Program for Enhanced Population Health Infostructure (PEPHI)

A report of responses to the November 2000 discussion paper

NSW DEPARTMENT OF HEALTH

NSW⊕HEALTH
Working as a Team

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Summary and recommendations

In November 2000, the *Program for Enhanced Population Health Infostructure (PEPHI) Discussion Paper* was distributed both internally and externally throughout the NSW public health system. Thank you to all those who provided responses. A summary of the distribution strategy appears at the end of this document, along with a list of organisations that responded.

This report of the responses to that discussion paper includes the text of the original discussion paper, and begins with a summary of responses and recommendations. An abbreviated list of the responses has been incorporated into the main body of the report against each discussion point. The summary incorporates comments received between December 2000 and February 2001.

The glossary in this report briefly describes the principal terms referred to.

Further responses are welcome and encouraged, both to the original discussion paper and to this report. Details of how to provide further responses are provided in Chapter 6.

Many of the issues raised in the responses are beyond the direct control of the Epidemiology and Surveillance Branch. However, under PEPHI, the staff of the Epidemiology and Surveillance Branch can, where appropriate, provide support in steering information developments in a direction that improves access to information about population health. Recommendations, therefore, relate to specific activities under PEPHI, as well as to less specific support roles.

INFORMATION RESOURCES AND DATA COLLECTIONS

The existing resources and data collections produced by the Epidemiology and Surveillance Branch appeared to be well utilised by respondents. These resources were complemented by national resources, and by more local resources where available.

The Commonwealth HealthWIZ product is the only product comparable to the Health Outcomes and Information Statistical Toolkit (HOIST) facility available in New South Wales. HealthWIZ has advantages in that is publicly available and has an integrated environment that does not require programming ability. However, its use in NSW is limited by delays in data being made available, and by the inability to analyse data at the area health service level. HealthWIZ requires a strong degree of skill in using the product and in interpreting the results. The timeliness of HealthWIZ may improve in the future, with national efforts to standardise and streamline the process of incorporating new data into HealthWIZ. Also, the capacity to analyse by NSW area health services will be available in a subsequent release.

A large number of data collections were suggested as being potentially useful for population health-related statistical reporting. There was strong interest in resources and data collections that extend outside typical 'health' publications and collections, particularly those relating to the concept of 'social capital'. Examples include crime, transport, and social security statistics.

There were requests to increase the availability of linked data between collections. Data linkage currently requires NSW Department of Health Ethics Committee approval and is labour intensive; therefore, linkage projects are limited. Also, the Automatch linkage software currently used is no longer in production and is becoming obsolete. The advent

of universal patient identifiers in the future in NSW will facilitate a higher volume of data linkage. There remains a need, however, to continue performing ad hoc data linkage; and an opportunity exists to develop data linkage software using up-to-date software methodologies.

Respondents reported a strong demand for data on local and smaller areas in NSW, as well as improved availability of information on selected populations, such as indigenous people and people from non-English speaking backgrounds. The variables to conduct these analyses are generally available in data collections. However, the pitfalls of small-area analysis, such as changing boundaries and information privacy considerations—as well as the high volume of analyses that would be required for the almost 200 local government areas in NSW—has prevented widespread availability of information at these levels. Data quality concerns, and the sensitivity of information on selected populations, have also presented barriers to greater information availability. Under PEPHI, greater automation of information analysis and the development of vehicles for making small area data more widely available are envisaged. The National Public Health Information Development Plan project to develop best practice guidelines for small area data analysis, which is being conducted under PEPHI, will assist this process greatly. In relation to selected populations, concerns about data quality and sensitivities about information are beyond the direct control of PEPHI; however, involvement and support for information initiatives at the Departmental level can be continued.

Recommendations

- Prioritise and initiate the acquisition of additional data collections, to increase the scope of population health-related data in HOIST.

- Support the ongoing development of the Commonwealth HealthWIZ product and provide support in streamlining the dataset release process.

- Initiate a project to develop low-cost and flexible probabilistic data linkage software that has wide health-related application.

- Where appropriate, facilitate, implement, and support information developments that provide statistical information on small areas, and for selected populations.

PRINTED PUBLICATIONS

There was an overwhelming demand for continued production of printed copies of reports. This would provide access to that section of the market that lacks the resources or training required to obtain electronic documents. While Acrobat Reader software is now almost universally available to Internet users, and while PDF files provide a useful means of distributing high-quality electronic documents, larger documents can be unwieldy to print or colour printers may be required.

Recommendations

- Always generate an Acrobat PDF version of electronic reports and make it available on Health Net and Health Web.

- Publicise available documents through both electronic and non-electronic means.

- Investigate mechanisms for providing printed copies of electronic documents on order, such as through the Better Health Centre. This mechanism may extend

to providing small area population health reports based on standard templates, when available.

