australia (CDNA), which is a national committee formed by representatives from states and territories and the federal Department of Health. The surveillance systems implemented in individual states and territories are discussed below.

2.3.5.1 Queensland

Searches on the Queensland Government websites produced no relevant results. Up-to-date surveillance data for STIs are published in the weekly 'Queensland Health Statewide Weekly Communicable Diseases Surveillance Report', which does not

report any testing data for STIs. The only surveillance reports available on the Queensland Health website which contain analysis on trends over time for STIs are 'Notifiable Conditions Counts & Rates 2003-2007 by Area Health Service & Health Service District' and 'Notifiable Diseases Report 2002-2006'. Neither of them contains reporting on STI testing data.

One research report was found that reported the results of enhance surveillance of STIs in South East Queensland during 2003-2005.[17] Aggregate laboratory testing data were collected from four pathology laboratories servicing the area. They included the total number of requests received for urogenital chlamydia testing and the number of positive tests, which together allowed the calculation of test positivity rates. However, whether there were duplications in the testing data provided was not mentioned, and the short study period did not allow any trend analysis. The study was conducted without an ethics approval. The authors did explain that the study was a study of the epidemiology of a notifiable disease conducted under the provisions of the Queensland Health Act 1937, which was implied as the reason for exemption from ethical approval.

2.3.5.2 Australian Capital Territory (ACT)

In the ACT, there is no regular health department surveillance report for STIs. ACT Health publishes the 'ACT Population Health Bulletin' quarterly with a theme in each issue. A recent issue published in 2014 was focused on issues raised by STIs and

BBVs, but testing data were not discussed or reported. No relevant research papers could be found for the ACT.

2.3.5.3 Tasmania

In Tasmania, the Department of Health and Human Services publishes 'Communicable Diseases Quarterly' every quarter, which includes quarterly figures of STI notifications without reporting any testing data. Health indicator reports are published every five years reporting five-year trends in various health indicators, including numbers and rates of STI notifications.[44] No reporting of STI testing is included.

One journal paper was found that reported trends in chlamydia notifications in Tasmania during 2001-2007; no testing data were included in data collection or analysis.[45]

2.3.5.4 Victoria

Surveillance reports for STIs are published in the quarterly *Victorian Infectious Diseases Bulletin* (downloadable from this web address: http://ideas.health.vic.gov.au/surveillance/diseases-bulletin.asp). These reports have never included any analysis of testing data.

However, testing data for STIs have been collected and used in a local sentinel surveillance system for high risk populations and the provision of testing data by participating pathology laboratories is on a voluntary basis. Funded by the Victorian Government Department of Health, the Victorian Primary Care Network for Sentinel Surveillance on STIs and HIV (VPCNSS) has been implemented by the Burnet Institute in collaboration with the Victorian Infectious Disease Reference Laboratory and the Melbourne Sexual Health Centre since 2006.[46] According to Goller et al. who reported their results of assessing the system,[46] the VPCNSS regularly collects client survey data and linked testing data on STIs and HIV from sexual health clinics and selected primary care clinics which target young people and women at high risk. The aim of the sentinel surveillance system is 'to address gaps in Victoria's BBV and STI surveillance activities, and, in particular, support interpretation of passive surveillance trends by establishing a system capable of monitoring testing trends, demographic information, risk behaviours and the proportion of positive tests among individuals from high-risk populations routinely tested for these infections at primary care clinics.'[46] Because the system regularly collects data on routine testing for STIs and HIV in a consistent manner, it is able to monitor the trend in the test positivity rate among the clients of the participating clinics over time in the light of testing patterns. The authors argued that this data can be used to assist in the interpretation of surveillance data collected by the passive surveillance system, especially among the high risk groups. The primary care clinics included in the VPCNSS have mainly heterosexual clients (in contrast to sentinel surveillance systems conducted at sexual health clinics that have a high proportion of gay, lesbian and transgender clients) so that, when the testing rates are adequately high, the positivity rate of the common STIs such as chlamydia can act as a good indicator of its prevalence in the population tested.[14, 36] The results

of this sentinel surveillance system have been reported annually since 2010 and the latest version for 2013 is available: https://www.burnet.edu.au/projects/97_the_victorian_primary_care_network_for_sentinel_surveillance_on_bbvs_and_stis. However, because of its nature as a sentinel surveillance system, its major limitation with regard to monitoring the epidemiology of STIs in the general population lies in its uncertain external validity because it includes only a small proportion of primary care clinics, and hence only a small proportion of notified STI cases. For instance, it captured only 7.5% of chlamydia notifications reported in Victoria during the period between April 2006 and June 2008.[46]

In addition to testing data collected from pathology laboratories, publicly accessible Medicare data about nucleic acid tests for chlamydia have been used in epidemiological research projects conducted for Victoria.[8, 9] Gold and co-authors have used chlamydia testing data from both Medicare (for non-government funded clinics) and the VPCNSS (for the five government-funded clinics) to evaluate the impact of a chlamydia awareness campaign in Victoria.[47]

2.3.5.5 New South Wales (NSW)

In New South Wales, surveillance data for STIs are currently reported in '*Sexually Transmitted Infections Notification Data Quarterly Report*' published by the Communicable Diseases Branch of Health Protection, NSW (available at: http://www.health.nsw.gov.au/Infectious/reports/Pages/STI-reports.aspx). According to the report for the 2nd Quarter of 2014, laboratory testing data for chlamydia and

gonorrhoea have been collected and analysed from 14 public and private pathology laboratories since January 2012. This data collection was part of the NSW Denominator Data Project, which collected laboratory data for 20 selected notifiable conditions for which testing amount may influence notification rates.[48] One additional private laboratory started to provide data from 2014. Overall, these laboratories accounted for 90% of all tests for chlamydia and gonorrhoea performed in NSW, making them sufficiently representative of all tests performed in NSW for chlamydia and gonorrhoea.

However, the testing data provided by these laboratories were aggregate number of tests performed per month with no demographic (such as sex, age, location, type of health service, Indigenous status) or test-related variables (such as test date, specimen type and test results). As a result, the testing statistics reported in the Quarterly Reports were limited to the total number of tests per quarter and the ratio positive. Further, the ratio positive can only be calculated by dividing the total number of tests with the number of notified cases, making it different from the test positivity rate that can be calculated with more detailed laboratory testing data.

It was also noted that duplications occurred in testing data because an individual may have had multiple tests performed after one clinical encounter, so that one 'testing episode' produces multiple test records. For example, a patient tested for gonorrhoea with nucleic acid and culture tests at the same time would have been counted twice in the testing data (but only once in the notification data). Another source of duplication in the testing data is the repeated testing of the same individual during a reporting

period. The ratio positive could be an underestimate of the actual test positivity rate (when the duplicated tests contain both positive and negative results), and it could be an overestimate too (when all duplicated tests are positive). Because it is impossible to determine the amount of the various types of duplications it is not known whether the total number of tests performed is an accurate indicator of testing trends over time, or whether the ratio positive is a reliable measure of disease prevalence in the population. As the level of duplications may vary from year to year and there is no way of measuring it, its impact on the calculated testing statistics and their trends is also unknown. These are the limitations that need to be borne in mind when interpreting these statistics.

A number of researchers have used chlamydia testing data from Medicare for the NSW population in epidemiological studies[7, 21] and program evaluation.[8]

2.3.5.6 Western Australia (WA)

The WA Department of Health publishes surveillance data for STIs regularly on its website (http://www.public.health.wa.gov.au/3/480/2/sexually_transmitted_infections_and_bloodborne_vir.pm) in the quarterly report entitled '*Quarterly surveillance report-Notifiable sexually transmissible infections and blood-borne viruses in Western Australia*.' An annual report for STIs and blood-borne viruses (BBVs) is also published on the same website each year, and the latest version available is for 2014. While the

quarterly reports do not contain any statistics on testing data, there is detailed analysis on STI testing data in the annual reports.

Since 2009, WA has started to collect de-identified aggregate testing data for STIs from five of the seven pathology laboratories servicing WA. In addition to the annual report for STIs and BBVs mentioned above, analyses of the STI testing data were also published in dedicated annual reports for testing data.[23, 49, 50] The testing data reported are mainly the number of tests undertaken for WA clients by these five laboratories collected on a quarterly basis. The data contain some demographic variables, including age at time of testing, sex, and region of residence. Test-related variables included in the data are the disease for which the test was conducted and the type of test, including: nucleic acid tests for chlamydia and gonorrhoea; culture tests for gonorrhoea; and serological tests for syphilis, hepatitis B, hepatitis C and HIV. However, the data do not contain information on Indigenous status or test results.

According to the latest report on testing data,[22] the five laboratories currently supplying the testing data accounted for an average of 69% of STI and BBV notifications in WA between 2009 and 2013. Therefore, the authors assumed that it also represents the proportion of STI and BBV testing amounts undertaken by these laboratories. However, one of the two laboratories that did not supply testing data was a major pathology service provider in WA and this could have impacted on the representativeness of the testing data to some extent. Nonetheless, the authors are confident that the testing data from the five laboratories are sufficient for the purpose of monitoring trends in test numbers and testing rates over time.

The report described that the data retrieval method used by the five laboratories has been consistent. In particular, all possible duplications due to multiple testing events, types of tests, and specimens or specimen types for the same episode of testing have been eliminated by the laboratories before the data are sent to the Health Department. Testing data collected in this manner allowed the authors to calculate and report a number of population-level testing statistics, including crude testing rates (calculated by dividing the number of tests by the corresponding population figure), and test positivity rates (calculated by dividing the number of notifications reported by laboratories providing testing data by the total number of tests conducted by these laboratories). All these rates could be stratified by the variables contained in the testing data, providing detailed testing statistics to supplement and assist in the interpretation of surveillance data. As the data collection is ongoing, trends over time can also be analysed and monitored with the accumulation of more data.

2.3.5.7 South Australia (SA)

The Communicable Disease Control Branch of SA Health publishes annual surveillance reports for STIs and blood borne viruses, which are available from the following website: http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/health+statistics/surveillance+of+notifiable+conditions. According to the reports currently available on the website (2010 to 2014), SA has been collecting total number of tests performed as well as numbers of positive tests from 3 sentinel pathology laboratories annually and the earliest data reported was for 2004. These

surveillance reports reported annual number of chlamydia tests and positivity rate by sex and their trends over time. There is no description on the data retrieval and data management processes. Neither is there any sign of using testing data to assist in the interpretation of surveillance data, as the reporting on surveillance data and that on testing data are completely separate. This could be because the testing data were provided in an aggregate form (in summary tables) and did not contain breakdown by other important variables, such as age and residential location, which would limit their utility in assisting in the interpretation of surveillance data. It is also not possible to determine the external validity of the reported testing statistics as the reports did not provide details on the representativeness of the testing data provided by the 3 sentinel laboratories in the population. In sum, the usefulness of the laboratory testing data collected and reported in SA is limited by the lack of important demographic variables and the unknown external validity.

2.3.5.8 Northern Territory (NT)

Reporting on surveillance data for STIs has been regularly published in the Sexual Health and Blood Borne Virus Unit Surveillance Update, which is available from the website of the NT Department of Health: http://www.health.nt.gov.au/Centre_for_Disease_Control/Publications/Sexual_Health_Surveillance_Updates/index.aspx. Testing data have not been regularly reported alongside surveillance data in this 6-monthly report, but have been used irregularly to assist in the interpretation of surveillance data (for example[51]).

According to the Sexual Health and Blood Borne Virus Unit, the NT has been collecting disaggregate, test-based testing data for STIs from Western Diagnostic Laboratory (WDP), since 2004. The data transmission occurs monthly and the variables contained in the data include sex, age, residential location, test performed, specimen type, and test results. As WDP is the sole provider of pathology services for almost all remote clinics (including both government-serviced and Aboriginal-controlled ones, with only a small number of remote clinics on the Queensland border serviced by an interstate laboratory), the testing data provided by WDP forms a comprehensive dataset for remote NT districts. Because of the comprehensive coverage, this data has proved very useful in interpreting trends and patterns of notifications of STIs, especially given the extremely high rates of STIs in remote Aboriginal communities, and the consequently and frequently implemented interventions promoting testing that can considerably increase case-detection. It is this data from WDP that was used in the Surveillance Update mentioned above.[51] This testing data has also been used to investigate the positivity rate for STIs as an indicator for the effectiveness of an annual STI screen implemented in Central Australia,[52] and in investigating the amount of chlamydia testing performed by various types of health care providers in the NT.[53] As the data also contains culture results for *Neisseria gonorrhoeae*, it was also used to investigate a sharp decrease in culture numbers for *Neisseria gonorrhoeae* in the NT following a change in a Medicare item number for STI testing.[54]

2.3.5.8 Other initiatives

The Australian Collaboration for Chlamydia Enhanced Sentinel Surveillance (ACCESS) was established in 2007 with funding from the Australian Government

Department of Health and Ageing.[6] The ACCESS system involved five clinical networks (including sexual health services, family planning clinics, general practices, antenatal clinics, and Aboriginal Community Controlled Health Services) and one laboratory network. Its purpose was to trial the monitoring of the uptake and outcome of chlamydia testing in Australia. In particular, it monitored the positivity rate for chlamydia testing among the clients whose data were collected via the six networks, as a surrogate for prevalence. With the inclusion of more detailed demographic data routinely collected by health services (for example, Indigenous status), data collected by this system have been used to determine chlamydia testing rates and positivity rates among the clients of the various networks covered by the system, and discuss their implications for chlamydia testing practice and policy as well as assist in the interpretation of surveillance data.[55-61] The data has also been used to assess the differences in chlamydia testing rates and positivity rates between Indigenous and non-Indigenous clients.[55]

2.4 Discussion

This review of literature has found that the traditional passive surveillance system continues to be the only system for STI surveillance in most Australian states and territories as well as most other countries surveyed. In recent years testing data (both laboratory testing data and administrative testing data) have been used in many research projects either as the denominator data or for calculating population testing rates. However, there have been only a few examples of incorporating testing data into the regular STI surveillance system. Given the rapidly increasing and very high

rates of STIs in the NT, there is a real need to push for including testing data in the STI surveillance system in a regular and sustainable manner.

As shown in this literature review, there are several factors to consider when establishing a system for collecting and analysing testing data as part of the STI surveillance system. Firstly, the frequency of data collection should be reasonably short to enable reporting and interpretation of recent trends in both testing and diagnoses. Quarterly data collection and reporting appeared to suffice for the systems implemented in the Waikato District of New Zealand, the NCSP of the UK, Denmark, Norway, Sweden, and Western Australia. However, monthly collection proved feasible in the NT and would allow even more up-to-date reporting; this might be important for evaluating the impact of public health interventions. For example, monthly collection and reporting of testing data would be very helpful in a syphilis outbreak situation, because in such an outbreak up-to-date statistics of testing activities in the targeted population are crucial to the monitoring and evaluation of the outbreak control measures.[63] Therefore, for general surveillance purposes, a quarterly frequency of data collection and reporting should be adequate, especially given that the majority of STI surveillance reports are published on a quarterly basis. However, if the data retrieval and transmission can be set up as an automatic computerised process involving only a minimal amount of labour, a monthly frequency of data collection would be preferable, even if reporting is carried out on a quarterly basis.

Secondly, for the data to correctly reflect the testing amount and results and to be accurately interpreted, it is essential to ensure that the system has a de-duplication

mechanism in place to eliminate duplications due to two or more tests being performed for the same testing episode (as described in[23]), which can occur if more than one test is performed, different types of test are performed, or multiple specimens are collected and tested. This mechanism can be set up either at the pathology laboratories that provide that data, or at the health authorities that receive the data. Without such a mechanism, the number of tests reported by the surveillance system will be inflated.

Thirdly, the system should collect at least the same variables as the ones collected by the passive surveillance system, given that they both come from the same source. These should include sex, age, residential area or district (or postcode), and the health care facility where the test was taken. As most pathology laboratories do not collect client information on ethnicity, it is probably unrealistic to ask them to provide this variable. Of course it would be ideal to include all variables relevant to the epidemiology and disease control of STIs, but as a minimum and for the sake of efficiency and sustainability, setting up the system to collect computerised routinely collected data will be more feasible and more likely to secure the support of pathology laboratories. Ideally, individual test results should be included. Firstly, the inclusion of test results enables the direct calculation of positivity rates with the testing data alone. Secondly, it can also provide the number of positive diagnoses, which can be used to assess the completeness of laboratories' reporting positive diagnoses of notifiable STIs. Therefore, where possible, the Health Department should negotiate for the inclusion of test results in the laboratory testing data. However, in the case that pathology laboratories do not agree to include test results, the testing data is still useful for disease surveillance purposes described above, as long as pathology laboratories'

statutory reporting of positive diagnoses to the Health Department is reasonably complete (that is, the numerator data, or, the notification data routinely collected by the passive surveillance system is reasonably complete and accurate). One paper from New Zealand reviewed above was able to include a national person-based unique identifier in the testing data to facilitate the specific type of statistical analysis performed for the study. However, it is unlikely that identifiable information could be collected with any testing data and used for disease surveillance purpose in Australia, given the local legislation on privacy protection.

