

Evaluation of Australia's National Notifiable Disease Surveillance System

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Abstract

The Australian National Notifiable Diseases Surveillance System (NNDSS) is a passive surveillance system that collects information on communicable diseases. The Australian Government manages NNDSS under the auspices of the Communicable Diseases Network Australia (CDNA). Data collected by each state and territory are collated, analysed and disseminated by the Australian Government Department of Health and Ageing. We report the first evaluation of NNDSS since it was established in 1991. Three primary stakeholder groups were surveyed: (a) CDNA members, (b) the National Surveillance Committee and (c) the readership of *Communicable Diseases Intelligence*, the primary means of data dissemination from NNDSS. The evaluation revealed that the system was acceptable, structurally simple, and that the data collected were actively used by stakeholders. However, the lack of clearly documented aims and objectives for NNDSS, inflexibility to changing needs, lack of timeliness and complexity in processes were seen as problematic. The results of this evaluation, supported by recent federal funding to enhance national biosecurity, will provide the framework for enhancing NNDSS to meet national communicable disease surveillance requirements in Australia. *Commun Dis Intell* 2004;28:311–323.

Introduction

Evaluation is an important part of communicable disease surveillance. Systematic and objective evaluation of surveillance determines the relevance, effectiveness and impact of such systems.

History of national surveillance in Australia

The occurrence of disease and death in Australia has been recorded since settlement in 1788. Each colony recorded information on an ad hoc basis¹ on the main diseases affecting the population. The *Quarantine Act*, 1832 of New South Wales was the first legislation relating to public health and was the first to introduce mandatory notification of diseases to local health authorities in Australia. Over time, the actions of New South Wales prompted other colonies to establish their own legislation for communicable disease control and reporting.¹ In 1901, the colonies of Australia joined together to form a federation, which led to the creation of the Commonwealth Government. The new Commonwealth Constitution protected the powers and the interests of the states in relation to public health. However, the Commonwealth was given powers of quarantine

for specified communicable diseases under the *Quarantine Act*, 1908. The *Quarantine Act* remains the sole legislative authority the Commonwealth has in relation to communicable diseases, to this day.

From 1917 to 1922, national data on notifiable diseases provided by the states and territories were published in the *Medical Journal of Australia*. From 1924 onwards, the Commonwealth Department of Health has published aggregated national data in various government publications.² In the mid 1980s, as the AIDS epidemic unfolded, the need for national surveillance was highlighted. The Communicable Diseases Network Australia New Zealand (CDNANZ) was formed in 1987, to enhance national surveillance and communicable disease collaborations. CDNANZ later became the Communicable Diseases Network Australia (CDNA), reporting to the National Public Health Partnership whose members are state and territory Chief Health Officers.

In 1988, a National Health and Medical Research Council (NHMRC) Workshop on National Disease Surveillance recommended that a Working Party be formed to establish a nationally consistent cooperative approach to surveillance.³ The main

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issues considered by the Working Party were the list of communicable diseases to be nationally notifiable, the construction of an inventory of existing communicable disease surveillance activities in Australia, a uniform approach to a national surveillance network and uniform basic data requirements for a surveillance database.

By 1991, the National Notifiable Diseases Surveillance System (NNDSS) was established. Data on the agreed list of nationally notifiable diseases were sent via diskette or paper from the states and territories to the Commonwealth. Officers in the Commonwealth health department, now the Australian Government Department of Health and Ageing (DoHA), would collate the data and publish surveillance summaries in the fortnightly publication *Communicable Diseases Intelligence (CDI)*. In 1996, the National Communicable Diseases Surveillance Strategy was released on behalf of the Chief Health Officers of Australia. The Strategy aimed to improve communicable disease surveillance and to provide comprehensive epidemiological data on which to base risk management decisions and public health policy. The Strategy recommended that NNDSS be improved by review of data quality, timely reporting, regular review of the diseases to be notified and case definitions, and expansion of the minimum dataset for specific conditions.⁴ The recommendation was adopted by both the Commonwealth department of health and CDNA.

The NNDSS database has been undergoing redevelopment since 2000. A new information technology platform has been created to automate the transmission of notification data from jurisdictions to the Commonwealth, new data fields were added to the minimum dataset and the case definitions have been under review since 2001. Throughout the development of NNDSS, the overall system has never been formally evaluated.

Aims of the evaluation

The aims of this evaluation are to systematically and objectively evaluate the attributes of NNDSS and highlight areas for improvement.

Methods

The framework detailed in the *Updated Guidelines for Evaluating Public Health Surveillance Systems*⁵ was used for this evaluation, because of the comprehensive nature of these guidelines. The evaluation focussed on the national surveillance system as a whole, which included stakeholder networks as well as the database that houses notification data, the analysis and interpretation of the collated data and the feedback mechanisms to stakeholders. It was beyond the scope of this evaluation to examine

enhanced surveillance for selected diseases using NNDSS. The evaluation includes a description of NNDSS and the public health importance of the events under surveillance.

The assessment of quantitative system attributes (timeliness, data quality and representativeness) was conducted by an analysis of NNDSS data including an analysis of data completeness of all 25 data fields. The sensitivity and positive predictive value (PPV) of NNDSS was beyond the scope of this evaluation. Qualitative system attributes (simplicity, flexibility and acceptability) were assessed through survey-based consultation with stakeholders. Usefulness of and accessibility to NNDSS data were also assessed using surveys. The three main stakeholder groups and the methods of consultation are described below.

Communicable Diseases Intelligence readership

A questionnaire was sent to all persons and organisations on the subscription list for *Communicable Diseases Intelligence*. The questionnaire was one page long and asked participants what their profession was, whether they use NNDSS, what they used it for, how they access the data and how easy it was to access the data. The self-administered questionnaire was distributed with a subscription renewal form for *CDI*. A postage paid envelope was included with each questionnaire.