EASY-TO-USE INTERACTIVE ANALYSIS AND REPORTING

There is a strong demand for such facilities and the demand extends outside the NSW public health system. It was initially planned that any interactive facilities would only be available within the NSW public health system. Because users would not have access to the underlying unit record data (microdata) through such facilities, if properly designed and tested, there should not be a barrier to wider availability. It would be wise to implement the systems internally, within the NSW public health system, for an initial settling-in period. Appropriate standards covering metadata, privacy and confidentiality, statistical methodology, and interpretation must be incorporated into such a system.

A large number of suggestions were made about the functionality and the qualities of such systems and these can be taken into account in their development.

Recommendations

- Develop standards for the systems incorporating usability, metadata, privacy and confidentiality, statistical methodology, and interpretation for such systems.

- Trial the systems initially within the NSW public health system.

- After a period of settling-in and testing consider whether access could be extended outside the NSW public health system.

HEALTH OUTCOMES AND INFORMATION STATISTICAL TOOLKIT (HOIST)

There is continued strong demand for availability of the HOIST system, although several barriers to its use were identified. Demand extends outside the NSW public health system into other NSW government departments and non-government organisations. One of the main difficulties is information privacy, for which there are clear responsibilities for employees of the NSW public health system but not for people outside of that system. Some of the external demand may be able to be met by other products such as the interactive facilities and the Commonwealth HealthWIZ product described above.

Recently, Business Objects software was selected as the reporting tool for the NSW Health Information Exchange (HIE). It is anticipated that Business Objects will be available for use throughout the NSW public health system. As well as providing report generation capacity, it also provides Web-based infrastructure for widespread delivery of reports and report generation capacity to end users within the public health system. Business Objects is also flexible in the data sources it can utilise, and is not restricted to use with the HIE. A worthwhile PEPHI project would be to develop reporting capacity for HOIST data collections through Business Objects, to meet many of the simple population health reporting needs of the NSW health system. However, it will not meet the needs of users who require sophisticated statistical analyses.

The message that the need for SAS programming ability is a major barrier to using HOIST came through strongly. Ways of managing this issue include developing alternative methods of access to HOIST data, and offering a HOIST training course. Many of the analysis and reporting developments already described will help this process, but there is also scope for making HOIST data available to other, more user-friendly, statistical analysis software. One of the main barriers to this is the need to have a SAS software licence to be able to extract data from HOIST for use in other packages, although the number of SAS licences required might be reduced if HOIST was used in this way. Users would then only need to know enough SAS programming to be able to

subset and export data. SAS Enterprise Guide is a product marketed by the SAS Institute that aims to provide a user-friendly, non-programming interface for SAS analysis. This should be investigated as a possible alternative.

Recommendations

- Develop a HOIST training course.
- Participate in the Business Objects implementation process at both the Department of Health and area health service level to ensure the needs of users of population health information are met.
- Develop population health reporting capabilities through the Business Objects initiative.
- Develop a plan to meet the needs of HOIST users who do not have the time or capacity to learn SAS programming, but who have the data analysis skills to use alternative products.
- Evaluate SAS Enterprise Guide as a user-friendly alternative to the traditional SAS interface.

FACILITIES FOR LOCATING POPULATION HEALTH INFORMATION

Web-based search facilities were the most popular methods for information searching among respondents. A structured search facility that incorporated an index and standard thesaurus was the most popular choice, followed by the Clinical Information Access Project (CIAP), followed by standard Web text search engines. These options are not mutually exclusive. CIAP is a Web-based bibliographic and clinical information support resource available within the NSW public health system, which appears to be popular among Departmental, area health service, and clinical staff. It would provide an ideal vehicle for an indexed search facility for population health information. Incorporation of a population health resource into CIAP would promote a population health perspective to information users throughout the system.

EXTENSION OF CIAP AND INTRANET SERVICES OUTSIDE THE NSW PUBLIC HEALTH SYSTEM

Several respondents raised the issue of making the Clinical Information Access Project (CIAP) and the NSW Department of Health Intranet (Health Net) available to non-government organisations, such as divisions of general practice. While these issues are outside the direct control of the Epidemiology and Surveillance Branch, PEPHI can play a role in advising on policy on information dissemination. However, CIAP is a commercial product, and extension of the service to private general practitioners (GPs) would interfere with the commercial relationship between the supplier of CIAP and GPs. GPs who are also visiting medical officers, or who have other formal roles within area health services, do have access to CIAP.

There was a perception from some respondents that the Intranet content should be more widely available: for example, to non-government organisations and other government departments. Health Net is a secure environment for officers of the public health system and some content is not appropriate for external organisations. One solution would be to develop an 'extranet' (see glossary) that permits authorised individuals or oganisations outside the NSW public health system to view selected content. A simpler solution, however, would be to establish clear criteria for when restricted—that is, Intranet only—access is required, allowing all other information products to be made publicly available.

Recommendation

- Establish a set of criteria on which to base publishing decisions for products of the Epidemiology and Surveillance Branch.

- Support NSW Department of Health information developments, where appropriate, which increase access to information for individuals and organisations outside the NSW public health system.

- Establish a population health link within CIAP.