Lastly, the format of the data should ideally be de-identified, disaggregate and testing-episode based; data in this format is already provided by one laboratory (WDP) in the NT surveillance system. Disaggregated data would allow for more detailed statistical analysis than can be done with aggregate data (for example, the aggregate testing data collected by the surveillance system in WA). However, this will depend on the level of support the pathology laboratories would agree to give and the capability of their information system and staff. As a minimum, testing data in an aggregate format with the essential demographic variables mentioned above should be adequate for the purpose of STI surveillance.

None of the papers reporting using laboratory testing data for surveillance purposes commented on the minimum testing coverage in the population that is required for the testing data to be representative. This is obviously a gap in the current literature for this topic. Further research will be required to determine such a threshold value for the testing coverage in the population to qualify a collection of testing data as

representative of the population. Research is also required to investigate ways to interpret population-level testing trends with laboratory testing data despite the limitations in testing coverage.

Another factor to consider in determining the representativeness of the testing data is the reason for testing. A high proportion of people tested due to symptoms will lead to a considerable selection bias making the positivity rate (proportion positive) an overestimate of population prevalence. Unfortunately, information on reason for testing is usually not collected by laboratories or provided in laboratory testing data. This makes it impossible to detect any selection bias described above. Despite this, when testing data is collected regularly and consistently, the positivity rate is still a useful indicator for monitoring trends of population prevalence.

As evaluated by Guy et al.,[6] the ACCESS system and the data it collected had great feasibility, simplicity, flexibility, timeliness, sustainability, internal validity, sensitivity and usefulness. However, one major limitation of ACCESS is the unknown representativeness of the data it collected for the population from which the data was drawn. This unknown external validity is almost inevitable as ACCESS was established as a sentinel surveillance system covering a large Australian population. In contrast, the ASSIST system implemented in the UK's Avon District[33] had more certain and better representativeness, and is therefore a more ideal approach for the purpose of STI surveillance, especially for a jurisdiction such as the NT.

The data collection system for STI testing data implemented in WA is both useful and effective, as evidenced by the annual reports for STIs and BBVs that include the analysis of testing data in the interpretation of the trends and pattern of STI notification rates, and also the annual reports on STI testing data providing even more detailed analyses. The system of data collection is also low cost and can be run automatically with minimal attention, because, once set up properly, both the data retrieval and processing at participating pathology laboratories and the transmission of data can be programmed and scheduled to take place regularly. As long as the statutory notification of new diagnoses is complete (that is, no missed notifications), and the coverage of notified cases by the testing data remains high, this system should be able to satisfy the purposes it is intended for, and is therefore suitable for and should be considered for implementation in the NT.

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Chapter 3: A public health surveillance system for sexually transmitted infections–what should be expected of it?

The surveillance of sexually transmitted infections (STIs) is part of broader public health and communicable disease surveillance systems. Although there have been considerable criticisms on the inadequacy of the passive STI surveillance system currently implemented in Australia,[1-4] it is important to examine these criticisms as well as the effectiveness of such a system in the context of public health and communicable disease surveillance systems. In this chapter I reviewed and examined the definitions, aims and scope of these surveillance systems and their development and evolution over time. Based on this review, I then discussed the attributes and performance that should be expected of an ideal STI surveillance system.

3.1 Public health surveillance

3.1.1 Development of the concept of surveillance - a historical perspective

The term 'surveillance' takes its origin from the French words *sur* and *veiller*, meaning 'to watch over.'[5] In the context of public health, it means the 'close monitoring of the occurrence of selected health conditions in the population'.[6 (p759)]

In its early stage, the development of the concept of surveillance was mainly focused on the control of infectious diseases. Hippocrates (*ca*. 460 BC – *ca.* 370 BC) was attributed as the person who proposed the first idea of surveillance, which included collecting and analysing relevant data, and then formulating a course of action in response accordingly.[7] However, the first documented public health action attributable to the use of disease surveillance data occurred more than a thousand years later during the time of epidemic bubonic plague in Europe in the 1300s.[8] In order to prevent the spread of the plague, the health authority in a port near the Republic of Venice prevented passengers from coming ashore.

The modern concepts of public health surveillance were mainly developed in the nineteenth century and two prominent figures made a significant contribution.[8] Lemuel Shattuck (1793-1859) published his seminal work, *Report of the Sanitary Commission of Massachusetts*, in 1850, the first of its kind to describe the association between living conditions and death, infant and maternal mortality and communicable diseases.[9] The most important things with regard to disease surveillance he proposed were the establishment of a permanent state-wide public health infrastructure with health offices at the state and local levels for gathering statistical information on public health conditions. Though not adopted at that time, his proposal was widely implemented as routine public health activities in the twentieth century.

William Farr (1807-1883) is generally recognised as the founder of the modern concept of surveillance.[10] Between 1839 and1879, he worked as the superintendent of the statistical department of the Registrar General's Office of England and Wales

and dedicated himself to collecting, assembling, analysing, and reporting vital statistics.[8, 10] His way of carrying out disease surveillance was described as 'more active and rewarding than the relatively passive functions of monitoring or auditing,' because he communicated epidemiological facts with his own clear-cut conclusions and specific recommendations to public health authorities in a 'forceful' way and thereby actively participated in the dynamic health movements of his time.[10] For example, his reporting of vital statistics in a timely fashion played a pivotal role in controlling the cholera epidemic in London in 1853.[10]

Before 1950, the term '*surveillance'* had a focus on individuals and was largely used to refer to public health activities dealing with monitoring contacts of serious communicable diseases, such as smallpox, and detecting early symptoms so that suspected patients could be isolated in time and spread of disease curbed.[10, 11] By contrast, in the 1950s, the concept of surveillance was expanded with its focus turned to occurrence of specific diseases in the population, and consequently the methodologies adopted were also changed to systemic collection and analysis of relevant data and dissemination of the results to all who needed to know.[10]

The 1960s was an important stage in the development of disease surveillance because attempts had been made to consolidate concepts of disease surveillance into clear definitions during this time. In 1963, Alexander D. Langmuir provided this definition of disease surveillance:[12]

> *'The continued watchfulness over the distribution and trends of incidence through the systematic collection, consolidation and evaluation of morbidity and mortality reports and other relevant data.'*

He also pointed out that fundamental to the concept of surveillance was the regular dissemination of 'the basic data and interpretations' to 'all who need to know', i.e. those responsible for taking necessary actions, as the focus of that time was on 'the control of disease.'[10] In other words, he clearly distinguished the role of disease surveillance from that for disease control activities (which he thought was a job for 'decision-makers') as well as that for epidemiologic research (which is not on-going).[10, 12] He also broadened the application of surveillance from monitoring those *individuals* ill with communicable diseases to monitoring the trends of incidence in *populations.*[11] Although his definition still mainly applies to 'disease' surveillance, he did make allowance for 'other relevant data' in his definition.

Concurrent with this development, in 1965, an Epidemiological Surveillance Unit was established within the Division of Communicable Diseases at the World Health Organisation (WHO), which adopted and promoted a more broadly defined term, 'epidemiologic surveillance'.[11] According to this definition, epidemiological studies of diseases were included as part of the activities for surveillance.

A major change in the concept and scope of disease surveillance occurred in the 21st World Health Assembly held in 1968. During the discussion in the Assembly, the scope

was broadened to include the responsibility for disease control while the range of targeted health events were also widened to include public health problems which were not communicable diseases.[11] This marked a shift in scope from the narrower one for communicable disease surveillance to the wider one for public health surveillance.

Another major achievement in the development of the concept of surveillance was also made in the 1968 Assembly. Alexander Langmuir wrote a working paper on disease surveillance at the invitation of the Director General of the WHO, and in this paper he listed and described the three main features of surveillance, namely, the systemic collection of relevant data, the consolidation and analysis of these data, and the prompt dissemination of results to those who need to know.[8] The paper was formally endorsed in the Assembly.

Following the endorsement of Langmuir's definition of disease surveillance, the new term 'epidemiologic surveillance' and its inclusion of epidemiological studies proposed by the Epidemiological Surveillance Unit of WHO described above started to come under criticism. Thacker and Berkelman of the Centre for Disease Control (CDC) of the United States of America (USA), supported Langmuir's definition and argued that surveillance is and should function as only one element of public health practice, that surveillance data should be used to identify areas in need of research, service (including intervention programs) and training, and, therefore, that surveillance does not include research or service.[8, 11] Based on these reasons, they proposed that the

more clearly defined and less confusing term, ‘public health surveillance’, be used instead, which describes both the scope (surveillance) and the context (public health).

In line with their recommendations and Langmuir’s definition, the CDC of the USA defines ‘public health surveillance’ as[13]:

> *‘the ongoing, systematic collection, analysis, and interpretation of data (e.g., regarding agent/hazard, risk factor, exposure, health event) essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those responsible for prevention and control.’*

This definition (referred to as the USCDC definition henceforth) has since been widely adopted internationally.[8] The definition given in the book, *A Dictionary of Epidemiology*,[14 (page 239)] is also very close to the USCDC one:

> *‘Systematic and continuous collection, analysis and interpretation of data, closely integrated with the timely and coherent dissemination of the results and assessment to those who have the right to know so that the action can be taken.’*

In sum, the concept and practice of surveillance has evolved in four major aspects over the last two centuries. Firstly, the focus of surveillance has shifted from monitoring the status of infection of *individuals* in the early stages of the development of

surveillance to monitoring the occurrence of a wide range of health conditions in *populations*. Secondly, in terms of the scope, the work of surveillance was initially limited to a number of deadly and highly contagious *communicable diseases*, but has been expanded since the mid- to late 1900s to include an increasingly wider range of *health problems* and *risk factors*, including non-communicable chronic diseases. Thirdly, the context for the work of surveillance has evolved from '*disease surveillance*' in the early stages to the widely recognised and more broadly defined '*public health surveillance*', which aims to not only control specified health conditions but also prevent their occurrence. Finally, the tasks of surveillance are focused on collecting, analysing and interpreting health-related data and disseminating the results to those who need to know, and do not include disease control activities that were involved in the early forms of disease surveillance.

3.1.2 The functions and purposes of public health surveillance

It is evident from the previous section that, after a long period of development, public health surveillance has become an essential part of the comprehensive range of modern day public health practice.[15] Three primary tasks can be identified in the USCDC definition for public health surveillance:

1. ongoing and systemic collection of health data;

2. analysing and interpreting the data; and

3. disseminating the results to those who need to know.

The third point is essential because the functions of public health surveillance cannot be realised without putting to good use the data collected and the information generated from the analysis. As rightly stressed by Foege et al.:[16 (page 30)]

> *'The reason for collecting, analysing, and disseminating information on a disease is to control that disease. Collection and analysis should not be allowed to consume resources if action does not follow.'*

Thacker and Stroup stated that such surveillance data and information are used to 'assess public health status, define public health priorities, evaluate programs, and identify emerging problems and research priorities.'[15 (page 61)] This statement has actually spelled out the functions of and purposes for conducting public health surveillance. Berkelman et al. stated that a surveillance system should be designed in a way that meets the needs of public health intervention and prevention programs, and maintained that the purposes of a public health surveillance system should include[6 (page 761)]:

> *'To define public health priorities;*
>
> *To characterise disease patterns by time, place, and person;*
>
> *To detect epidemics;*
>
> *To suggest hypotheses;*
>
> *To identify cases for epidemiological research;*

To evaluate prevention and control programmes;

To facilitate planning, including projection of future trends and health care needs.'

In a nutshell, the role of public health surveillance in the public health system is similar to what the department of intelligence is to the national defence system. Therefore, it can be inferred that, in order to achieve these purposes mentioned above, a public health surveillance system should collect data on the occurrence of selected health conditions or diseases (number of cases, frequency, distribution, temporal and geographical trends and patterns) in an accurate and timely fashion. It should also provide a means to predict what can be reasonably expected to occur in the near future (projections), so that appropriate public health policy responses can be planned and implemented, prevention and/or intervention programs can be devised and carried out, and needs for research and training can be identified. In addition, as the collection of surveillance data is ongoing and systematic, after the implementation of prevention and intervention programs, the surveillance system should also be able to be used to produce indicators to evaluate and measure the effectiveness of these public health programs.[15, 6]

3.2 Communicable disease surveillance

3.2.1 Definition and scope

As mentioned in Section 3.1.1, the scope of public health surveillance of today is no longer limited to communicable diseases as it was a few decades ago. It now includes a wide range of health conditions and even their risk factors. However, as this thesis is focused on STIs, which are communicable diseases by nature, a more in-depth and specific examination of public health surveillance for communicable diseases (called communicable disease surveillance henceforth) is warranted.

Because of their infectious nature and potential to result in enormous mortality and morbidity in a short period of time, communicable diseases have been important targets for surveillance. According to a more recent and specific definition, communicable disease surveillance is:[17]

> *'the continuous monitoring of the frequency and the distribution of disease, and death, due to infections that can be transmitted from human to human or from animals, food, water or the environment to humans, and the monitoring of risk factors for those infections.'*

This definition highlights four key aspects of communicable disease that a surveillance system should collect data on, all of which are essential to a comprehensive understanding of the epidemiology of the communicable disease as well as the

planning, implementation and evaluation of prevention and intervention programs, and public health policy-making. They include:

1. *frequency*, referring to the number of persons contracting the disease (morbidity) and the number of deaths due to the disease (mortality) in a given period of time;

2. *distribution*, referring to the geographical patterns of the locations where the infection takes place; in addition, the demographic data of the infected should also be collected to provide information on how the infection is distributed among subgroups of the population;

3. *sources of infection*, which may include humans, animals, food, water and the environment; and

4. *risk factors*, referring to factors predisposing individuals to contracting and/or spreading the infection.

Based on this definition, it is therefore essential that a communicable disease surveillance system is capable of effectively collecting data that can be used to produce statistical information about these four aspects of the infectious disease under surveillance. These data can then be used to compile timely surveillance reports to inform public health authorities so that informed measures can be taken and appropriate intervention and prevention programs can be devised and implemented to control the disease.

3.2.2 Notifiable disease surveillance system

All States and Territories in Australia have introduced a surveillance system for communicable diseases based on passive notification of new diagnoses of selected diseases. It is usually established and operated by the state/territory health department based on the power granted by a specific notifiable disease legislation. With such a system governments can oblige health care providers, health practitioners and pathology laboratories to report all new diagnoses of notifiable diseases in order to ensure the comprehensiveness and timeliness of data collection, both of which are important to understanding the epidemiology of communicable diseases and to controlling them.

For example, in Australia, State and Territory governments have the legislative responsibility for the surveillance and prevention of communicable diseases.[18] The formulation of the legislation usually starts with deciding on a list of notifiable diseases and conditions together with respective case definitions, and follows it by specifying who is responsible for notification (e.g. clinicians and/or laboratories), the respective means of notification (e.g. by phone, by post) and level of urgency (i.e. a length of time after diagnosis within which the diagnosing clinician or laboratory is expected to have completed the notification process). The next step is to define the power of the government to control the listed notifiable diseases. Finally, the relevant legislation procedures needs to be completed so that such disease notification becomes mandatory by law and the government has the power to enforce it.

The notifiable disease surveillance system is by nature a *passive* surveillance system as it depends on the diagnosing health professionals and laboratories to report new diagnoses as they are made.[19] Studies have shown that notifiable disease reporting, despite being required by law, is generally incomplete or delayed for the majority of diseases.[6, 20-25] However, this kind of system is still thought to be able to collect the majority of new diagnoses, particularly when a laboratory-based notification system is included due to its superior completeness in case reporting.[20, 26, 27] With the advance in computer and internet technology, the disease notification process can now be automated by using pre-programmed electronic transmission, and this has been shown to further improve the completeness and timeliness of disease notification.[6, 28-31]

The data collected by the notifiable disease surveillance system are generally called notification data and the disease rates calculated using notification data (as the numerator) and relevant population data (as the denominator) without any age standardisation are called crude notification rates. Under normal circumstances and excluding the scenario of asymptomatic screening, for a person contracting a notifiable communicable disease to be notified in a notifiable disease surveillance system, all the following need to happen:

1. The patient becomes symptomatic;

2. The patient seeks medical attention;

3. A correct diagnosis is made either by a clinician or a laboratory diagnostic test;

4. Either the diagnosing clinician or the laboratory processing the test (or both) notifies the new case to the health authority; and

5. The health authority receives the notification and records the case in its notifiable diseases database.

Failure or delay in any of these steps leads to a missed or delayed notification. This serves to illustrate some of the limitations of a passive surveillance system, which have been described in detail elsewhere.[6, 21, 24, 25] In fact, notification rates calculated using notification data have been known to underestimate disease incidence.[2] This will be explored further in the next section.