Communicable Diseases Network Australia membership

A questionnaire was sent to selected members of the Communicable Diseases Network Australia. The survey contained quantitative and qualitative components. Participants were asked whether they use NNDSS, what they used it for, what they think the objectives of national surveillance should be and their opinions about the strengths and weaknesses of NNDSS. The members of CDNA surveyed were the Chair, the Jurisdiction Executive Group and representatives from OzFoodNet, the National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases (NCIRS) and the National Centre for HIV Epidemiology and Clinical Research (NCHECR). Each member was interviewed by telephone. Transcripts of the interviews were analysed for key themes. A qualitative approach was chosen for this group of stakeholders to obtain a richness in detail of participants' perspectives and opinions that quantitative methods alone could not achieve.

National Surveillance Committee membership

The National Surveillance Committee (NSC) is a sub-committee of CDNA and consists of jurisdictional epidemiologists and data managers and epidemiologists from the national centres (NCIRS, NCHECR and OzFoodNet). These people have frequent interactions with NNDSS as data providers and users. Two surveys were used in the stakeholder consultation of NSC: (a) a survey for the epidemiologists (n=11) and (b) a survey for the data managers (n=8). The surveys were sent via email and respondents were asked to complete the survey electronically. Descriptive analyses were performed on the quantitative results from the NSC survey and the qualitative components were analysed for key themes.

Results

The *CDI* questionnaire was sent to 2,167 subscribers and responses were received from 537 participants. Of the subscribers to whom *CDI* is sent, 901 are institutions (i.e. *CDI* is addressed to the institution rather than an individual) and we did not expect to receive a response from them. Overseas subscribers (n=262) were not surveyed. Therefore, the total number of people from whom we could expect a response was 1,004. The response rate for the *CDI* questionnaire was 53 per cent (537/1,004).

All of the CDNA members (12/12) participated in the survey, however, four (30%) members reported that they had not prepared because they were too busy. One member did not have time for a telephone interview and sent a completed handwritten survey. Over three-quarters of the NSC members (78%, 14/18) responded to the electronic questionnaire sent to them.

Objectives and utility

Objectives of the National Notifiable Diseases Surveillance System

The objectives of NNDSS were not clearly stated in the corporate records held by the DoHA. By deduction from current system functioning, the purpose of NNDSS is to monitor trends in disease incidence nationally to help understand the epidemiology of communicable diseases Australia-wide.

When NNDSS was being established, the Working Party on National Disease Surveillance drafted a list of objectives that a national communicable disease surveillance system should have.⁶ These were:

- control communicable diseases;
- alert state or territory health authorities to communicable disease episodes which require public health action across jurisdictional borders;
- coordinate national responses to disease threats; and
- act as a clearing house for the dissemination of information.

There were some differences of opinion amongst CDNA members about the objectives of a national surveillance system (Table 1). Most members thought the main objective would be to examine national trends in diseases. There were strong differences of opinion with regards to the role of NNDSS in outbreak detection, where seven members (58%) thought that national surveillance data should be used to detect outbreaks and four members (33%) thought national surveillance systems should not be used to detect outbreaks. There was recognition amongst some in this group (n=3) that NNDSS was not primarily designed to detect but to document outbreaks:

Table 1. Responses from Communicable Diseases Network Australia members on the objectives of a national surveillance system

| Objective | Number who listed objective (n=12) |
|--|------------------------------------|
| Examine national trends | 10 |
| Outbreak detection | 7 |
| Evaluation of interventions | 7 |
| Research | 3 |
| Meet international reporting obligations | 2 |

‘National surveillance can provide a global picture of an outbreak, but not actually identify outbreaks—that’s done at a public health unit level’

Some of the other objectives for NNDSS proposed by CDNA members include economic evaluation of disease control programs such as immunisation, informing the production of disease control guidelines and providing information to inform government spending.

Uses of National Notifiable Diseases Surveillance System data

The stakeholder surveys were the main sources of data used to judge the usefulness of NNDSS. Both CDNA members and NSC members mainly used NNDSS to examine national trends and to examine trends across each state and territory (Table 2). The jurisdictional members of CDNA reported that when examining trends in other states and territories, they usually compare the rate of disease in their jurisdiction with the national rate. Within the CDNA membership, there was an obvious spectrum of enthusiasm for using NNDSS data, where one member reported:

‘I feel ashamed to say it, but I don’t actually use it [NNDSS]’

Another member reported:

‘Yes, I use it [NNDSS] a lot...but we could do more with it, we could do a lot more with it’

Half of the CDNA members reported using NNDSS for general interest. This is an indirect indicator of engagement within the system. For example, ‘general interest’ describes the use of the system outside of work requirements.

Of the 537 people who responded to the *CDI* readership survey, 502 (94%) reported reading the quarterly reports of the surveillance highlights from NNDSS in *CDI*. Similarly, 502 (94%) reported reading the annual report of NNDSS. Eight-five per cent (n=454) of *CDI* readers reported using NNDSS data. The main use of NNDSS data to the *CDI* readership was general interest, followed by research (Table 3).

Of the 83 *CDI* readers who said they do not use NNDSS, nine (11%) reported they did not use NNDSS because it was too difficult to access, 22 (27%) were not aware that NNDSS data were available and 40 (48%) reported that NNDSS data were not relevant to them. The remaining 12 respondents who did not use NNDSS did not provide a reason.

In terms of guiding public health action, NNDSS data have been used mainly in the area of vaccine preventable diseases. For example, one of the CDNA members reported that the Meningococcal Vaccine Working Party and the Meningococcal Control Working Party used NNDSS data to inform policy advice for the recent introduction of the meningococcal C vaccine to the national immunisation schedule. The National Sexually Transmissible Infection Committee, the National Arbovirus and Malaria Advisory Committee, the National Tuberculosis Advisory Committee and other national expert committees also use data from NNDSS to inform policy and program decisions.

Table 2. Reported uses of National Notifiable Diseases Surveillance System by members of Communicable Diseases Network Australia and the National Surveillance Committee

| Uses of NNDSS | CDNA | NSC |
|--|------|-----|
| Monitor national trends | 11 | 11 |
| Examine trends in other states and territories | 10 | 10 |
| Research purposes | 7 | 8 |
| Policy development | 7 | 7 |
| Inform program management | 6 | 6 |
| General interest* | 6 | 6 |
| Outbreak detection | 4 | 4 |
| Other† | 2 | 3 |

* General interest is defined as using NNDSS outside of work requirements

† Other includes teaching purposes, media and evaluation of a public health intervention

Table 3. Uses of National Notifiable Diseases Surveillance System reported by *Communicable Diseases Intelligence* readership

| Use of NNDSS data | Number who use data | Percentage of all respondents |
|---------------------------|---------------------|-------------------------------|
| General interest | 317 | 59 |
| Research | 180 | 34 |
| Inform policy | 150 | 28 |
| Outbreak detection | 142 | 26 |
| Inform program management | 125 | 23 |
| Training and education | 55 | 10 |

Data from NNDSS are routinely sent to the National Centre for HIV Epidemiology and Clinical Research and the National Centre for Immunisations Research and Surveillance on a monthly basis. National data are also sent to OzFoodNet, but they often contact jurisdictions for additional data on foodborne diseases. Surveillance data on zoonotic diseases are sent to the Australian Government Department of Agriculture, Fisheries and Forestry every quarter.

Monthly data for 21 diseases are also sent to the Regional Electronic Surveillance System for Notifiable Diseases in the Western Pacific Region, maintained by the World Health Organization (WHO). NNDSS is used to help Australia meet its international reporting obligations. For example, each year WHO asks the Commonwealth to send data on tuberculosis notifications, treatment and control in Australia. This information is collated with data from the rest of the world and published in the annual *Global Tuberculosis Control: Surveillance, Planning and Financing* report.⁷ WHO also requests national data on leprosy, vaccine preventable diseases (e.g. polio) and quarantinable diseases (e.g. cholera, plague).

Health events under surveillance

In 2003, there were 57 communicable diseases under surveillance at a national level. AIDS and HIV data are collected, analysed, interpreted and disseminated by NCHECR.

The criteria used to determine whether a disease should be nationally notifiable are:⁸

- *Feasibility of collection:* The collection of data for the disease must be relatively simple to collect.
- *Priority:* There are diseases that are important at state and territory level, but the disease must have a demonstrated priority at a national level (i.e. disease affects most or all jurisdictions).

- *Immediacy of an intervention:* The disease requires an immediate response to prevent transmission through the community.
- *Outbreak potential of the disease:* The disease is prone to outbreaks that have a substantial burden on the community.
- *Potential for disease control programs:* The disease should be preventable through the implementation of control programs.
- *High-case fatality rate:* There is a high proportion of deaths from this disease relative to the number of cases of the disease.
- *Community or political concerns:* Some diseases may be of high concern to the community or the occurrence of the disease may have political implications.
- *International concern:* Diseases spread across international boundaries and it is important to recognise diseases that are a concern in the region.
- *Evaluation of programs:* Surveillance data can be used as a tool to evaluate existing and future communicable disease control programs.
- *Importance to Indigenous health:* Diseases that have an impact on the Indigenous communities throughout Australia should be under surveillance.

The list of nationally notifiable diseases has changed several times over the past 15 years. In 2003, the list of nationally notifiable diseases was changed to include severe acute respiratory syndrome (SARS), smallpox, tularaemia, syphilis (<2 years duration) and syphilis (>2 years duration or unknown). The general consensus from CDNA members was that the current list of nationally notifiable diseases was acceptable.

The case definitions for the nationally notifiable diseases were recently reviewed (2001 to 2003) by CDNA and are being phased in during 2004. The previous 1994 case definitions⁹ were not used uni-

formly by jurisdictions as there were some deviations because jurisdictions occasionally used their own case definitions. The recent consensus review of case definitions will lead to consistent reporting throughout Australia by early 2005.

System operation

Legislation

There is no legislative requirement for states and territories to send notifiable disease data to the Commonwealth and hence, NNDSS depends on the commitment and cooperation of CDNA. There are eight separate public health Acts in Australia and each jurisdiction has its own list of notifiable diseases and reporting channels for notification written into the Acts or the Regulations under the Acts. CDNA members have different opinions about the legislative status of NNDSS. Some members do not think the variation of public health Acts is a problem and others did not even mention legislation in the interview. However, other members consider it to be a significant obstacle, with members saying:

'We try to cobble together a national communicable disease system out of what is essentially eight colonies. We do very well considering we all have different public health acts'.

'[One of the main] weaknesses of NNDSS is its limited formal standing in Australia's legislative framework for public health'

Data sources

Data from jurisdictions are sent to the NNDSS database in a de-identified format. The jurisdictions receive their notifications from clinical sources (e.g. general practitioners and hospitals) and from laboratories (both public and privately funded) via paper, telephone and fax. Results from the NSC survey indicate that the majority of notifications in all jurisdictions come from laboratories. Clinical notifications are sometimes received for vaccine preventable diseases, vectorborne disease and invasive meningococcal disease. Population data for the calculation of crude notification rates comes from the Australian Bureau of Statistics.