In view of the limitations of the passive surveillance system, health authorities have been trying to supplement it with other forms of disease surveillance. For example, an *active* surveillance system is a system in which the public health authority regularly contacts reporting sources (e.g. physicians) to solicit more disease reports.[19] This has been shown to improve reporting of a range of infectious diseases in a primary care provider setting.[21] However, given the presence of a comprehensive passive surveillance system and the resources involved, active surveillance systems are deemed as neither feasible nor required for surveillance of some conditions.[19]

Enhanced surveillance is another method used in Australia to supplement the usual passive surveillance system for STIs by providing epidemiological information that can be used in focusing STI control efforts.[32-34] It requires follow-up on already notified cases, and the enhanced data commonly collected include the reason for testing, treatment, contact tracing, sexual exposure, and the suspected source of infection. Enhanced STI surveillance data have been collected in most Australian jurisdictions for gonorrhoea, donovanosis and infectious syphilis since 2005.[33]

A *sentinel* surveillance system is one in which only a limited number of selected health care providers report specific diseases based on the belief that the data thus collected may be generalised to the whole population.[35] This kind of surveillance system may be useful for common conditions for which complete case counting is not essential and public health action is not taken for individual cases, and it may also be cheaper to operate (a good example for this is influenza).[35] A sentinel surveillance system is also useful for some infectious diseases where a considerable proportion of those infected tend to seek diagnosis and treatment at the sentinel sites rather than other health care providers (these usually are government-funded specialist clinics which provide free services). For example, a sentinel surveillance system was implemented in the NT for monitoring the antimicrobial sensitivity of *Neisseria gonorrhoeae*, and the sentinel sites were chosen because they 'best represent the population groups who were likely to present with resistant gonorrhoea and those most at risk of acquiring gonorrhoea.'[36] The Australian collaboration for Chlamydia Enhanced Sentinel Surveillance (ACCESS) as implemented in Australia between 2007 and 2010 (a

limited version of ACCESS continued after 2010) represents a combination of enhanced surveillance and sentinel surveillance, and was found to provide a useful mechanism to allow long-term close monitoring of chlamydia epidemiology in Australia and to support the evaluation of chlamydia control measures and programs.[37, 38] The ACCESS system included 5 networks of clinical sites, including sexual health clinics, where electronic clinical databases were used to record clinical and testing data.[38] This permitted the ACCESS system to use an automated data extraction program to regularly retrieve de-identified data for analysis. This is a good example that illustrates the usefulness of clinic-based sentinel surveillance systems, which, with their added benefits of including detailed data on clinical presentations and common risk factors, can be implemented to supplement the passive surveillance system and provide testing, clinical and behavioural data to assist in the interpretation of surveillance data.

3.3 An ideal surveillance system for STIs

This section will focus on describing an ideal surveillance system for STIs based on the various definitions, objectives, and attributes mentioned in previous sections. The purpose of this is to describe what such an STI surveillance system should be able to achieve under ideal circumstances. It is hoped that this description may serve as a prescription of an ideal STI surveillance system for public health authorities to consider in their ongoing effort in improving their STI surveillance system.

However, as the focus of this thesis is for the STI surveillance system in the NT, this description needs to take into consideration two important factors about STIs

(particularly the most common ones such as gonorrhoea, chlamydia and trichomoniasis) which make them different from many other notifiable communicable diseases. They are discussed in the following section first.

3.3.1 Factors to consider about an ideal STI surveillance system in the NT

The first factor that makes the common notifiable STIs in the NT (namely, gonorrhoea, chlamydia and trichomoniasis) vastly different from many other notifiable communicable diseases is that only a small proportion of those infected will be detected and notified to the passive surveillance system currently implemented. This is because these STIs are largely asymptomatic. Studies have shown that over 80% of genital chlamydia in men and women can be asymptomatic.[39-42] As high as 80% of gonococcal infections in women can also be asymptomatic, while the asymptomatic proportion in male patients is much lower and was estimated at approximately 1-3%.[43] However, the proportion of asymptomatic patients varies in different populations and with duration of infection.[43] For example, a study conducted in a group of male army recruits with a low prevalence of gonorrhoea reported that 60% of those infected were asymptomatic.[41] This was obviously higher than the estimates mentioned above. Trichomoniasis infections are asymptomatic in most infected men and women.[44, 45] Considering the five key steps that need to take place for a patient to be notified described in Section 3.2.2, asymptomatic patients are unlikely to seek medical attention, let alone being detected or notified.

Furthermore, even when the patients are symptomatic, only a proportion of them would eventually go through all the necessary steps to be treated and their partner traced and treated too, as well illustrated in the Piot-Fransen model of STI management proposed using statistics from randomised trials conducted in Africa (Figure 3.1, modified from [46]). Similar to the situation in Africa, the success rate at each step in the NT can be expected to be much less than 100%. For example, Central Australia has consistently recorded the highest rates of STIs in the NT in the last few years.[47] In the annual community based STI screen conducted in this region in 2004, a prevalence of STI (gonorrhoea or chlamydia or both) of 18% among those screened was reported, and among them only 24% were either symptomatic or having signs suggesting an STI.[48] Without the screen, only a proportion of these symptomatic patients were likely to seek treatment and be tested. There are several possible reasons why symptomatic patients do not seek treatment. Poor access to culturally acceptable health services may prevent patients, especially Aboriginal patients, from seeking treatment.[49-53] It can also be due to the poor understanding of STI symptoms,[54 55] the tendency to delay seeking treatment despite worrying about having contracted an STI,[56] or, the setting of the clinical consultation making it difficult for patients to disclose or acknowledge symptoms.[50] Consequently, as shown in Figure 3.1, among those with STIs (represented by box B) only a small proportion will be tested and notified, some of them symptomatic (represented by box F) and others asymptomatic (represented by the pink box Bt), and an even smaller proportion would eventually be treated and their partner traced and also treated. It is also clear from Figure 3.1 that the notification rate (=(Bt+F)/A) will considerably underestimate the actual population rate (=B/A).

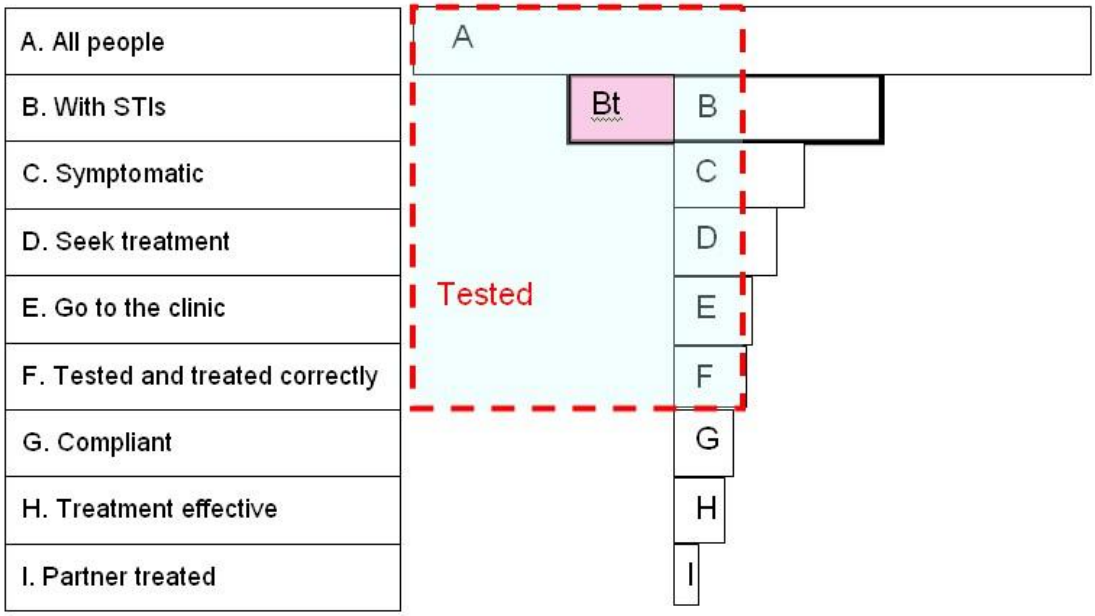

Figure 3.1: Piot-Fransen model of STI management, adapted for the Northern Territory situation from Hayes et al.[46] Bt represents people infected with STIS who were tested and notified, but were asymptomatic.

The second factor is related to the first one. The notification rates of common STIs (gonorrhoea and chlamydia) in the NT have been by far the highest among all Australian states and territories in the last decade.[57] For example, in 2013, the notification rate of chlamydia in the NT was 1,104.2 per 100,000 population, about 3 times the rate for Australia at 358.7 per 100,000.[58] Given such high rates, it can be inferred that there is a large number of prevalent cases at any time and many of them are asymptomatic and undetected. It is very likely, therefore, that performing more tests, particularly screening tests, will lead to more diagnoses (and thus more notifications) of asymptomatic cases. For example, an ecological study has shown that increased testing will lead to higher chlamydia diagnosis rates among the Australian population.[59]

A conceptual model is shown in Figure 3.2 to further illustrate how the number of notifications can change with the amount of testing in a high prevalence area. Scenario X-Z represent the scenarios to which the current status of STI testing and notification can change in a short period of time (for instance, a quarter, 6 months or a year) with the population rate of STI (= B/A) remaining largely unchanged. In Scenario X, when the testing decreases, the number of STI diagnoses also decreases, as do the number of notifications (D) and the notification rate for the period (=D/A). In contrast, in Scenario Y, when the testing increases, both STI diagnoses and notifications also increase. In Scenario Z, the majority of the population has been tested, and this gives a high testing coverage rate (=T/A). However, in all three scenarios, the proportion of positive tests (namely, the positivity rate, used as an estimate for the proportion of tested people who test positive) would show comparatively much less change. This is because, when the increased testing is conducted in the same population, especially when the increase occurs as tests performed for asymptomatic screening or opportunistic testing, the proportion of positive tests among those tested should remain at about the same level. In Scenario Z, because of the high test coverage rate, the positivity rate will be close to the disease prevalence in the population. Studies have shown that the positivity rate for chlamydia can be used as a proxy measure for population prevalence,[60, 61] and other studies have used the positivity rate to monitor the changes in the prevalence of STIs at the population level[59, 61-63] and for sexual health and reproductive clinic settings.[64-66]

Targeted opportunistic screening tests and community-wide screening programs have been recommended as important measures to control STI rates in Australia,[67, 68] and they have been conducted in many urban and remote areas in the NT in the past few years. As a result, sporadic, one-off or seasonal increases or decreases in testing amount can occur from time to time in some regions, followed by similar changes in notifications. For example, the regular increase in STI notifications in the NT that occurred in the April-June quarter each year between 2000 and 2009 had been attributed to the annual STI screens conducted in the Alice Springs remote communities.[62, 69, 70] The social marketing campaign, 'Safe Sex No Regrets', conducted in NT urban areas in 2008/9 has been linked to a considerable increase in chlamydia testing and diagnoses in the sexual health clinic promoted as the place for STI testing by the campaign.[71] Further, a number of Australian studies have shown a strong positive correlation between testing rates and notification rates for STIs, which indicates that passive surveillance systems may be biased by testing patterns.[59, 72-74] Therefore, without a good understanding of testing activities, it would be difficult for the health authority to explain these changes in notifications, and the health services would not be able to monitor or evaluate the effectiveness of the sexual health services they provide. In contrast, as shown in the above examples, when suitable and comprehensive testing data were available, both testing rates and positivity rates could be calculated and analysed together with notification rates to determine whether the increase in notifications was related to increased testing.

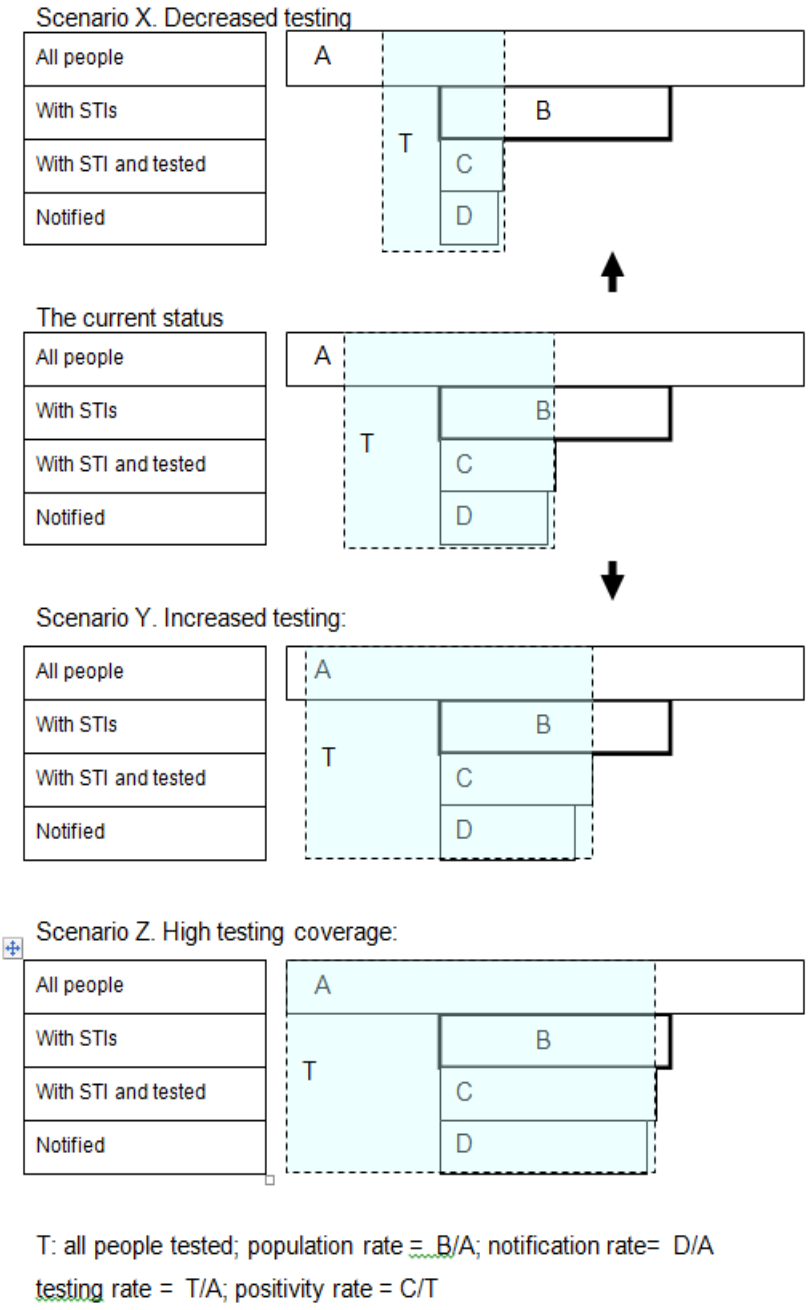

Figure 3.2: A conceptual model for illustrating the relationship between testing and notification statistics

There is always a proportion of STI cases in the population that will remain undetected and therefore the number of notified cases will always be smaller than the total number

of cases. Only when the whole population has been screened can the surveillance system possibly record all actual cases, but this is highly unlikely to happen. However, although it is often not possible to attain a full understanding of the epidemiology of STIs, it is possible, and I would argue that it is necessary, for an ideal surveillance system to monitor testing activity in order to properly monitor the occurrence of STIs. More specifically, an ideal surveillance system should be able to collect suitable and adequate data so that both the number of tests performed and the number of positive tests (this can be used to calculate the test positivity rate) and the proportion of the population tested (represented by the testing rate) can be determined in addition to the number of notifications (used to calculate notification rates). This is because only with a good understanding of testing activities can the extent to which the notification data are representative of the actual disease epidemiology be assessed, which is essential to a correct interpretation of notification data and evidence-based public health responses.