Information collected

The system collects 25 data fields for each notification of the diseases under surveillance, where relevant (Box). To protect the confidentiality of people with notifiable diseases, the NNDSS database does not receive or record any identifying personal information. A unique notification ID is provided that can be used to trace a report back to a jurisdictional health department if more information is required.

Box. Data fields reported to National Notifiable Diseases Surveillance System

| |
|--|
| Jurisdiction —source of report |
| Notification ID —unique identifier |
| Disease code —code representing a communicable disease |
| Organism code —code that identifies a specific organism and serogroup/subtype where applicable |
| Organism name —a full text scientific name of the causative organism for the specified disease |
| Serogroup/subtype —a full test name of the causative serogroup/subtype for the specified disease |
| Confirmation status —whether a case is confirmed or probable according to the case definition |
| Laboratory diagnosis method —one or more diagnostic methods used |
| Vaccination status —vaccination status of the individual with the disease |
| Vaccination validation —how was the vaccination information validated? |
| Vaccine doses —the number of doses of relevant vaccine received by the individual at the time of disease onset |
| Resident postcode —permanent residential postcode of the individual |
| True onset date —the earliest estimated date of disease onset |
| Specimen date —date when the first laboratory specimen was taken or when it was logged into their computer system |
| Notification date —date when the health professional signed the notification form or the laboratory issued the results |
| Notification received date —date when the notification was received by the communicable diseases section of the state or territory health authority |
| Date of birth —the date of birth of the individual |
| Age at onset —the age of the individual at the date of onset |
| Sex —the current sex of the individual |
| Indigenous status —a single character field indicating the Indigenous status of the individual (Aboriginal, Torres Strait Islander, Aboriginal and Torres Strait Islander or non-Indigenous). |
| Died —did the patient die from the notifiable condition? |
| Outbreak reference —a reference ID for a known disease outbreak that is or has been under investigation |
| Case found by —how was the case identified? |
| Imported from overseas —whether the disease was believed to be acquired in another country |

The compulsory fields are jurisdiction, notification ID, disease code, resident postcode and notification received date. All other data fields are completed when the information is available.

The issue of how to record notifications of disease in persons not resident in the state or territory of disease acquisition is not clearly defined. The current provision in the data specifications is to record the postcode of residence of the case. However, this does not indicate the likely location of exposure leading to infection for diseases such as Ross River virus infection where people may visit endemic areas for recreational activities, become infected and then return home. This means that any spatial analysis of disease incidence may be misleading at the national level. The issue needs to be resolved so that location and source of infection can be appropriately assigned.

Transfer and management of information

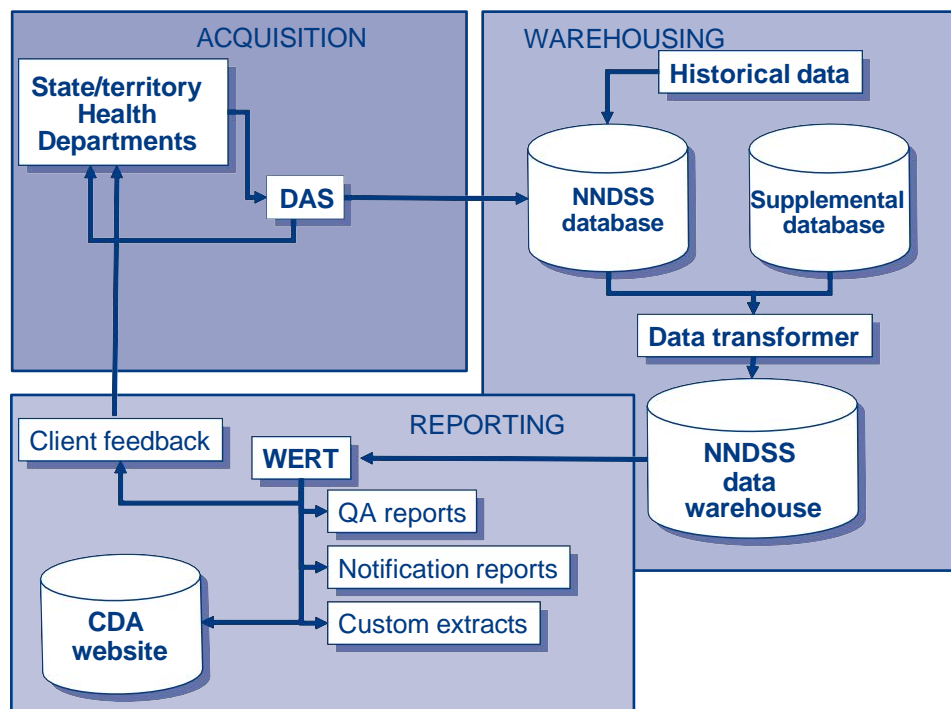
The NNDSS database has been under going an information technology redevelopment since 2000. The main aspect of redevelopment has been improving the national collation of data from jurisdictions to the Commonwealth and the subsequent 'warehousing' of data. In the past, data from the jurisdictions were sent in paper form, on diskette or electronically

and then entered into a Microsoft Access database. Since 2002, the jurisdictions and the DoHA have been working closely to implement the Data Acquisition System (DAS). An export facility was installed at the jurisdiction end and the DoHA end uses DAS to receive the data in a format that can be automatically loaded into the Microsoft Access NNDSS database.

When the DAS system is fully operational, the DoHA will acquire data on a daily basis. Four jurisdictions are currently (July 2004) transferring data daily and the remaining jurisdictions will be sending daily data before the end of 2004. Data constraints are set in DAS as a quality control measure to ensure that the data downloaded into NNDSS are valid. Updates (including notifications requiring deletion) of existing notification records can be sent at any time.

Data accepted via DAS are stored in the data warehouse. Population data loaded into the warehouse provide the denominator for automatic calculation of crude notification rates. Data can be extracted from the warehouse by each of the epidemiologists in the Surveillance Section of the Commonwealth health department using the Warehouse Extraction and Reporting Tool (WERT) to produce frequency tables and/or cross tabulations. The interaction between DAS, the data warehouse and WERT is given in Figure 1.

Figure 1. Components of the National Notifiable Diseases Surveillance System data



CDA Communicable Diseases Australia.

DAS Data Acquisition System.

NNDSS National Notifiable Diseases Surveillance System.

QA Quality Assurance.

WERT Warehouse Extraction and Reporting Tool.

The jurisdictional data managers were asked to comment on DAS in the NSC survey. Of the four data managers who participated, three were currently using DAS. These data managers reported that DAS has either made no change to the ease of operation (n=1) or has made it easier to send data to NNDSS (n=2). Two of the data managers reported that the process of changing over to DAS had been easy.

Analysis and interpretation of data

Data received from the jurisdictions are analysed by the Surveillance Section epidemiologists every fortnight. A table of the number of notifications received in the past fortnight and for the year to date (YTD) are listed for each jurisdiction and each disease. A national five-year mean of YTD notifications is also calculated for each disease. The current YTD notifications at a national level are compared against the five-year mean YTD +/- two standard deviations. Data are interpreted through the cooperation of the DoHA and jurisdictions through CDNA and the NSC.

Notification tables are published in each quarterly edition of *CDI*. Each jurisdiction is asked to comment on any outbreaks or communicable disease events in that quarter that warrant attention. The largest analysis conducted by the DoHA is done for the annual report of NNDSS. Each disease is examined in detail and the year's data are compared with historical data to determine if the epidemiology of the disease is changing. Maps showing the notification rates by Statistical Division are produced for selected diseases. Each year a surveillance survey is sent to all jurisdictions asking whether they have changed surveillance practices or implemented any disease control programs. The results from the survey enable DoHA epidemiologists to interpret the data held in NNDSS.

There are two major problems relating to the analysis of NNDSS data by the DoHA. Firstly, there has been a long history of disagreement between DoHA notification totals and jurisdictional notification totals. This usually results in a time consuming process of determining where the discrepancies might arise and trying to harmonise the data. In theory, the number of notifications should be the same. There is a requirement for state and territory data managers to have access to their own data located in the warehouse at DoHA.

The second major issue is that NNDSS data are not timely and not sufficiently detailed (e.g. serotype and phage type information is required for all *Salmonella* notifications) to detect multi-jurisdictional outbreaks. NNDSS data are published quarterly in tables and hence only serve as an historical record. This

issue was cited as a major flaw by six of the CDNA members. However, it was generally recognised by the members that a lack of epidemiologists within the Surveillance Section at the DoHA has been a major limitation in the past. Currently, there are four epidemiologists at the DoHA who have contact with NNDSS. There is a need for the DoHA to conduct regular analyses to determine possible multi-jurisdictional outbreaks for appropriate diseases.

Data analyses are conducted in response to requests from the public, research organisations or community groups. The DoHA can produce basic aggregated data and provide some interpretation of the data. Requests for more detailed information, such as a list of notifications for a certain disease must be approved by CDNA. This process protects the integrity and the confidentiality of the data.

Reporting procedures

The main reporting channels of NNDSS data are through *CDI* and the *Communicable Diseases Australia* (CDA) website. The main reports published in *CDI* are the quarterly surveillance reports and the annual report of NNDSS. In terms of reporting to jurisdictions at CDNA teleconferences, the DoHA provides a fortnightly table of notifications received from each state and territory and also provides brief commentary on disease activity. The report is then put on the CDA website for public access.

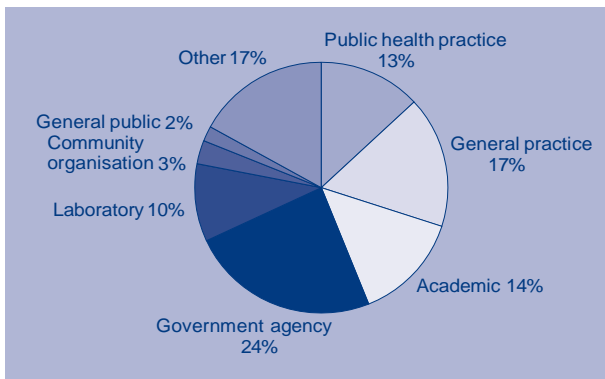
Dissemination of data

The main channels of dissemination are through the CDA website and *CDI*. The Commonwealth health department has produced *Communicable Diseases Intelligence* since 1976. *CDI* was originally published fortnightly as surveillance data with commentary, but changed to a monthly publication. Currently, *CDI* is published as a quarterly journal which also contains peer-reviewed articles on communicable diseases in Australia.

Results from the *CDI* survey suggest that *CDI* has a diverse readership. A quarter of the respondents were from government agencies and 17 per cent were from general practice (Figure 2). Some of the professions included in the 'other' category include, vaccine manufacturers, aged care facilities, health ethicists, private practitioners and infection control consultants.

The *CDI* readership were asked how they access NNDSS data. Of the 454 people who said they use NNDSS data, 451 (99%) reported using data published in *CDI*, 24 (5%) reported accessing the data through requests to the Commonwealth and 160 (35%) accessed NNDSS data through the CDA website. *CDI* readers reported that the easiest way

Figure 2. Profession of respondents to the Communicable Diseases Intelligence readership survey



for them to access NNDSS data was through the hard copy of *CDI* (Table 4). The CDA website, which was recently redeveloped, was reported as difficult to access. This is supported by some of the CDNA members who think that the CDA website should be redesigned to allow greater access to summary level data.