Monitoring testing activities also enables the health authority to differentiate different causes for a low number of notifications. When accompanied by a low testing rate in an area known to have high levels of STIs, the low number of notifications only reflects the lack of sexual health services and is no reason for optimism. In contrast, the combination of a high testing rate, a low positivity rate and a low number of notifications is a good indication that there is only a low level of STIs. For example, the divergent trends in testing rates (trending up and staying high) and positivity rates (trending down and staying low) have been used in an evaluation study to illustrate the effectiveness of a sexual health program aimed at controlling STIs.[63]

In conclusion, considering these two factors in the NT, an ideal STI surveillance system should collect data on and monitor the trends of both incidents of new diagnoses and testing activity.

3.3.2 An ideal STI surveillance system: what should be expected of it?

An STI surveillance system is both a public health surveillance system and a communicable disease surveillance system, therefore, an ideal STI surveillance system should have the capability of performing all the essential functions described in the definitions of these surveillance systems discussed in previous sections. They include the following:

1. *Ongoing and systematic collection of all relevant data:*

The STI surveillance system should be one that undertakes ongoing and systematic collection of data concerning the occurrence of STIs as specified in the various definitions for public health surveillance and communicable disease surveillance cited in Sections 3.1.1 and 3.2.1. The data collected should include both incidents of new diagnoses and the testing activity. The database of the surveillance system should be set up in such a way that information on frequency, geographical distribution, sources of infection and relevant risk factors can be produced, as described in Section 3.2.1.

2. *Analysing and interpreting the data:*

As specified in the definitions for public health surveillance and communicable disease surveillance, analysis of the data collected should form an essential part of the STI surveillance system. Therefore, an ideal STI surveillance system should be set up such that its data are retrieved, epidemiological analyses are carried out and trends in both testing and notification are interpreted and monitored on a regular and timely basis. When the data collected are of desired quality and the analysis and interpretation of the data is carried out regularly, it is then possible for the system to fulfil the seven functions of public health surveillance system as described in Section 3.1.2. For STIs, this should include the calculation of the essential statistics of STI epidemiology, including the notification rate, the testing rate and the test positivity rate, with breakdown by region, sex, sexual orientation, ethnicity, age groups and time periods.

3. *Disseminating the results to those who need to know:*

An ideal STI surveillance system should be able to publish regular surveillance reports to disseminate the results of analysis of the data collected to all those who need to know. With up-to-date information on STI notification and testing, the health authority can undertake informed and evidence-based public health actions and program responses for STIs; coordinators of sexual health programs can monitor or evaluate the progress of their programs; and health services can assess their delivery of sexual health services.

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Chapter 4: Evidence for a sharp decrease in gonococcal cultures and its implications for the surveillance of antimicrobial sensitivity

4.1 Preface

This chapter consists of a short paper that presents the results of an investigation into the decreasing trend in the number of gonococcal cultures and discussion on the implications of such trends to the surveillance of antimicrobial sensitivity for *Neisseria gonorrhoeae* in the Northern Territory (NT). The study used aggregate testing data provided by a major pathology laboratory for this study. As this pathology laboratory has been providing pathology services to almost all remote health services in the NT (the total number of remote health services is >200 and only <5 health services used a different laboratory at any time) as well as a large proportion of urban-based health services and general practices, it is believed that the testing data should be representative of the situation for the whole of the NT outside of the public hospitals, the prison clinics and the sexual health clinics. Therefore, this chapter serves to illustrate the utility of laboratory testing data in monitoring the trends in gonococcal cultures at jurisdictional level. The importance of this analysis is also discussed in the paper.

This chapter has been published in the Northern Territory Disease Control Bulletin (available from this website: http://health.nt.gov.au/Centre_for_Disease_Control/Publications/NT_Disease_Control_Bulletin/index.aspx):

Su J-Y, Pell C. Evidence for a sharp decrease in gonococcal cultures and its implications for the surveillance of antimicrobial sensitivity. *Northern Territory Disease Control Bulletin*. 2009;16(3):11-4.

I designed the study, conducted the research, including data collection and analysis, and wrote the early draft of the paper. Dr Cathy Pell provided advice on the interpretation of the analysis results, and contributed to the review and revision of the manuscript submitted to the Bulletin.

This work was published in 2009; the context described in the Introduction section and the comments and conclusions in the Discussion section were current at that time.

4.2 Introduction

The introduction of nucleic acid amplification tests (NAATs) for the detection of common bacterial sexually transmitted infections (STIs) such as *Chlamydia trachomatis* and *Neisseria gonorrhoeae* in the 1990s has had a dramatic impact on both the reported trends and diagnostic methods for these STIs.[1-4] For *N. gonorrhoeae*, NAATs offer several advantages over traditional diagnostic methods. They have higher sensitivity, do not require viable organisms for diagnosis, can be used effectively on non-invasive specimens (such as urine and self-administered swabs), take less time to produce results, and the same specimen can be used to test simultaneously for *C. trachomatis*.[5, 6] These advantages make them suitable not only for symptomatic patients but also for screening purpose in asymptomatic clients, particularly in remote settings.

However, the limitations of the NAAT for *N. gonorrhoeae* have also been well documented.[5, 6] The most important among them concerning the control of genital gonorrhoea is that the NAAT cannot provide antimicrobial sensitivity data. Without this, clinicians cannot confidently treat their patients as *N. gonorrhoeae* has a tendency to develop antimicrobial resistance through various genetic modifications.[7] Furthermore, at the population level, the surveillance of the antimicrobial sensitivity pattern and the formulation and revision of recommended treatment for locally acquired gonococcal infections depends on the collection of adequate representative samples for culture and antimicrobial sensitivity testing. If clinicians switch to the convenient NAATs exclusively for gonorrhoea diagnosis, there will not be adequate or representative

culture samples to conduct the surveillance of gonococcal sensitivity. This will have a negative impact on the treatment and control of gonococcal infection.

In this paper, we examine the amount of gonococcal cultures performed at the population level in the Northern Territory (NT) in recent years and discuss the implications of the findings, particularly in relation to the control of genital gonorrhoea.

4.3 Methods

This is a retrospective descriptive study. De-identified testing data for gonorrhoea culture were provided by a private pathology laboratory which, for the vast majority of NT remote health centres, is the only pathology services provider. It also provides pathology services to a high proportion of urban-based general practices and Aboriginal-control medical services. It is therefore believed that the data from this laboratory should be representative of the situation for the whole of NT.

The dataset included all persons tested in the NT by this particular laboratory regardless of their resident status. For comparison purposes, we also retrieved relevant data from the Annual Reports of Australian Gonococcal Surveillance Programme (AGSP) for 2004-2007[8-11] to calculate the number of isolates from urethral sites (which included urine specimens) by Australian jurisdictions.

4.4 Results

The total number of cultures was considerably higher in females than in males. In females, it showed a decreasing trend from 2005 to 2007, but the number increased slightly in 2008 (see Table 4.1). In males, the number decreased by 24% from 2005 to 2006; from 2006 to 2007 there was a nearly 90% decrease, and it further decreased in 2008.

Figure 4.1 and 4.2 display the number of cultures from the most commonly used specimen types in males and females respectively. In females, the number of cultures from high vaginal swabs, vaginal swabs and cervical swabs all increased between 2006 and 2008. In contrast, the number of cultures from urine showed a dramatic decrease from 2005 to 2007 and remained at about the same low level in 2008.

The national data from the AGSP demonstrates a similar decrease in the number of urethral gonococcal isolates from men between 2005 and 2007 in all jurisdictions except South Australia (see Figure 4.3).

Table 4.1: Number of cultures performed per year and culture yield by sex, NT, 2004-2008

Category	2004	2005	2006	2007	2008
Female					
Number of cultures	15,111	15,178	14,327	11,882	12,879
Culture yield (%)	0.7	0.7	0.4	0.2	0.3
Male					
Number of cultures	5,889	6,347	4,838	525	448
Culture yield (%)	3.1	2.8	2.6	6.3	6.9

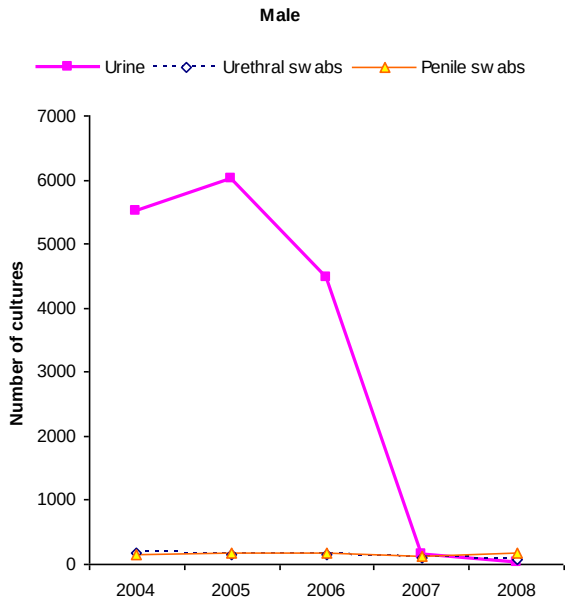

Figure 4.1: Number of cultures by specimen type, NT, 2004-2008 (male)

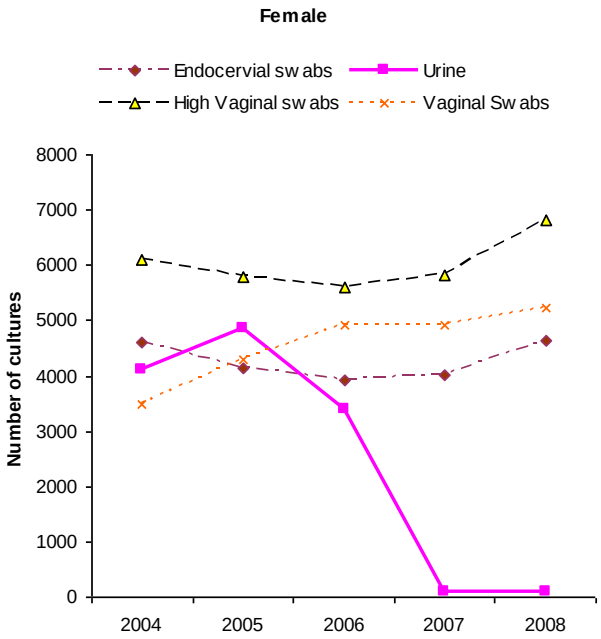

Figure 4.2: Number of cultures by specimen type, NT, 2004-2008 (female)

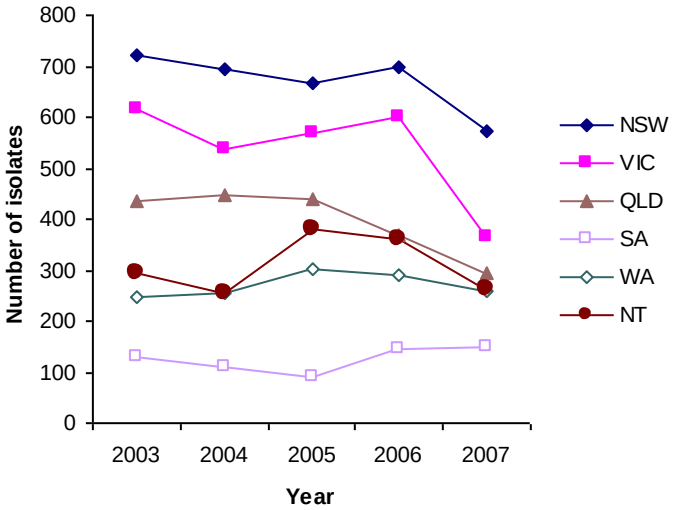

Figure 4.3: Number of urethral isolates of N. gonorrhoeae by jurisdiction and year reported by the Australian Gonococcal Surveillance Programme, 2004-2007

4.5 Discussion

Using the available laboratory testing data, we have shown in this paper that there was a significant decrease in the number of urine cultures in both sexes in the NT between 2005 and 2008. In contrast, during the same period, the number of cultures by other specimen types showed a mild increasing trend.

We believe the decrease in urine cultures was a direct consequence of a change in the combined pathology item in the Medicare Benefit Schedule (MBS, # 69315) which allowed culture and nucleic acid testing to be done in one single request. A ruling by the Federal Government in 2005 removed this combination item.[12] Consequently, pathology companies gradually stopped performing gonococcal culture on urine specimens submitted for nucleic acid testing unless specifically requested, as Medicare no longer covers the cost otherwise. This change affected only gonococcal culture which is paid for through Medicare, but not those paid through other funding sources, for example those performed in public hospital laboratories. This also explains the decrease in urethral isolates from almost all jurisdictions as examined by the AGSP during the same.

When cultures are not done, antimicrobial susceptibility testing is not possible. This cannot be compensated for by any increase in test numbers or positive tests by the NAT urine tests. The implications of this decrease in urine cultures for gonorrhoea for the NT are more significant than in other jurisdictions. The NT, where the highest rates of gonorrhoea in Australia are consistently recorded, is the only jurisdiction where, for

locally acquired disease, the gonococcal organism remains penicillin sensitive and penicillin-based regimens can be effectively used.[13] A dramatic decline in gonococcal cultures means that gonococcal antimicrobial sensitivity surveillance is not as effective and without a sensitive surveillance system current treatment guideline revision is difficult. Should penicillin-resistant gonococcal infection go undetected, the ramifications for public health would be serious.

With the recent resurgence of HIV and STIs among men who have sex with men[14] and the reported emergence of gonococcal strains resistant to multiple antibiotics including to the third generation cephalosporin ceftriaxone,[11] this decrease in gonococcal culture and hence antimicrobial sensitivity testing may also have similar implications for other States/Territories.

In the face of decreasing availability of gonococcal isolates for antimicrobial sensitivity monitoring we wish to bring this issue to the attention of clinicians, as a simple change may help to boost the number of isolates and thereby greatly improve the situation. We therefore recommend:

1. In remote settings, clinicians specifically request gonococcal culture on all urine specimens collected for NAAT;

2. In other settings, gonococcal culture be specifically requested for each specimen taken from all persons who have symptoms of an STI or who are tested as part of contact tracing;

3. In non-remote settings, culture is not indicated when doing routine or opportunistic screening in asymptomatic men, but should be performed if the initial urine nucleic acid test is positive for gonorrhoea.

When requesting gonococcal culture for urine specimens, it is important that clinicians write specifically on the pathology request form ‘MC&S for gonorrhoea.’

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Chapter 5: Trends in testing and notification for genital gonorrhoea in a northern Australian district, 2004-2008

5.1 Preface

This chapter presents a paper that describes trends in testing and notification for gonorrhoea in the Darwin Remote District during the period 2004-2008 and illustrates the utility of laboratory testing data in assisting in the interpretation of notification data. Comprehensive de-identified laboratory testing data were collected from the pathology laboratory providing pathology services exclusively to this district during the study period. As the data used were de-identified, a deterministic matching method was used to identify and then estimate the number of unique individuals in this district tested in a calendar year. This is essential to determining the representativeness of the data for the population. The reasons and justifications for its use and the method are described in detail in the chapter. Identification and removal of results from multiple specimens collected for the same testing episode can also be done with the dummy identification number produced with this method.

The paper has been published in the journal Sexual Health:

Su J-Y, Condon JR. Trends in testing and notification for genital gonorrhoea in a northern Australian district, 2004-2008. *Sex Health*. 2012; 9(4):384-8.

In addition, an abstract based on this paper was accepted by the Australasian Sexual Health Conference 2010 as a poster presentation. The poster presented at the Conference is not included in this chapter.

I designed the study, conducted the research, including data collection and analysis, and wrote the original draft of the paper. Professor John Condon provided advice on the study design and data analysis, and contributed to the review and revision of the manuscript submitted to the journal.

This work was published in 2012; the context described in the Introduction section and the comments and conclusions in the Discussion and Conclusion sections were current at that time.

5.2 Abstract

Background: The study aimed to examine the trends in notification and testing for genital gonorrhoea (*Neisseria gonorrhoeae*) in the Darwin Remote District of Northern Territory, Australia, between 2004 and 2008.

Methods: Using laboratory testing data and notification data, we calculated the annual sex- and age-specific notification rates, testing rates and positivity rates, and examined their trends. A deterministic matching method was used to identify unique individuals tested in order to estimate the number of years out of five in which each individual was tested. The correlation between testing rates and notification rates was calculated.