Flow of data through NNDSS

The structure and flow of data through NNDSS are shown in Figure 3. The flow of data starts from the person who presents to a health service when they are ill, to the state or territory health authority who then collates and verifies the data and responds to the report if required. The jurisdictions then send the data to the DoHA for inclusion into the nationally aggregated dataset. The data are analysed and interpreted and then disseminated through *CDI*, the CDA website and requests. CDNA provides the forum for jurisdictions and the Commonwealth, along with other institutions and stakeholders, to manage and discuss surveillance data. All levels of surveillance depicted in the flow diagram (Figure 3) represent networks of people (i.e. epidemiologists, data managers, data providers), infrastructure (i.e. offices, computers, telephones and faxes) and resources (i.e. funding).

Evaluation of system attributes

The evaluation of system attributes is a process that depends largely on the objectives of the system. Since NNDSS has no documented objectives, the evaluation of the attributes is relative to the current use of NNDSS and existing DoHA structures. Another complicating factor in evaluating the attributes of NNDSS is that there are differences in perceptions about NNDSS amongst the key stakeholders. For example, some people thought that NNDSS is just the database of notifications held at the Commonwealth. Others see NNDSS as the whole network of people and data systems that provide and/or use data to contribute to national biosecurity.

Simplicity

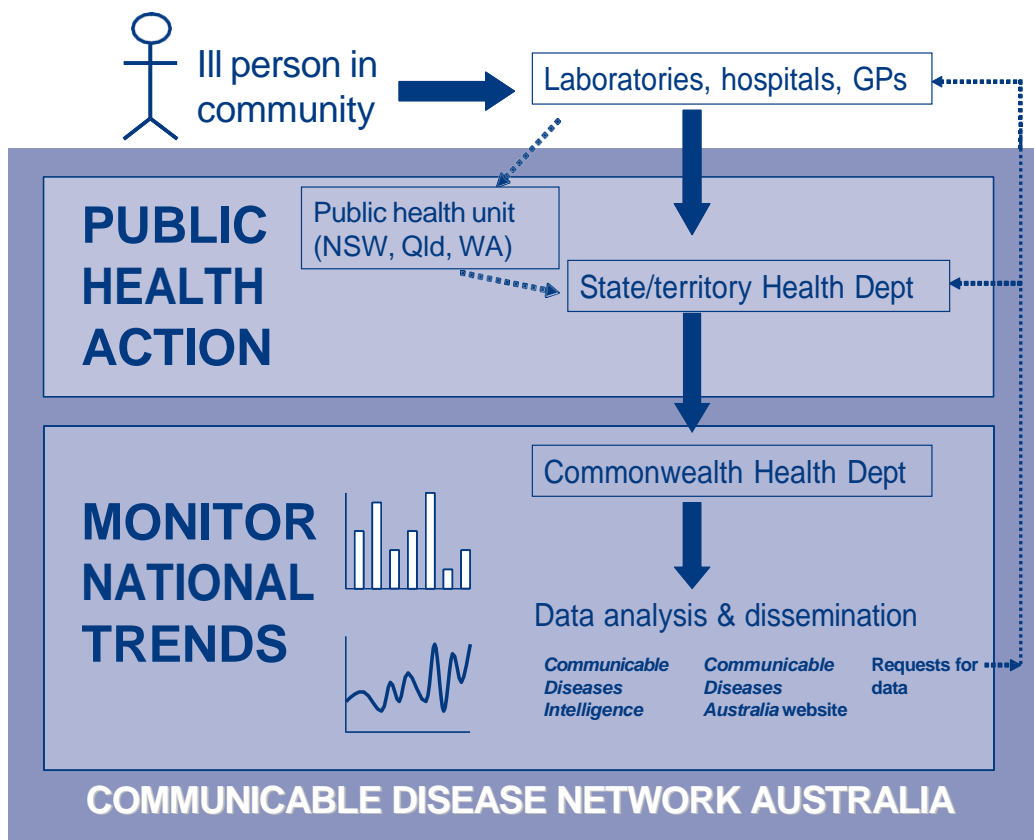
The structure of NNDSS is quite simple, as summarised in Figure 3. However, the operation and processes that govern NNDSS are complex and inefficient. Given that there are eight different jurisdictions which collect surveillance data in their own way, it has taken a long time to develop a standardised national database.

Data analysis procedures have been traditionally based in Microsoft (MS) Access, where standard queries have been written and used to extract the data into a MS Excel spreadsheet for the production of graphs. The process of analysis is currently under redevelopment. The Warehouse Extraction and Reporting Tool has the facility to extract data from the warehouse and import it into MS Excel. This feature will be used mainly for generating the standard tables in the *CDI* quarterly reports and other routine reporting (e.g. reports for expert committees). There will still be an ability to interrogate the NNDSS database using MS Access queries for ad hoc analyses.

Table 4. Accessibility of the three main forms of dissemination of National Notifiable Diseases Surveillance System data, Communicable Diseases Intelligence readership survey

| Form of NNDSS data | Accessibility (% respondents who reported using NNDSS data) | | |
|----------------------|--|---------|-----------|
| | Easy | Neutral | Difficult |
| <i>CDI</i> hard copy | 81 | 18 | 1 |
| CDA website | 65 | 30 | 5 |
| Request | 60 | 24 | 16 |

Figure 3. Structure and flow of data through National Notifiable Diseases Surveillance System



Flexibility

One of the main weaknesses of the NNDSS database is its inability to implement changes in national surveillance rapidly. Although a national surveillance system does not have to be flexible, there were still several areas where the inflexibility of the database resulted in significant delays to improvement within the system. Given the federated nature of governance in Australia, it will always be difficult for NNDSS to be flexible as any proposed changes to NNDSS have to rely on consensus of CDNA members.

The inflexibility of the system was highlighted with the recent revision of the case definitions. The case definitions have been under review for the past two years. The process has been driven by CDNA, but there have been prolonged negotiations over some of the case definitions, which has delayed the process. In addition, the revision of case definitions was a low priority during the SARS epidemic.

Data quality and completeness

The quality and completeness of data sent to NNDSS through DAS from 1 January to 28 May 2002 was examined. The main issues identified were the differences between jurisdictions in the use of the

names of specific organisms and their serogroup and subtype names, miscoded dates and ambiguity in the coding for unknowns for postcodes. Some data fields were not being reported at all, such as 'case found by' and 'imported from overseas'. One jurisdiction was using the outbreak reference data field, but this requires further development. One of the most poorly reported data fields was Indigenous status. There is a national effort attempting to resolve the poor reporting of Indigenous status in disease reporting through the *Improving Identification in Communicable Disease Reporting Project Steering Committee*.

Acceptability

One of the major strengths of NNDSS is its high level of acceptability. Despite the lack of a legislative requirement for jurisdictions to report to the Commonwealth and limited Commonwealth funding of jurisdiction surveillance activities, all states and territories participate in NNDSS. Participation was judged by the attendance of a jurisdictional representative at every CDNA teleconference and NSC teleconference and that each state and territory sends data to the DoHA at regular intervals. Acceptability also goes beyond jurisdictions, as members from key institutions and national centres are also active participants in NNDSS.

From the CDNA member survey, even though nearly every member reported being very busy, there was still an obvious engagement with the system and its value was recognised:

'In Australia, we have the continuing problem of federalism where we need to line up jurisdictional requirements for notification...problems in relation to communicable disease control are not that huge, as people are very cooperative.'

There was a wide spectrum of engagement in NNDSS. The main reason for less enthusiastic participation in NNDSS has been competition with other priorities within the jurisdiction. One member described the situation in that they are ultimately responsible to their state or territory Health Minister, not the federal Health Minister. One member described the situation:

'the issue that always comes up [with national surveillance] is, what are the state/territory's priorities and what are our resourcing levels?'

Representativeness

Given that all jurisdictions are participating in NNDSS, the entire population of Australia should be under surveillance. The representativeness of NNDSS will only ever be as good as the jurisdiction based surveillance activities. It is unlikely that NNDSS, like any other national surveillance system, will be fully representative. NNDSS does not have to be representative to be useful, but we must be aware of possible over-represented and under-represented populations. The main barrier to representativeness in Australia is geography. There are many communities living in remote and rural locations in Australia which are generally under-serviced in terms of access to health care.

Representativeness is also affected by the lack of uniformity in diagnostic and reporting practices by clinicians. For example, a person might go to their General Practitioner (GP) with gastrointestinal complaints. A GP in one area will ask for a stool sample for laboratory testing, which may lead to a notification, while a GP in another area will not take samples for testing and notification will not occur.

The Indigenous population in surveillance data is likely to be under-represented. This is due to complex socio-political factors associated with identification as an Indigenous person. The main issues are related to identification (i.e. self identifying or community acceptance) and whether there should be a requirement to ask people their Indigenous status.

Areas of better ascertainment in NNDSS are largely disease specific. For diseases that have screening programs in selected jurisdictions, the surveillance data are more reflective of the screening process and are biased towards more complete ascertainment of cases in subpopulations. For example, sexually transmissible infection screening amongst Indigenous people and screening for *Chlamydia* in people attending sexual health clinics will lead to more notifications because the health authorities are looking for the disease.

Timeliness

The timeliness of NNDSS will only be as good as the jurisdiction with the slowest reporting time to the system. An analysis presented in the *Report of the Communicable Disease Surveillance Project*¹⁰ suggested that from 1992–1998, the average number of days from onset of illness to notification to jurisdictions (for all diseases) was 18.1 days (ranging from an average delay of 12.3 days in Australian Capital Territory to 20.9 days in Victoria). There were further delays of up to a fortnight in jurisdictions sending data to DoHA. However, the introduction of DAS has meant that jurisdictions can now send daily updates. This will enable NNDSS to detect outbreaks, if the sensitivity is high enough for the diseases of interest and if the data are of high quality.