Results: The notification rates for the 15–24 year age group increased sharply from 2004 to 2005, and then trended downwards between 2005 and 2008, with a decrease of 48.2% in females and 59.9% in males. No evident trends were found in testing rates. The positivity rates for this age group decreased by 46.3% in females (from 8.9% to 4.8%), and by 70.4% in males (from 10.8% to 3.2%) between 2004 and 2008. Over 76% of the population in this age-group had been tested at least once during the study period. A moderate correlation was found between notification rates and testing rates in both sexes.

Conclusions: There was a significant decreasing trend in the notification rate of gonorrhoea between 2005 and 2008, which was most probably due to a decrease in prevalence. This study demonstrates the importance and utility of population-level testing data in understanding the epidemiology of common bacterial sexually transmissible infections such as gonorrhoea.

5.3 Introduction

Genital gonorrhoea (*Neisseria gonorrhoeae*) occurs much more frequently among Aboriginal Australians than in the general Australian population. The Northern Territory (NT) has the highest proportion of Aboriginal people among its population (29%) of any Australian state or territory, and by far the highest notification rate of gonorrhoea in the last decade.[1] In the NT in 2008, Aboriginal people comprised 91.8% of notified cases of gonorrhoea and their crude notification rate (2,207.2 per 100,000) was about 26 times the non-Aboriginal rate.[2]

However, the true extent of genital gonorrhoea infection among the NT Aboriginal population is not known because the notification rate is not an accurate measure of either disease incidence or prevalence. For example, the total NT genital gonorrhoea notification rate decreased by 8.0% between 2004 and 2008,[2, 3] but it is impossible to know whether this indicates that genital gonorrhoea became less frequent in the NT population or that fewer tests were performed in later years.

Interpretation of the notification rate is difficult because notified cases are only a minimum level, based on the number of laboratory-confirmed cases.[4, 5] The notification rate is calculated from the number of positive laboratory tests notified to the communicable disease notification system. In a population in which the disease is very common and may be asymptomatic, the number of positive tests is not only determined by the frequency of the infection in the population but, to a considerable extent, also depends on the number of tests, particularly screening tests, performed.

Only a proportion of new infections with genital gonorrhoea will be notified to the health authorities. First, the infections may not be diagnosed because there are no symptoms, the symptoms may be mild or abate spontaneously and medical attention is not sought, or simply because access to healthcare facilities is poor. Second, sometimes new cases may have been treated without a laboratory diagnosis. Third, even when a laboratory diagnosis is made, it could be missed in the disease notification process. The notification rate, therefore, does not accurately measure disease incidence. In addition, if population screening for genital gonorrhoea infection is occurring, the notified cases will be a mix of new infections (incident cases) and existing untreated infections (prevalent cases).

The number of cases diagnosed as a result of screening tests (unrelated to the onset of symptoms) could be used to estimate the prevalence rate if those screened are representative of the entire population, either because they are an unbiased, preferably random, sample of the population or because a very high proportion of the population was tested. However, disease prevalence cannot be calculated from notification data because neither the reason for the test (recent onset of symptoms or population screening) nor the total number of tests performed is known from notification data.

Systematically collected, population-based sexually transmissible infection (STI) testing data provide information on the level of testing, which can assist in interpreting

passive surveillance data and might be able to be used to estimate disease prevalence.[6-9] A range of testing data has been used by researchers in Australia to achieve a better understanding of STI epidemiology in recent years. Data concerning STI tests performed through Medicare (Australia's universal health insurance system) have been used to calculate testing rates or to provide denominator data to calculate proxy test positivity rates.[10-13] Though useful to some extent, Medicare data are limited by their inability to provide information on test results or specimen types. Data from individual primary care clinics or their pathology laboratories have been used to calculate prevalence among the clinic's clients,[14-16] but it is not clear that this is representative of the population served by the clinic.

In this study, we used population-based notification and testing data to examine the trends in notification of, testing for and prevalence of genital gonorrhoea in the population of the Darwin Remote District (DRD) of the NT between 2004 and 2008. The DRD, located in the northern part of the NT outside of urban Darwin, consisted of 16 predominantly Aboriginal communities and had an estimated resident population of 16 216 in 2008, of which ~72% was Aboriginal.[17] Health services in most communities are provided by government-run community clinics, with a small number of Aboriginal community-controlled health services and private practitioners. There were no dedicated sexual health clinics in this region and basic sexual health services were provided by remote area nurses and fly in–fly out medical officers.

Genital gonorrhoea is known to be common in the Aboriginal population of the DRD; their gonorrhoea notification rate was 1026.6 per 100 000 in 2005.[18] A previous study

in Aboriginal women living in the Top End region of the NT gave an overall gonorrhoea prevalence of 17% for those aged 11 years and over in 1999.[4] A retrospective cross-sectional study published in 2000 based on medical record audits found that 27% of females in a large DRD community had a history of gonorrhoea.[19] There were no published reports on gonorrhoea epidemiology for males in this district.

Opportunistic screening of asymptomatic people for genital gonorrhoea infection is performed in the DRD during antenatal care, routine health checks and other suitable health service encounters; targeted screening events were also conducted in some communities on an irregular basis.[20]

5.4 Methods

The study population was defined as the resident population of the DRD. De-identified testing data were obtained from Westerns Diagnostic Pathology (WDP), which provided almost all primary care laboratory services for the entire DRD during the study period. The testing data included all results for the nucleic acid amplification tests (NAAT) for genital gonorrhoea performed for residents of the DRD between 1 January 2004 and 31 December 2008. Twenty-four records with missing demographic data (sex or date of birth) were excluded. The NAAT used by WDP for diagnosis of gonorrhoea during the study period was the COBAS AMPLI-COR Test (Roche Molecular Systems, Branchburg, N.J. USA) until November 2005; *porA* pseudogene PCR (an in-house LightCycler assay)[21] between November 2005 and July 2006; and the APTIMA COMBO 2 Assay (Gen-Probe Inc., San Diego, CA, USA) after July 2006.

A positive result from the primary test needed to be confirmed with a supplementary NAAT before a positive diagnosis was made.[22]

De-identified data on notified cases of genital gonorrhoea were retrieved from the local health authority for the same population and time period. Some individuals were tested more than once in each calendar year. A deterministic matching method was used to identify unique individuals with NAAT results to determine the number of people tested (rather than the number of tests performed) and the number of people with a positive test (rather than the number of positive tests) for each calendar year and for all years combined. Records with the same value combination of sex, date of birth and community of residence were deemed to be of the same individual. Positive NAATs recorded less than 30 days after a preceding positive test were excluded from the analysis to reduce double-counting of the same episode of infection.

The testing rate was calculated as the number of individuals tested each calendar year divided by the population of the DRD for the same year, including the crude rate for those aged 15 years and over, and the age-specific rate (for age groups 15–24 years, 25–34 years, 35–44 years, and 45 years and over). The notification rate was calculated in the same way using the number of notification as the numerator. The annual population data for the DRD for 2004-2008 was supplied by the NT Department of Health, based on Estimated Resident Population (ERP) data (by year, age group, sex and statistical local area) published by the Australian Bureau of Statistics.[17]

To assess whether those tested over the 5-year period were representative of the total population (or whether they were a minority who were tested repeatedly while a large proportion of the population were never tested), the number of years (out of five) in which each individual was tested was calculated by sex and age group.

The positivity rate was calculated as the number of positive tests in a calendar year divided by the total number of individuals identified for that year. The positivity rate is therefore used in this study to estimate the period prevalence (for calendar year periods) of genital gonorrhoea infections, not of individuals infected at any time during the period.

All statistical analyses were performed using STATA for Windows (ver. 11.0, STATA Corporation, College Station, TX, USA). The χ^2-test for trend was used to assess the trends in the various rates, whereas correlation coefficients were used to examine the correlation between notification and testing rates. Two-sided *P*-values of <0.05 were considered significant. Ethics approval to conduct this study was granted by the Human Research Ethics Committee of the NT Department of Health and the Menzies School of Health Research.

5.5 Results

5.5.1 Notification rates

Eighty notifications (of a total of 661) that were diagnosed by a laboratory other than WDP (mostly patients treated at Royal Darwin Hospital) were excluded to make the notification data consistent with the testing data. A total of 581 notifications of genital gonorrhoea from WDP were identified for DRD residents between 2004 and 2008, including 362 females (62.3%) and 219 males (37.7%). The notification rate was higher for females than males in almost all age groups and years (Table 5.1). The age-specific notification rates were by far the highest in the 15–24 year age group, in which more than half of all notifications were recorded.

The overall notification rates increased considerably between 2004 and 2005 (females by 34%, males by 59%) but then declined progressively until 2008, when they were below the levels of 2004; this decline was statistically significant (χ^2-test for trend, P = 0.0059 for females, P = 0.0038 for males). The same pattern was seen in the 15–24 year age group, in which the decrease between 2005 and 2008 was 48.2% in females (P = 0.021) and 59.9% in males (P = 0.029). The notification rate decreased for all other age groups between 2005 and 2008, although the rates were lower than in the 15–24 year age group and the trends were not as consistent from year to year.

5.5.2 Testing rates and positivity rates

A total of 15 861 records of gonorrhoea NAAT results were identified for 7543 individuals aged 15 years and over (3239 males and 4304 females), of which 33.2% and 30.1% were recorded in the 15–24 and 25–34 year age groups, respectively. The number of individuals tested at least once was 70% of the ERP (83% for females and 58% for males); 43% of females and 38% of males among the identified individuals were tested two or more times within the 5-year period (Table 5.2).

The testing rate was higher for females than males in all years (Table 5.1). For females, the overall testing rate increased considerably between 2004 and 2005, and remained at a higher level than 2004 in subsequent years. For males, the overall testing rate was stable between 2004 and 2006, then increased considerably in 2007 and 2008. The overall positivity rate decreased between 2004 and 2008 from 5.2% to 2.8% for females and from 6.5% to 2.3% for males.

In the 15–24 year age group, the age group most at risk of genital gonorrhoea infection, the testing rate fluctuated around 40% for females and 20% for males over the 5 years (Table 5.1), with the testing rate in 2005 being higher than that in 2004 by 27.7% in females and 18.6% in males. The positivity rate decreased between 2004 and 2008 by 46.3% in females and 70.4% in males; both decreasing trends were statistically significant (χ^2-test for trend, $P = 0.0016$ for females, $P = 0.0005$ for males). In this age group, the number of female individuals tested was 113% of the corresponding ERP (this is possible, as the testing data might include tests performed in people who were

not residents of the DRD) and the number of males tested was 76% of the ERP for males; 50% of females and 34% of males were tested in 2 or more of the 5 years (Table 5.2).

A moderate correlation was found between the notification rates and testing rates in both females (r = 0.73, P = 0.00030) and males (r = 0.53, P = 0.0169).

Table 5.1: Results of notification rates, testing rates and positivity rates, in Darwin Remote District, Northern Territory, Australia, 2004–2008

Type of rates and age group	Female					Male				
	2004	2005	2006	2007	2008	2004	2005	2006	2007	2008
Notification rate (per 100 000)										
15–24	2803	4120	2900	2673	2135	1770	2364	1696	1350	947
25–34	731	1461	732	1519	850	403	1205	642	867	838
35–44	793	1056	1302	734	815	729	1052	1098	168	671
45 and over	47	225	260	0	122	41	194	148	145	105
15 and over	964	1525	1141	1046	846	596	996	731	534	520
Testing rate (%)										
15–24	35.8	45.7	40.4	36.9	38.7	19.4	23.0	16.2	21.8	25.1

25–34	34.9	41.2	39.1	37.8	39.4	20.0	20.3	18.9	23.9	27.6
35–44	25.1	27.4	26.0	29.6	34.7	13.9	13.8	16.1	21.2	26.1
45 and over	5.9	7.5	6.4	7.9	9.4	3.9	3.5	4.6	8.2	9.7
15 and over	22.5	26.9	24.3	24.5	26.6	12.2	12.7	11.8	16.4	19.3
Positivity rate (%)										
15–24	8.9	8.2	5.0	5.7	4.8	10.8	7.9	7.6	5.5	3.2
25–34	2.8	3.0	1.9	3.8	2.4	4.4	4.0	3.0	3.0	2.8
35–44	3.2	4.6	3.6	1.9	2.1	5.9	3.8	5.8	1.2	2.3
45 and over	3.9	2.4	2.7	0.0	0.4	2.1	4.5	1.6	1.3	0.7
15 and over	5.2	5.2	3.4	3.5	2.8	6.5	5.4	4.7	2.9	2.3

Table 5.2: Proportion of individuals tested, by age group, sex and number of years (out of five) in which they were tested, Darwin Remote District, Northern Territory, Australia, 2004–2008

Sex and age group (years)	Number of individuals tested (n)	Proportion of ERP tested[A] (%)	Number of years in which individuals were tested[B]					
			5 (%)	4 (%)	3 (%)	2 (%)	1 (%)	Total (%)
Female								
15–24	1524	113	2	7	15	26	50	100
25–34	1337	109	2	5	14	23	56	100
35–44	865	80	2	4	10	21	63	100
45 and over	578	37	0	2	7	19	72	100
15 and over	4304	83	2	5	12	23	57	100
Male								
15–24	981	76	1	2	8	23	66	100
25–34	932	75	1	3	8	21	67	100
35–44	737	62	0	1	5	25	68	100
45 and over	589	32	0	1	5	16	78	100

15 and over	3239	58	0	2	7	22	69	100
All 15 and over	7543	70	1	4	10	23	62	100

[A]ERP stands for estimated resident population for the Darwin Remote District. These are calculated based on population data published by the Australian Bureau of Statistics.

[B]The data listed in the columns below are proportions (%) of total individuals in each age or sex group that were tested in this number of years. Data excluded 24 nucleic acid amplification tests with incomplete demographic information.

5.6 Discussion

This paper has produced evidence to explain the rise and fall of gonorrhoea notification rates in DRD during the period 2004–2008. The increase in notification rates in both sexes between 2004 and 2005 was most probably due to increased testing, as evidenced by the sharp increase in testing rates during the same time. It was unlikely to be due to increased prevalence because there was a concurrent decrease in positivity rates in both sexes. It is likely that the decrease in notifications in both sexes between 2005 and 2008 was not an artefact of changes in testing practice but reflected a decrease in population prevalence because: (a) the testing rates showed no significant changes over time in females and increased slightly in males; (b)

more than half of the resident population had been tested at least once during the 5-year period; and (c) there were consistent and significant decreasing trends in the positivity rates in both sexes. Furthermore, the change in the nucleic acid assay at the end of 2005 and in mid-2006 did not appear to have an impact on the trends in diagnoses.

The notification rate rose considerably between 2004 and 2005 and then declined progressively until 2008 to a level slightly lower than it had been in 2004. With access to notification data alone, it is impossible to determine whether this indicated a sudden increase in disease occurrence that then returned to previous levels or simply reflected an increased detection of prevalent infections. The moderate correlation between testing and notification rates in both sexes indicates that the notification rate is significantly influenced by the amount of testing performed and is thus a poor indicator of disease prevalence. It is therefore important to obtain population-level testing data to calculate positivity and testing rates to assist in the interpretation of surveillance data for common bacterial STIs such as gonorrhoea.

The testing data do not definitely distinguish between an increase in disease occurrence or increased detection of prevalent infections. The positivity rate did not increase between 2004 and 2005, but this is consistent with either more symptomatic people presenting for testing, or with more detection of infection in asymptomatic people during screening. However, the

considerable and consistent decline in the positivity rate between 2004 and 2008, while testing rates remained high, does suggest that genital gonorrhoea was becoming less frequent in this population. Further studies using other data sources (such as gonorrhoea diagnosis rates among newly incarcerated prisoners) are needed to validate this finding.

In females in the 15–24 and 25–34 age groups, in which ~40% of the population were tested each year after 2004, the positivity rate is a reliable estimate of the period prevalence of disease in this population. The decrease in the positivity rate indicates that there has been a considerable reduction in the prevalence of genital gonorrhoea in females in this population over this period. The proportion of the resident population tested and the proportion tested in more than 1 year are both lower for males than females, and the testing rates for males were consistently below 30%; the fall in positivity rate is thus not as reliable an indicator of disease prevalence for males.

As males are usually tested much less frequently for STIs than females, it is encouraging to see the testing rates increasing considerably in males during 2006–2008 and even reached 25% in the 15–24 year age group in 2008. However, these data may not represent the situation of the whole district, as the large majority of this increase occurred in three larger communities (data not shown). In females, the testing rates decreased slightly in the most at-risk 15–24 year age group during 2005–2008. Both findings indicate health

services still need to put more effort into sexual health services so as to further reduce the prevalence of gonorrhoea.