Stability

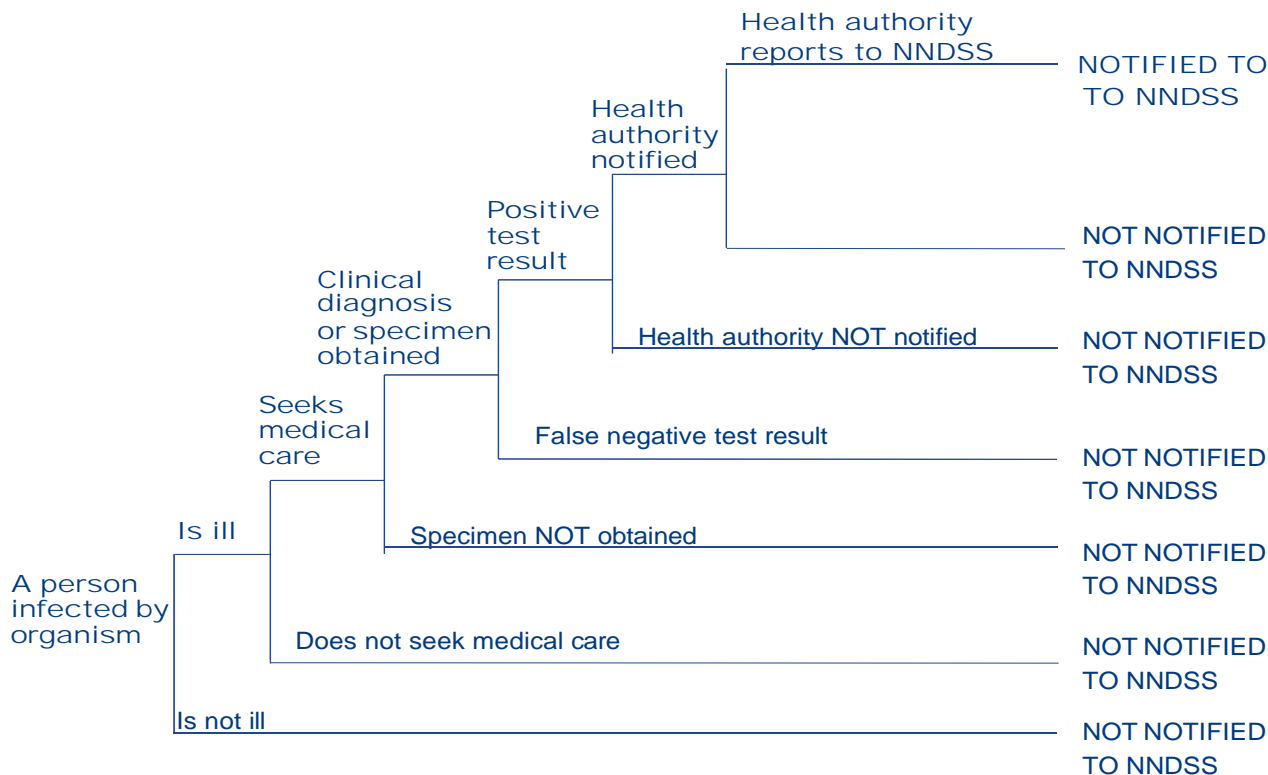
NNDSS is generally stable. Quarterly surveillance reports and annual reports are usually published on time. There have been periods in the past where annual reports have been several years out of date. The challenge is now for the DoHA to provide more frequent reports on disease activity at a national level. Epidemiologists at the DoHA can access NNDSS data whenever it's required.

Sensitivity

The sensitivity of NNDSS will vary across diseases and across jurisdictions. Figure 4 conceptualises the steps in surveillance that determine the fraction of cases that will be notified to NNDSS. The notification fraction will be different for each disease under surveillance. At a national level it is difficult to establish what proportion of true cases in the community are not notified.

Surveillance systems for most diseases do not have to detect every single case for the system to inform public health action. Varicella became notifiable in South Australia in January 2002 and sensitivity calculations indicate that only 4 per cent of cases were detected by the system.¹² Even with these data it is possible to gain sufficient information as a base line to monitor current and future trends.

Figure 4. Fraction of cases notified to National Notifiable Diseases Surveillance System ¹¹



Discussion

The new biosecurity environment has provided the impetus for this evaluation of NNDSS. Stakeholder interviews were structured to obtain qualitative and quantitative results, which provided essential insights into the functioning of Australia’s national communicable disease surveillance system. Although NNDSS has no clearly written objectives, there was universal agreement amongst stakeholders that the following points were being addressed through NNDSS:

- NNDSS provides a nationally coordinated surveillance system for notifiable communicable diseases;
- NNDSS is enmeshed in local, state, national and international public health practice;
- through CDNA and other key stakeholders, NNDSS collects and disseminates interpreted public health information to direct action at all levels of the health system.

NNDSS has been used to inform public health action, mainly in the area of vaccine preventable diseases. To have a greater impact on communicable disease control, the data from NNDSS has to be linked to

control activities. This can be done through setting national priority areas and using NNDSS to monitor progress towards controlling diseases that are priorities. The process of communicable disease control and surveillance prioritisation could be conducted through a review of the National Communicable Disease Surveillance Strategy.

The major strength of NNDSS lies in its universal acceptability by the stakeholders and its accepted role as the primary source of national communicable disease data. Members of CDNA are committed to participation in the system, but emphasised that jurisdictional priorities come first. NNDSS was also found to be stable and simple in structure.

The foundation of notification rests in the Australian Constitution, which gives the legislative power for notification to the states and territories. Therefore, any changes to notification parameters and mechanisms require consensus from CDNA. NNDSS was found to be inflexible to rapid change and was not timely. The issue of timeliness was strongly related to whether NNDSS should be used to detect national outbreaks. There was disagreement among stakeholders about whether this should be an objective of NNDSS. If the DoHA is moving towards the daily updates of notification data from the jurisdictions, then there is no reason why, with

the appropriate information technology support, that cluster analyses and mapping cannot be conducted at a national level. Data completeness and quality will also have to be addressed for valid analyses to be conducted.

The evaluation of NNDSS had several limitations. Firstly, there was some selection bias when choosing the stakeholders to be included in the consultation. The stakeholder consultation should have included every member of CDNA, not just the jurisdictions and representatives from the national centres. Major public health laboratories should have also been included in the stakeholder consultation. Secondly, there was a poor response to the data managers survey. It would be valuable to know the barriers to participation amongst the data managers. Thirdly, the consultation process did not include all stakeholders from within the Commonwealth. However, the use of NNDSS data by Commonwealth Sections and/or expert technical committees was included in the evaluation.

In summary, NNDSS is a highly valued and important source of information on communicable disease activity in Australia. The system has undergone significant change over the past few years to improve its functioning. With the recent federal funding for biosecurity, the opportunity exists to improve NNDSS to enable it to meet its full potential within the existing federated framework of disease surveillance and control in Australia.

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