There are several limitations in this study. First, there were ~5% of records in the original testing dataset (for all tests performed in the NT) with insufficient data in the community field to be categorised into districts; this would tend to underestimate testing rates. Second, matching of testing data to estimate the number of individuals tested was done with de-identified data, matching on date of birth, sex and community of residence. People who moved from one community to another and were tested in both would have been counted as more than one individual. Among the 7971 individuals (including all ages) identified by the matching process, there were 6214 (78%) unique combinations of date of birth and sex. In a population of only 16 000 people, only a small proportion would share the same sex and date of birth, so some people have been counted as more than one individual, which would tend to overestimate testing rates. More specific identification data are needed to reduce this double-counting. Third, as described above, the testing rates in males were lower than for females, which limits the validity of using positivity rates as proxy measures of prevalence for males in particular. Fourthly, 80 notifications not diagnosed by WDP were excluded from the analysis, which would reduce the notification rates calculated here to a small extent. Lastly, the testing data did not contain information on reasons for testing or whether the clients were symptomatic or not, both of which are important in interpreting the trends in notifications and testing. For example, it is known

that a community-wide sexual health screen was conducted in three adjoining communities in the DRD in 2004 and 2005, and over 550 people were tested in each screen.[20] This should have increased the testing rates considerably and, to some extent, reduced the positivity rates in these 2 years. It is not possible to isolate the influence of these two screens from this study.

5.7 Conclusion

The study found a significant decreasing trend in the notification rate of gonorrhoea in the DRD between 2005 and 2008, which was most probably due to a decrease in prevalence. The utility and importance of population-level testing data in understanding and monitoring the epidemiology of common bacterial STIs such as gonorrhoea have also been illustrated in this paper. It is therefore important to incorporate the regular collection and analysis of such data into the surveillance system for STIs.

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Chapter 6: An assessment of the Tiwi Sexual Health Program, 2002-2005

6.1 Preface

Chapter 4 presents the results of an evaluation of the Tiwi Sexual Health Program implemented between 2002 and 2005 in the Tiwi Islands of the Northern Territory. Comprehensive de-identified laboratory testing data for the communities of the Tiwi Islands were collected from the two pathology laboratories providing pathology services exclusively to the community clinics of Tiwi Islands at different periods during the four years of the program implementation. This project illustrates the utility of laboratory testing data in assisting in the interpretation of surveillance data, monitoring the epidemiology of STIs at the community level, and evaluating the effectiveness of intervention and prevention programs for STIs. As the paper was written in 2007-2008, the time periods discussed in it were all based on this reference point in time.

This chapter has been published in the Australian and New Zealand Journal of Public Health:

Su J-Y, Skov S. (2008). An assessment of the effectiveness of the Tiwi Sexual Health Program 2002-2005. *Aust NZ J Public Health*. 32(6): 554-8.

The study contained in this chapter was also presented as an oral presentation at the Australasian Sexual Health Conference, 2008.

I designed the study, conducted the research, including obtaining the relevant approvals from the local ethics committee and the Tiwi Islands Health Board as well as data collection and analysis, and wrote an program evaluation report for the Centre for Disease Control and the Tiwi Health Board. The evaluation report is available from this web address: http://health.nt.gov.au/library/scripts/objectifyMedia.aspx?file=pdf/69/18.pdf&siteID=1&str_title=The%20Tiwi%20Sexual%20Health%20Program.pdf. Dr Steven Skov provided advice on the design of the evaluation and data analysis. Both Dr Steven Skov and I contributed to the writing of the manuscript submitted to the journal based on the evaluation report.

This work was published in 2008; the context described in the Introduction section and the comments and conclusions in the Discussion and Conclusion sections were current at that time.

6.2 Abstract

Objectives: To describe the key elements of a comprehensive sexual health program implemented between 2002-2005 in remote Indigenous communities on the Tiwi Islands and to assess its effectiveness in reducing rates of bacterial sexually transmitted infections (STIs).

Methods: A descriptive study using STI notification and laboratory testing data to analyse the occurrence of STI diagnoses over time compared to nearby similar regions.

Results: Over the four years' period of program implementation, the numbers of tests and individuals tested increased substantially and were sustained. The notification rate of chlamydia decreased from 1581.3 to 80.0 per 100000, that of gonorrhoea from 2919.2 to 1159.7 and that of syphilis from1743.4 to 200.0, representing a decrease of 94.9%, 60.2% and 88.5%, respectively. No similar trends in notification rates were observed in nearby regions. During the same time, the positivity rate (the number of positive tests divided by the total number of tests) of nucleic acid tests for gonorrhoea decreased from 5.9% (56/952) to 3.9% (39/1004), and that for chlamydia decreased from 5.2% (38/1003) to 0.3% (3/1007), representing a decrease of 33.9% and 94.2%, respectively.

Conclusion and implications: The Tiwi Sexual Health Program was accompanied by a significant reduction in STI rates between 2002 and 2005. This model of a comprehensive sexual health program with a dedicated coordinator located within a Primary Health Care service can be recommended as an effective approach to address high rates of STIs in remote Indigenous community settings.

6.3 Introduction

Rates of sexually transmissible infections (STIs) in the Northern Territory (NT) have been the highest in Australia and rising in the past decade.[1 2] However, the burden of STIs is not evenly distributed and STI rates are substantially higher in rural and remote Indigenous communities than in the general NT population.[3] This is consistent with higher rates of STIs among Indigenous people observed in other jurisdictions.[2] Inadequate access to health care services[4] and substance abuse,[5] in addition to a range of determinants of ill health of Indigenous people (such as dispossession, unemployment, lack of education and their sequelae), have been implicated as important contributing factors.

There are few examples of programs addressing high rates of STIs in Indigenous communities[6 7] which have attained any measurable success. This paper describes the experience of a sexual health program (SHP) implemented in the Tiwi Islands of the NT and evidence suggesting its effectiveness in reducing rates of STIs.

6.4 The Tiwi Sexual Health Program

6.4.1 Background

The Tiwi Islands are situated about 80 km north of Darwin in the Arafura Sea. They contain three major Aboriginal communities, namely Nguiu, Pirlingimpi

and Milikapiti, with a total population of 2512 people in 2006. As with many remote Indigenous communities, substantial barriers exist to the delivery of sexual health services, including a very high burden of ill-health (much of which is considered to be more imperative than sexual health matters), high staff turnover, particularly of non-Indigenous staff, and high mobility of the client population making follow up difficult.

In June 2000, primary health care (PHC) services on the Tiwi Islands were provided by the Tiwi Health Board (THB), an Aboriginal community controlled organisation. At the invitation of the THB, the then AIDS/STD Unit (now named Sexual Health and Blood Borne Viruses Unit: SHBBVU) of the NT Department of Health and Community Services (DHCS), conducted a wide ranging situation analysis of sexual health program activity on the Tiwi Islands. The analysis included a case note audit of all occasions of care involving an STI test during a 12-month period, a separate audit of all past STI history in a random selection of 10% of all persons aged 15 and over, a review of clinic infrastructure, systems and education resources, an analysis of community health promotion and education, and stakeholder interviews.[8] Key findings from the situation analysis were:

1. *High rates of STIs*: rates of bacterial STIs were 3-10 times higher than the NT as a whole and 47% of women had had at least one lifetime STI episode.

2. *High rates of complications of STIs:* 28% of women appeared to have had at least one lifetime episode of pelvic inflammatory disease (PID).

3. *Low rates of STI testing and suboptimal management*: only 61% of females and 28% of males over the age of 10 years had an STI test in the 12 month audit period; fully appropriate STI testing was only performed in two thirds of clinical situations requiring them; and, while appropriate treatment was given in 90% of all cases, it was given in only one quarter of women with a diagnosis of PID.

4. *Lack of access to STI education and prevention services*: a lack of sexual health education and promotion in the communities or schools; condoms were only available in the health clinics.

5. As a result of the report, the THB made sexual health one of its major priority areas and decided to develop a program with a comprehensive, whole of health service and community approach.

6.4.2 Development of the Program

A clinical working party comprising clinic staff and Tiwi community members was established, which, in conjunction with the SHBBVU, began addressing

some of clinical service issues in late 2000. Funding was obtained from the Office of Aboriginal and Torres Strait Islander Health (OATSIH) in June 2001. The model of the Nganampa Health Council sexual health program and the publication "STD Control Manual for Aboriginal Communities"[9] were important guides to the development of the program.

The key elements of the resultant program were:

- The employment of a dedicated program coordinator in February 2002, based at the local health service and without any responsibility for acute clinical care. Apart from developing the technical aspects of the program, a crucial role was to constantly interact with community and clinic staff to inform, motivate, take on board suggestions, provide feedback, and maintain their engagement.

- A steering committee consisting of community members to provide program direction and advice to the coordinator.

- Regular orientation and training for staff concerning the SHP.

- A strong focus on opportunistic testing whereby staff would systematically offer STI testing to clients presenting to the clinic for non-sexual health matters, particularly those in the most at-risk age groups.

- The introduction of STI screening (with parental consent) as part of school screening for those aged 12 years and above.

- Community wide intensive sexual health screens targeting 15-30 year olds (but open to all ages) in 2004 and 2005. These screens were preceded by substantial lead-up consultation, information and education work within the community aimed at maximising participation and increasing general awareness of sexual health matters.

- Participation in regional, centralised STI management database systems (operated by the SHBBVU) to facilitate diagnosis, treatment and follow up of people with STIs and their partners.

- Regular education initiatives with schools, community based organisations and men's and women's community meetings.

- Active condom promotion and distribution in a wide range of locations with an increase in the number of condoms distributed on the islands from 2800 in 2001 to 12,000 in 2002 and each subsequent year.

- Regular feedback to health service management and staff to keep them informed and keep the sexual health program on the agenda.

- Strong support from the SHBBVU in the provision of specialist public health and clinical expertise and occasional logistic support.

Unfortunately, in 2003 the THB collapsed and the DHCS took over management of the service. This was a time of great turmoil, staff losses and consequent health service program disruption. However, the SHP coordinator was retained and was able to maintain substantial continuity in the program. In February 2006 the coordinator left the program and, as is unfortunately common in many remote community health services, was not replaced for over a year.

6.5 Methods

The occurrence of STIs is usually monitored by the statutory surveillance data collected by health authorities. In the first part of this assessment we analysed trends in the numbers and rates of STI notifications from the Tiwi Islands using the NT Notifiable Diseases System database. In order to determine whether any trend was part of a broader secular trend, the same data was analysed for the Katherine district and the “Darwin Remote” district (rural and

remote areas surrounding Darwin but excluding the Tiwi Islands) where the population structure, community infrastructure and access to services is very similar to that on the Tiwi Islands.

A very large proportion of all STIs do not cause symptoms or, if they do, do not result in the person presenting to a clinic.[10] As a result, many STIs will only be detected if testing is offered to people who have not presented with symptoms: either by opportunistic testing or outreach screening activity. An increase or decrease in notified STIs may reflect a change in the number of people who are tested rather than a change in the transmission of infection. STI laboratory testing data from pathology companies provides information concerning the number, gender and age of people tested as well as types of tests done which allows for an understanding of the nature of health service activity as well as its interaction with the occurrence of infection. It can be also used to calculate the test positivity rate (calculated as the number of tests with positive results divided by the total number of tests). The positivity rate has been shown to closely approximate the prevalence of chlamydia and thus can be used to monitor its prevalence,[11] which is particular useful when the proportion of the population tested is high.

Data concerning STI testing in Tiwi and Darwin Remote communities during the period 2001 to 2006 was obtained from Western Diagnostic Pathology and Queensland Medical Laboratories. Laboratory data from the Katherine region was not accessible. The data was de-identified but included

demographic details, type of specimen and test, and results of tests. Estimates were also made of the number of different individuals tested by examination of dates of birth and community. All entries of the same combination of gender and date of birth were considered to be the same individual. This method under-estimates the total number of individuals tested as it is not possible to distinguish between different individuals with the same date of birth being tested.

Estimated resident population data for the Tiwi Islands were derived from the 2001 and 2006 Census data provided by the Australian Bureau of Statistics (see Table 6.6). All statistical analyses were carried out using Stata for Windows.[12]

Permission to conduct this study and publish its results was granted by the Tiwi Health Advisory Committee, which has been established to develop a new governance structure as part of an eventual aim to hand back control of the PHC service to Tiwi people. Formal ethics approval was obtained from the relevant local ethics committee.

6.6 Results

6.6.1 STI notifications

During 2002 there was an increase in the number of bacterial STIs diagnosed; this was followed by a general decline in notifications of chlamydia, gonorrhoea and syphilis (see Table 6.1). The trends of the downward decline in notification rates during the period of program implementation (2002-2005) were statistically significant (chi-square test for trend, p <0.005 for all three STIs).

Table 6.1: STI notification numbers and rates (per 100 000 population), Tiwi Islands: 2000-2006

Year	Chlamydia		Gonorrhoea		Syphilis	
	Number	Rate	Number	Rate	Number	Rate
2000	22	919.5	26	1086.7	14	585.1
2001	25	1018.3	24	977.6	14	570.3
2002	39	1581.3	72	2919.2	43	1743.4
2003	25	1009.0	41	1654.7	10	403.6
2004	26	1044.5	16	642.8	16	642.8
2005	2	80.0	29	1159.7	5	200.0
2006	7	278.7	13	517.5	1	39.8

6.6.2 Comparison of STI notifications with the Darwin Remote and Katherine Districts

No significant change was seen in notifications of gonorrhoea and chlamydia in the Darwin Remote and Katherine districts over the years 2002-2005 (see Tables 6.2-6.4). Syphilis notifications in these two districts declined, which was consistent with the trend throughout the NT during the period of 2002-2005.[13]

Table 6.2: Notification rates of chlamydia: Tiwi Islands, Darwin Remote and Katherine Districts, 2000-2006

Year	Tiwi Islands		Darwin Remote		Katherine	
	Number	Rate	Number	Rate	Number	Rate
2000	22	919.5	34	309.6	111	610.9
2001	25	1018.3	53	468.0	106	578.4
2002	39	1581.3	68	600.1	140	761.2
2003	25	1009.0	98	868.6	150	817.3
2004	26	1044.5	55	485.2	181	979.8
2005	2	80.0	66	572.6	131	700.1
2006	7	278.7	127	1098.9	148	803.8

Table 6.3: Notification rates of gonorrhoea: Tiwi Islands, Darwin Remote and Katherine Districts, 2000-2006

Year	Tiwi Islands		Darwin Remote		Katherine	
	Number	Rate	Number	Rate	Number	Rate
2000	26	1086.7	46	418.9	144	792.6
2001	24	977.6	48	423.8	144	785.8
2002	72	2919.2	97	856.0	192	1043.9
2003	41	1654.7	141	1249.8	132	719.2
2004	16	642.8	86	758.7	225	1217.9
2005	29	1159.7	112	971.7	186	994.1
2006	13	517.5	111	960.5	187	1015.6

Table 6.4: Notification rates of syphilis: Tiwi Islands, Darwin Remote and Katherine Districts, 2000-2006

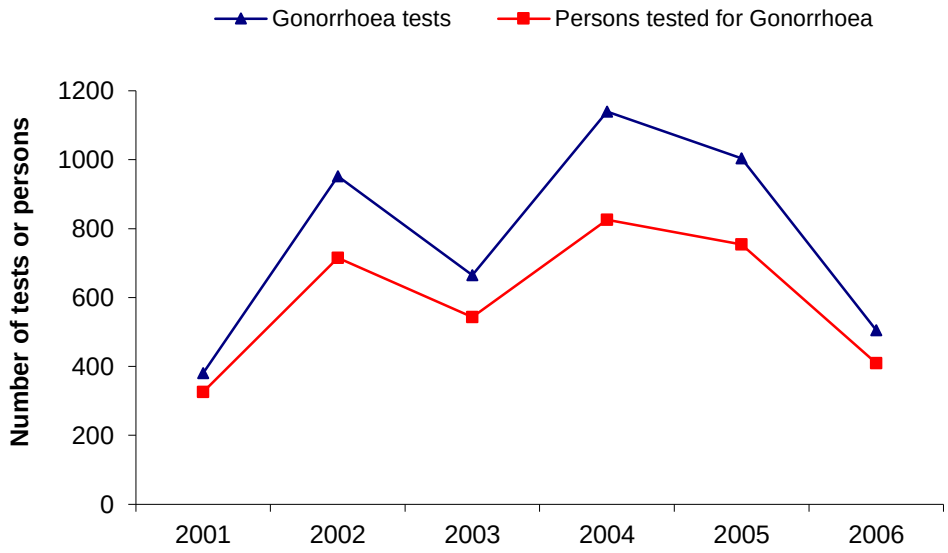
Year	Tiwi Islands		Darwin Remote		Katherine	
	Number	Rate	Number	Rate	Number	Rate
2000	14	585.1	20	182.1	34	187.1
2001	14	570.3	23	203.1	37	201.9
2002	43	1743.4	44	388.3	87	473.0
2003	10	403.6	10	88.6	20	109.0
2004	16	642.8	5	44.1	21	113.7
2005	5	200.0	16	138.8	21	112.2
2006	1	39.8	6	51.9	7	38.0

6.6.3 STI testing

Figure 6.1 demonstrates the number of tests done and the number of individuals tested for gonorrhoea (chlamydia test numbers being nearly identical because of the routine practice of testing for both infections). There was a dramatic increase in the amount of STI testing in 2002 when the program coordinator began work, which was largely sustained through to 2005. The increase in testing occurred in both sexes, although it was greater

in females (see Table 6.5). In 2006, once the coordinator had left, the amount of testing declined considerably.

Figure 6.1: Testing for gonorrhoea in Tiwi communities 2001-2006



The majority of STIs occur in younger, more sexually active people. In the NT, 81.1% of gonorrhoea and chlamydia notifications occurred in the 15-34 year age group in 2006.[3 13] This age group comprised between 63.6-79.4% of all tests for gonorrhoea done in the four-year period (see Table 6.5). Furthermore, during this period, the test positivity rate for both gonorrhoea and chlamydia tests declined in a statistically significant fashion (chi-square test for trend, $p<0.005$ for both). This was also true for the 15-34 year age group.

Table 6.5: Test results for gonorrhoea and chlamydia, Tiwi Islands, 2001-2006 (data presented as number of positive tests/total number of tests (% positive))

Test results for chlamydia

	2001		2002		2003		2004		2005		2006	
Sex												
Male	1/111	(0.9%)	11/420	(2.6%)	10/248	(4.0%)	12/425	(2.8%)	0/404	(0.0%)	0/174	(0.0%)
Female	12/307	(3.9%)	27/582	(4.6%)	18/451	(4.0%)	19/720	(2.6%)	3/603	(0.5%)	7/333	(2.1%)
Unknown	0		1								1	
Total	13/418	(3.1%)	38/1003	(3.8%)	28/699	(4.0%)	31/1145	(2.7%)	3/1007	(0.3%)	7/508	(1.4%)
Age (years, at time of testing)												
<15	1/14	(7.1%)	3/58	(5.2%)	6/72	(8.3%)	3/37	(8.1%)	1/33	(3.0%)	0/13	(0.0%)
15-24	9/140	(6.4%)	18/339	(5.3%)	13/252	(5.2%)	15/436	(3.4%)	1/463	(0.2%)	2/140	(1.4%)
25-34	2/124	(1.6%)	12/297	(4.0%)	7/187	(3.7%)	11/398	(2.8%)	1/335	(0.3%)	3/170	(1.8%)
35-44	1/82	(1.2%)	4/197	(2.0%)	1/110	(0.9%)	2/178	(1.1%)	0/102	(0.0%)	2/123	(1.6%)
45 +	0/58	(0.0%)	1/112	(0.9%)	1/78	(1.3%)	0/96	(0.0%)	0/73	(0.0%)	0/61	(0.0%)

Test results for gonorrhoea

	2001		2002		2003		2004		2005		2006	
Sex												
Male	3/100	(3.0%)	16/410	(3.9%)	12/229	(5.2%)	9/422	(2.1%)	14/403	(3.5%)	5/173	(2.9%)
Female	9/281	(3.2%)	40/541	(7.4%)	26/436	(6.0%)	25/717	(3.5%)	25/601	(4.2%)	10/331	(3.0%)
Unknown	0		1		0		1		0		1	
Total	12/381	(3.1%)	56/952	(5.9%)	38/665	(5.7%)	34/1140	(3.0%)	39/1004	(3.9%)	16/505	(3.2%)
Age (years, at time of testing)												
<15	0/12	(0.0%)	5/56	(8.9%)	3/52	(5.8%)	3/36	(8.3%)	1/30	(3.3%)	0/12	(0.0%)
15-24	10/132	(7.6%)	31/325	(9.5%)	24/248	(9.7%)	17/434	(3.9%)	29/463	(6.3%)	10/139	(7.2%)
25-34	2/117	(1.7%)	13/280	(4.6%)	7/182	(3.8%)	11/396	(2.8%)	5/334	(1.5%)	3/170	(1.8%)
35-44	0/73	(0.0%)	6/185	(3.2%)	3/108	(2.8%)	2/177	(1.1%)	2/103	(1.9%)	2/123	(1.6%)
45 +	0/47	(0.0%)	1/106	(0.9%)	1/75	(1.3%)	1/96	(1.0%)	2/73	(2.7%)	1/60	(1.7%)

Reliable laboratory testing data for remote communities in the Darwin Remote district was only available from 2003 onwards. In the years 2003 to 2006, the number of tests performed for gonorrhoea infection was 2389, 1694, 2269, and 2447 respectively with no trend apparent. Chlamydia tests were very similar in number. The total population for this area was approximately 14,000.

6.7 Discussion

We believe there was a significant decline in notifications of bacterial STIs which became apparent in the second year following the program coordinator beginning work on the full breadth of program activities (see Table 6.1). The initial increase in notifications in 2002 is probably related to the corresponding increase in testing for STIs in that year (see Figure 6.1). Thereafter, the trend of new notifications was downwards in spite of the amount of testing being sustained at the higher level: both in terms of the numbers of tests done and individuals tested. In addition, the positivity rates for gonorrhoea and chlamydia declined over time suggesting a reduced prevalence amongst those tested. Importantly, amongst 15-34 year olds, in whom the majority of STIs are known to occur, there was a both high and sustained level of testing and a reduced test positivity rate. Very similar low prevalences of infection were also observed during the 2004-05 community wide screening.[14] Over 550 people were tested each year including between 82.1% and 84.9% of 15-30 year olds considered by health staff to be normally resident. The combined prevalences of infection with either gonorrhoea or chlamydia for

males and females respectively were 1.8% and 3.1% in 2004 and 1.7% and 3.4% in 2005.

This decline in notifications was not observed in other similar parts of the NT. In the Darwin Remote and Katherine districts, rates of infection were relatively stable, with perhaps a slight increase during the same time period. This was also the case for notifications of gonorrhoea and chlamydia in Central Australia and for chlamydia in Australia as a whole.[2 3 13] In the Darwin Remote district, the amount of testing was stable during this time except for a decline in 2004. It is important to note that the same laboratory provided services to all remote communities in the Tiwi Islands and the Darwin Remote and Katherine districts during the time of the program and used the same diagnostic test throughout (Roche AMPLICOR™). Therefore, the reduced diagnoses of Tiwi STIs are unlikely to be related to laboratory issues.

We are of the view that there was a real decline in the transmission of STIs in the Tiwi communities on the basis that it was not related to reduced testing activity and was not observed in nearby similar regions. While we cannot definitively assert a causal relationship, we believe it highly likely the reduced rates of STIs are attributable to the Tiwi SHP. A very similar program in a similar setting, that of Nganampa Health Council in northern South Australia, has also been able to demonstrate reduced prevalences of infection during

their annual community STIs screens with 70% coverage of their target population.[7 15 16]

There have been very few published reports on the operation of sexual health programs in Aboriginal populations and fewer that appear successful. The Nganampa program is also a comprehensive program but much focus has been placed upon the community mass screening aspect of it. A significant difference between the Tiwi and Nganampa programs is the (relatively) lower rates of infection in the Tiwi region. In the Tiwi program it would appear that reductions in disease transmission were occurring prior to the first community mass screen in October 2004. This suggests that, at least in regions with relatively lower rates, day to day health service activity in systematically offering testing and treatment, combined with health promotion and education strategies, can have an impact in reducing disease transmission.

Detection of STIs is highly dependent on testing activity the analysis of which can contribute significantly to understanding the occurrence of STIs. Testing data can and should also be used by health services to monitor their level of service activity, whether their activity is being directed to the right groups in the population, and to determine the efficiency of testing activity in detecting STIs. We believe this is one of the few studies to demonstrate the utility of STI testing data in informing an understanding of the epidemiology of STIs and the effectiveness of health service activity.

6.8 Conclusion

This evaluation demonstrates that rates of STIs did decline on the Tiwi Islands between 2002 and 2005 and suggests that the Tiwi SHP contributed strongly to this improvement. A comprehensive sexual health program with a dedicated coordinator located within PHC services appears to be an effective model in reducing rates of STIs in a remote community.

Table 6.6: Estimated resident population of Tiwi Islands, 2001-2006 (based on the estimated resident population data from the 2001 and 2006 Census data retrieved from the Australian Bureau of Statistics*)

	2001	2002	2003	2004	2005	2006
Sex						
Male	1242	1249.8	1257.6	1265.4	1273.2	1281
Female	1213	1216.6	1220.2	1223.8	1227.4	1231
Age group (years)						
<15	774	768.0	762.0	756.0	750.0	744
15-24	497	489.4	481.8	474.2	466.6	459
25-34	464	460.4	456.8	453.2	449.6	446
35-44	322	338.2	354.4	370.6	386.8	403
45 and over	398	410.4	422.8	435.2	447.6	460
Total	2455	2466.4	2477.8	2489.2	2500.6	2512

*The populations for the intercensal years were calculated by distributing the difference between the 2001 and 2006 figures evenly.

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Chapter 7: Recommendations and Conclusions

7.1 Introduction

In a jurisdiction such as the Northern Territory (NT) where the notification rates of sexually transmitted infections (STIs) have been extremely high and where intense STI testing or screening activities occur frequently, it is very difficult, if not impossible, to monitor the epidemiology of these STIs and facilitate a correct and up-to-date understanding with a passive surveillance system alone. Although persistently high notification rates reflect a high prevalence and incidence in the population, variation in either transmission or testing activities can lead to variation in notification rates, and both can occur in this particular setting. In the absence of an understanding of the amount of testing, interpretation of surveillance data is difficult.

This research set out to explore whether and in what ways collecting and analysing laboratory testing data can improve the current passive surveillance system for common STIs in the NT (referring to system being implemented in 2015). This chapter synthesises the key findings of the research and proposes a number of recommendations to translate the research into practice.

7.2 Collecting and analysing laboratory testing data for STI surveillance

The current passive surveillance system implemented for notifiable diseases, including notifiable STIs, evolved from a surveillance system originally established to monitor the emergence and occurrences of serious infectious diseases. It may be effective for infectious diseases that are generally symptomatic, but not for common and largely asymptomatic STIs such as gonorrhoea and chlamydia, as illustrated by a sizeable body of literature and this research (especially in Chapter 3 and Chapter 5). This is mainly because of the high degree of correlation between testing rates and notification rates. Due to dissatisfaction with the nature of the passive surveillance system and the surveillance data it collects, there have been efforts to use various types of testing data to help in the interpretation of surveillance data and thus improve the effectiveness of the surveillance system for STIs, both in Australia and abroad.

7.2.1 Medicare testing data: convenient, but too limited for surveillance purposes

In Australia, researchers have extensively used publicly accessible Medicare testing data for chlamydia in epidemiological inquiries. For example, Medicare testing data have been used as the ‘denominator’ data in calculating population testing rates, positivity rates and testing-adjusted

notification rates to determine whether the increase in national chlamydia notification rates in recent years was caused by an increase in disease prevalence or was mostly due to increased testing.

There are good reasons why researchers use Medicare testing data to investigate the epidemiology of chlamydia. Medicare data is freely downloadable from the Medicare website, and it is not expensive to get more detailed data from the Medicare office. However, the approval process for access to Medicare data can be slow, which limits the availability of Medicare data for research purposes, but on-going access as part of a surveillance system would require this be done only once (with review of approval every few years). Furthermore, the data have been consistently collected in the private sector across Australia for a number of years. This means it is feasible to analyse time trends and regional variation.

However, Medicare testing data is collected for payment and reimbursement purposes and consequently has limited utility for research or disease surveillance. Little demographic information is available (only sex, age group and area of residence are available generally); there is no specific pathology item number for common STIs other than chlamydia; and the tests performed in public sector laboratories, including those performed at public hospitals and sexual health clinics, are not included in Medicare data. Therefore, for the purpose of STI surveillance, Medicare testing data is not a good choice.

7.2.2 Laboratory testing data: the way to go

A different but theoretically and practically better approach is to collect STI testing data directly from all pathology laboratories servicing the target population as a supplement to the existing passive surveillance system. This approach can be used for all common STIs (unlike Medicare testing data that does not have specific pathology item numbers for most STIs). It has the potential to cover the whole population, as long as all involved pathology laboratories are willing to provide data (unlike Medicare testing data that does not include testing data from public sector laboratories). Further, as virtually all pathology laboratories have a computerised database to manage their pathology data, once the data retrieval and transmission system between the pathology laboratories and the surveillance system is set up, data collection can be automated and run regularly at an appropriate frequency as a low cost surveillance system similar to the passive surveillance system.

When the population coverage is high, this approach allows the interpretation of surveillance data in the context of trends in testing (for example, by calculating testing-adjusted notification rates[1]), and thereby facilitates a better understanding and more effective monitoring of STI epidemiology. Recent initiatives in Western Australia[2] and New South Wales[3] to regularly collect comprehensive laboratory testing data for STIs and report them in STI surveillance reports are two good examples. Although the population

coverage of the laboratory testing data has not reached 100% yet in either State, the data already collected have enabled the health authorities to monitor, interpret and report STI surveillance data in relation to testing activities, and also monitor trends in STI testing.

This research has used comprehensive laboratory testing data for gonorrhoea for the Darwin Remote District in the NT to assist in the interpretation of trends in surveillance data (Chapter Four), and concluded that the decrease in gonorrhoea notification rates of this district between 2004 and 2008 was most likely due to a decrease in prevalence. The conclusion was made by considering that the amount of testing did not decrease but remained at a reasonably high level; and that during the same period of time, the positivity rate declined significantly in the same direction as the notification rate.

As the laboratory testing data can include data for gonococcal cultures, it is also possible to monitor the number of gonococcal cultures performed, and calculate culturing rates (the proportion of gonorrhoea cases with their specimens cultured for *N. gonorrhoeae*) for the purpose of enhanced surveillance for gonococcal antimicrobial sensitivity. This is of particular importance in the NT because the NT is the only State/Territory where inexpensive oral penicillin is still the recommended first line antibiotic for treating locally acquired genital gonorrhoea in its remote regions, where the gonorrhoea notification rates are extremely high (as of the time of writing in

December 2015). To maintain this favourable therapeutic situation, it is important to ensure the enhanced surveillance of antimicrobial sensitivity is operating effectively. This research examined the number of gonococcal cultures performed at one major private laboratory which provided pathology services to all but a small number of remote clinics in the NT, and found a dramatic drop in culture numbers between 2005 and 2007, and discussed its causes and implications for the control of gonorrhoea in the NT.

Population screening for STIs (i.e. testing of asymptomatic people) has been used as part of short-term STI control interventions in the NT because of the very high rates of STIs. It is virtually impossible to assess the effectiveness of such interventions with notification data alone because an increase in notifications could be caused by increased testing during the intervention or increased disease transmission despite the intervention. Comprehensive laboratory testing data can be used to differentiate the two situations to some extent by providing data on the number of STI tests performed and the proportion of positive tests (the positivity rate). As a demonstration of this use of laboratory testing data, this research used laboratory testing data to assess the effectiveness of a sexual health program implemented in the Tiwi Islands between 2002 and 2005. It found that an initial increase in notification rates was actually the result of an increase in the number of tests. As the program progressed the number of STI tests remained high but the positivity rate and the number of notifications decreased. At the same time there was no change in notifications in surrounding regions where there was no such program

operating, This indicates that the decrease in notifications was most likely due to reduced transmission and incidence of disease.

Regular collection and analysis of comprehensive laboratory testing data, including data on residential location (in the NT, at the level of community for remote areas and suburb for urban areas) enables a more sophisticated understanding of STI epidemiology as well as the delivery of sexual health services at the local level. This is particularly useful in remote communities that have only one health service provider; locally-specific information can be provided to staff in remote primary care services to give them a better understanding of the services they have been providing and help them identify areas for improvement. This data can also be used to assess public health interventions for STI control implemented in such settings.

Laboratory testing data also have other public health applications. These include monitor the delivery of sexual health services at remote Indigenous communities, monitoring STI testing practice, detecting suspicious changes in the performance of diagnostic tests for STIs, and monitoring the completeness of the disease notification practice by pathology laboratories. I have illustrated them in a poster which I presented at the Australasian Sexual Health Conference 2008 (see Appendix).

7.3 Limitations and difficulties to address

Despite the merits and applications mentioned above, there are practical limitations and difficulties that need to be considered and addressed in the process of establishing a surveillance system incorporating STI testing data as discussed above. Firstly, in the NT, pathology laboratories are obliged by the NT Notifiable Diseases Act to report positive test results to the Department of Health, but this does not apply to negative test results. Therefore, whether this surveillance system for STI testing can be established or not depends on the willingness of pathology laboratories to provide testing data, including both positive and negative test results. Private pathology laboratories are for-profit businesses; if the request for regular retrieval and transmission of STI testing data would incur significant financial or labour cost (for example, in setting up the laboratories' database system for this task), these pathology laboratories may be hesitant to comply. With modern computer technology, it may not be difficult or expensive to set up the data retrieval and transmission mechanisms for this purpose, as has been the experience of the NT Department of Health with one private pathology laboratory that has been supplying testing data to the Department for the last 10 years. If set up as an automatic data retrieval and transmission system, once established it will require only minimal attention or maintenance. In any case, the Department of Health still needs to make a good case to the pathology laboratories to convince them to agree to this request at the outset of setting up the surveillance system for STI testing—this is the very first hurdle to overcome.

Secondly, for the surveillance system for STI testing to function properly, the testing data collected need to be in a format that are amenable to correct counting of testing episodes, be they in a disaggregate line-listed format or in aggregate format as summary tables. This is especially important for STI testing data because the nucleic acid amplification tests (NAAT) for STIs, the most commonly used STI tests of today, are often taken with multiple specimens at multiple specimen sites; without proper de-duplication, duplicated counting of tests performed for the same testing episode on the same individual can happen and lead to inflated total numbers of individuals tested. Moreover, as results from different specimens taken from the same individual at the same testing episode may be different, with only some specimens testing positive (this is the major reason for taking multiple specimens from multiple sites), the de-duplication process may require relatively more complex data manipulation, particularly when it is to be done with de-identified disaggregate data. If the arrangement is for the pathology laboratories to provide testing data in the format of summary tables, then this de-duplication process has to be performed by the pathology laboratories before data transmission. In this case, it is important to assess whether each pathology laboratory has the skills to conduct this process correctly, to ensure that the data is reliable. As not all pathology laboratories are willing or able to perform de-duplication, this requirement may negatively impact on their willingness to provide the data. A potentially easier solution to this problem is for the pathology laboratories to provide de-identified disaggregate data and let the Department of Health deal with the de-duplication process. This is yet

another important aspect that needs to be properly thought through, negotiated and addressed in the process of establishing the surveillance system for STI testing. Furthermore, given that multiple pathology laboratories will be involved, it is also useful to ensure that the testing datasets are provided in a standardised format to facilitate data merging into the existing master dataset.

The third limitation concerns the potential ethical issues surrounding the use of laboratory testing data for disease surveillance without individual consent. Pathology laboratories are obliged by jurisdictional notifiable disease acts (for example, in the NT, it is the NT Notifiable Diseases Act) to report only positive test results of STIs to the health authority, and there is currently no legislation to support the collection of negative tests. Therefore, whether the collection of comprehensive testing data (including both positive and negative results) from laboratories is ethical or requires the usual ethical clearance for research is not clear. For instance, the NT Centre for Disease Control made an official request for STI testing data to a pathology laboratory in 2014, which was stalled because the laboratory's data custodian required that ethical clearance be obtained first (personal communication with Dr Peter Markey, Head of Surveillance). In contrast, ethical approval was not mentioned at all in the official epidemiological reports that used and reported laboratory testing data for STIs published by the health department of NSW and WA. Although it is not clear whether obtaining ethical clearance is really required for requesting laboratory testing data, given that ethical clearance is generally

intended for research projects, it is not difficult to understand why the laboratory would require this. The primary purpose of the laboratories testing data is clinical care, not disease surveillance; when used for disease surveillance, the testing data will be accessed and used without the consent of the individuals who contributed the data. Therefore, it is essential to ascertain that such use of the testing data is ethical and is managed in an ethical manner, and that individual privacy and confidentiality are protected.

The laboratory testing data can come in either aggregate or disaggregate forms. In an aggregate form, the laboratory testing data will be provided as summary tables for the population at the level of a large geographic area (for example, post code areas or districts), so there should be no ethical issues or concerns about individual privacy or confidentiality as no personal information is accessed or used. However, when the request is for disaggregate testing data in a line-listed test-based form, variables containing information about the individuals tested, such as sex, age, Indigenous status, and residential community or suburb, will be included in addition to health information such as test related data, thereby raising ethical concerns.

In Australia, the guidelines governing the collection of health information for the compilation or analysis of statistics relevant to public health or public safety, under which collecting and using disaggregate laboratory testing data for STI surveillance can be categorised, are stipulated in Section B of the ‘Guidelines approved under Section 95A of the Privacy Act 1988, 2014’

published by the Australian National Health and Medical Research Council (NHMRC).[4] According to the guideline document, the Australian Privacy Principles and related guidelines "…do not apply to de-identified information or statistical data sets, which would not allow individuals to be identified (in which case, the information ceases to be 'personal information' which would be covered by the Privacy Act)". The guidelines document also states that, 'under the Privacy Act, personal information is de-identified if the information is no longer about an identifiable individual or an individual who is reasonably identifiable.' If the testing data are provided in a de-identified format with the lowest level of geographic unit being a community or a suburb, the possibility to identify a particular person with the combination of sex, age, Indigenous status can be expected to be very low. In other words, because the disaggregate laboratory testing data are de-identified and very unlikely to be re-identifiable, the risk of breaching individual's privacy and confidentiality should also be very low.

However, collecting 'age' (usually expressed in years) in disaggregate testing data instead of date of birth may provide better protection of individual's privacy, but it will also limit the effectiveness of the de-duplication algorithm mentioned above and in Chapter 5. An acceptable and reasonable compromise is to collect the generalised form of date of birth which includes only the year and month of the date. This has been a common practice in data linkage projects that used various de-identified administrative data collections,[5-8] and the generalised date of birth should still allow the de-duplication algorithm to be carried out to some extent.

Given that the de-identified testing data are not deemed personal information under the Australian Privacy Principles and the NHMRC guidelines mentioned above, the requirement to obtain ethical approval which applies to research projects and other activities that need to access personal information should not apply to the collection and use of STI testing data for disease surveillance. In sum, as long as the testing data are provided in an appropriately de-identified format, there should not be ethical concerns in collecting and using them for disease surveillance purposes.

7.4 The best practice model

In order to regularly collect comprehensive laboratory testing data and incorporate them into the overall surveillance system for STIs, the surveillance system for STI testing should meet the following essential criteria:

1. *Comprehensiveness of the coverage*

For the system to be effective in monitoring the testing activities in the population, the coverage of the data should be as close to 100% as possible. When the coverage is low, the generalisability of the data to the entire population will be uncertain.

2. *Data quality*

As explained above, it is important to ensure that duplications due to multiple test records for the same testing episode are dealt with an effective and

transparent de-duplication process that can be monitored and audited. As the most important information to retrieve from testing data is the number of tests performed, this process is crucial and cannot be neglected.

3. *Sustainability of the surveillance system*

The system of data retrieval and transmission from the laboratories to the Department of Health should be set up to run automatically, requiring minimal manual attention or handling. A secure and efficient way for data transmission is for pathology laboratories to upload the testing datasets to a restricted access web portal. This ensures the whole process is consistent and reproducible, and the recurring cost for providing the data on the part of pathology laboratories is low. The Department of Health should also establish a stable and efficient system of data storage, analysis and reporting, with clearly assigned responsibility for management of the system.

4. *Integration of testing data into the STI surveillance system*

With the comprehensive laboratory testing data, the Department of Health should regularly monitor the following statistics and their trends over time and their breakdown by available demographic variables to ensure that surveillance data are always interpreted in light of testing activities and that testing activities are regularly monitored as an indicator for sexual health service provision:

- Numbers of rates of notifications
- Numbers of tests
- Rates of testing
- Test positivity rates

In addition, the following practical aspects about the data should also be considered:

1. *The format of data:*

Although aggregate data in the form of summary tables can suffice the basic needs of the surveillance system for STI testing, disaggregate data in line-listed form (that is, one record represents one test) are preferable. This is because disaggregate data allow the Department of Health to perform the de-duplication process (using either a deterministic or probabilistic matching method) to control the most important quality of the data, that is, the correctness. Further, disaggregate data also allow more types of statistical analyses, and greater flexibility in the breakdown and cross-tabulation of variables. Finally, data provided in this format will entail less work in data preparation on the part of pathology laboratories. In sum, where possible, the Department of Health should negotiate with pathology laboratories to obtain testing data in the form of de-identified disaggregate line-listed data.

2. *The variables included:*

The testing data should ideally include the variables listed below. Although pathology laboratories usually do not collect information on Indigenous status, this variable should be collected if available, particularly considering the high proportion of Indigenous people in the NT's population. The testing data should include tests for all common notifiable STIs in the NT, that is, chlamydia (NAAT), gonorrhoea (NAAT and culture), trichomoniasis (NAAT), and syphilis (both treponemal and non-treponemal tests).

- Age (in months, or, year and month of date of birth)
- Sex
- Residential suburb/community
- Postcode
- Date of test
- Specimen type
- Name of test
- Test result

3. Frequency of data transmission

Ideally, data retrieval and transmission should occur on a monthly basis. Considering the monthly data transmission frequency, the number of variables included, and the population of the NT, the size of the monthly dataset should small enough to be transmitted as a password-protected attachment to an email, which can be automated with most modern database systems. The ability to obtain the testing data for the last month is very useful to the STI surveillance system. It not only enables the system to monitor the

testing activities and the occurrences of STIs with very up-to-date data, but also allows the Department of Health to provide timely feedback to remote clinics with regard to their performance on the provision of sexual health services in terms of testing amount and positivity rates.

7.5 Conclusions

The concept of incorporating STI testing data into surveillance systems may be new and its implementation may not be universal yet, but two large Australian states have already established some form of such a system and are monitoring notification surveillance data and testing data together and reporting testing statistics for STIs regularly. With persisting high rates of STIs in the NT and the inherent limitations of the current passive surveillance system for STIs, it is imperative that the NT Department of Health follows the examples of NSW and WA, and negotiates with all pathology laboratories operating in the NT to regularly collect comprehensive testing data and establish the surveillance system for STI testing. A best practice model has been proposed here for consideration.

7.6 References

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Appendix

Public Health Applications of Laboratory Testing Data for Sexually Transmitted Infections — a poster presented at the Australasian Sexual Health Conference 2008:

DEPARTMENT OF **HEALTH AND FAMILIES**

Public Health Applications of Laboratory Testing Data for Sexually Transmitted Infections

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STI testing data: utility in understanding STI epidemiology

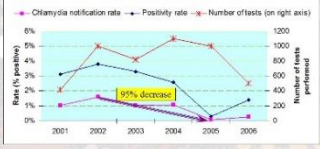
Analysis of STI laboratory testing data, which includes both positive and negative results, is useful in understanding STI epidemiology, because:

- ❖A large proportion of STIs (esp. chlamydia and gonorrhoea) are asymptomatic; hence, increasing testing (e.g. community screening) can lead to increased notifications without any real change in disease incidence/prevalence.
- ❖ Notification rates calculated using surveillance data tend to underestimate real STI rates, and are influenced by the amount of testing.
- ❖Positivity rates (the proportion of tests showing positive results) are usually better estimates of STI prevalence than notification rates, particularly when a high proportion of the population has been tested.

Example: An Evaluation of the Tiwi Sexual Health Program (SHP), 2002-2005

The chlamydia notification rate in the Tiwi Islands increased in 2001-02 but declined by 95% during 2002-05 (see Figure 1). The analysis of positivity rates and test numbers showed that the rate increase was associated with increased testing after the implementation of the SHP, and its decline was not due to a decrease in testing. Given that over 80% of population in the targeted 15-30 years age group were tested in community screens in 2004-05, it is highly likely that the rate decrease was due to a decrease in prevalence.

Figure 1: Epidemiology and testing of chlamydia, Tiwi Islands, 2001-2008



Other public health applications:

1. Monitoring the delivery of sexual health services to remote Indigenous communities

Case-finding is an essential component of sexual health services, especially in remote Indigenous communities in the NT, where STI rates are high. Analysis of testing data can provide information on the numbers of tests performed, whether the appropriate types of tests are being requested, and whether tests have been done in the most at-risk age groups. These are useful performance indicators for assessing the delivery of such services.

Example: Quarterly STI Epidemiological Reports for remote Indigenous Communities

Quarterly reports are being regularly generated for Darwin Rural communities. They contain data and analysis on STI notifications and tests performed with breakdowns of sex and age groups. Community health centre staff can see from these reports whether they are performing adequate and the right types of STI tests, whether tests are being performed in the targeted age groups, and also the trends in positivity rates. With this information, they can then adjust or improve their services accordingly. Such reports being regularly produced and sent to community health centre staff also serve to keep sexual health on their agenda. This is important as there is always a heavy disease burden and workload from other health issues in these remote communities.

2. Monitoring testing practice

Testing data contains information about specimen type and gonococcal culture results. These make it possible to monitor the following:

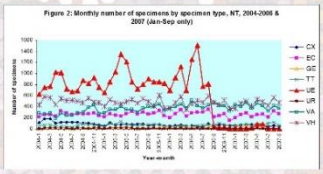
a. The culture rate for *N. gonorrhoeae* (the number of cultures/the number of nucleic acid tests, NAT)

b. What specimen types are being requested and their respective test yields

Example: An analysis of gonococcal culturing activities in the NT

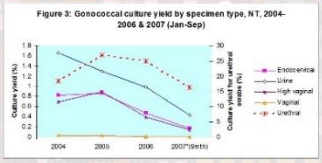
The number of urine cultures for *N. gonorrhoeae* (mainly performed in males) was found to decrease significantly in the NT in 2006-07 (see the line of UE in Figure 2, based on the testing data provided by a pathology company servicing all NT remote communities and a considerable proportion of the urban population). This was most likely related to the removal of a combination Medicare Benefits Schedule item for STI testing. The very low culture rate for males is likely to compromise the effectiveness of gonococcal sensitivity surveillance. This has special implication for the NT where the recommended treatment for locally acquired gonorrhoea is still oral penicillin. This finding has led to actions urging clinicians to specifically request culture when ordering STI tests.

Figure 2: Monthly number of specimens by specimen type, NT, 2004-2006 & 2007 (Jan-Sep only)



The culture yield for vaginal swabs was found to be extremely low and decreasing in the same analysis (0.05% in 2007, see Figure 3). As self- administered vaginal swabs have been used extensively in screening settings, this finding has prompted the re-consideration of whether to perform culture on vaginal swab in such settings.

Figure 3: Gonococcal culture yield by specimen type, NT, 2004-2006 & 2007 (Jan-Sep)

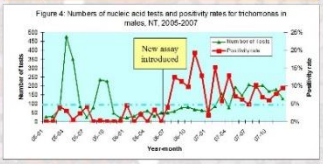


3. Detecting suspicious changes in the performance of diagnostic tests

Example:

The positivity rate of the NAT for trichomonas for males was found to be higher than expected (>5%, see Figure 4) in 2006-08. As the increase occurred right after the introduction of a new diagnostic assay and without a concurrent similar change in other STIs, this finding has led to a quality assurance study into the performance of this assay.

Figure 4: Numbers of nucleic acid tests and positivity rates for trichomonas in males, NT, 2006-2007



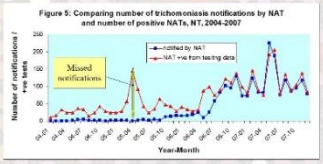
4. Monitoring disease notification practice by pathology laboratories

Comparing the number of notifications and the number of positive tests (from testing data) during the same period of time can reveal deficiencies in disease notification practice. This can serve as a quality assurance mechanism to ensure the completeness of disease notification.

Example:

Missed notifications of trichomoniasis between 2004-2006 (see Figure 5)

Figure 5: Comparing number of trichomoniasis notifications by NAT and number of positive NATs, NT, 2004-2007



Conclusion:

STI testing data should be collected and utilised to provide useful information for sexual health service delivery.

Acknowledgements:
Western Diagnostic Pathology; Dr. Steven Skov; Dr. John Condon

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