GOALS OF PEPHI

A number of respondents highlighted what they perceived to be shortcomings in the goals expressed for PEPHI. Some academic, non-government, and professional organisations—as well as other government departments—expressed the view that they are neglected by the PEPHI strategy. This may reflect past difficulties in obtaining information. There is also a certain level of complexity for academics and postgraduate students who work closely with the public health system but who are unable to access information systems such as HOIST because they are not directly employed by the health system. For example: non-government organisations also believe they could benefit from access to HOIST. As described above, there are legal problems relating to general HOIST access, although external organisations and individuals can apply for specific datasets by writing to the Chief Health Officer. Many of the recommendations already described should improve access to information for these organisations.

Some area health service respondents suggested that many staff working at the local area level do not have the resources or expertise to utilise some of the more sophisticated information developments. All PEPHI developments aim to be user-friendly and to address current information gaps. The lack of an information culture in the NSW health system is recognised in the NSW Government's Action Plan for Health (GAP) initiative, and policies are currently being developed to increase information management and technology skills of NSW healthcare workers.

MAIN STRATEGIES

A small number of respondents indicated a yes or no response to the discussion question on the adequacy of the strategies. The majority of these responses were negative, although it might be reasonable to assume that those who did not indicate a response considered the strategies adequate. A large number of alternative strategies were proposed by respondents. Many of these comments related to specific requirements rather than broad strategies. Where possible, these comments will be taken into account when developing PEPHI initiatives.

INFORMATION GAPS AND PROJECTS

A range of information gaps were mentioned. Again many of these were very specific and it is hoped that the proposed developments will improve access to the kinds of information mentioned. Other types of information such as biomedical risk factors, community health, indicator development, and social determinants of health, are being addressed through national, departmental, and Epidemiology and Surveillance Branch initiatives. PEPHI infrastructure developments should better facilitate the delivery of these kinds of information to 'end users' once these developments are in place.

It is clear that access to a greater range of data sources would be beneficial to many, particularly data on social aspects of health. Under PEPHI, support of HOIST will increase and where possible the range of data collections expanded. Unlike many data collections in HOIST, the collections of interest are held outside of the NSW Department of Health. It should be recognised that making each new external data collection

available requires substantial development work, including identifying and locating data sources, negotiating with custodians, and overcoming substantial bureaucratic hurdles. This means that new data collections do not appear quickly.

Many of the proposed information facilities are restricted to Intranet (Health Net) facilities at present, yet there is a strong external demand for these. To make these facilities available on the public Internet (Health Web) site could compromise the privacy of people about whom the information relates, because of the possibility of reporting on small numbers of people or communities. Staff of the public health system are covered by a range of legislation and policies that protect against misuse of information. For example, before being granted access to the data, HOIST users are required to sign a confidentiality agreement that draws their attention to these legislative requirements. Such legislative protection is not available for public access facilities, and is difficult to police. Automation of privacy protection in reporting systems is technically difficult, with a trade-off between flexibility of reporting and sophistication in privacy protection. We are currently looking for solutions to this difficulty.

There were no major criticisms of the PEPHI proposal or proposed projects. Many additional useful projects were suggested, and these will be considered as PEPHI proceeds.

CONCLUSION

There is a strong demand for population health information both within and without the NSW public health system. Much would be achieved by making information that is already available more visible to potential users. It is essential to maintain a mechanism for providing printed publications or reports to those consumers who have limited computing resources. Expanding the range of data collections available through HOIST, particularly those that describe social determinants of health, would be valuable. Making HOIST data more accessible—through providing training in the uses of HOIST, and a user friendly means of obtaining analyses from HOIST—would meet other needs. Finally, it is important to monitor the quality and relevance of PEPHI developments, to ensure that these needs are being met and that PEPHI is meeting its goals.

1. About this report

This report summarises the responses to a discussion paper released in November 2000, which introduced the NSW Department of Health's Program for Enhanced Population Health Infostructure (PEPHI). The report also promotes and encourages further discussion about PEPHI. The program comprises a series of projects to improve access to—and analysis and reporting of—population health information in NSW. The program has been funded through the National Health Development Fund of the Commonwealth Department of Health and Aged Care.

Useful and meaningful information about the health of people living in the community is central to providing health services and other public health interventions that meet community needs. The health information referred to here include: statistical information describing the health and disease status of people living in the community, the health services used by these people, and the outcomes of those health services.

The way information is used is important in determining the value of an information collection, and is central to the evaluation of information collections. Only through being extensively used can information collections improve. Further, it is important to provide information in ways that are accessible and meaningful to those who use it, and attractive to those who are considering using it.

Several PEPHI projects are considered by the Public Health Division of the NSW Department of Health as an immediate priority, and will contribute to the infrastructure for later projects to be completed under PEPHI. Other projects are evolving and, along with advice from the PEPHI Steering Committee, input from interested individuals and organisations will help guide their development. The PEPHI discussion paper was intended to describe and promote discussion on the proposed developments. This report is intended to report that discussion, and to promote and encourage further discussion on the proposed developments.

Questions to promote further discussion and prompt a structured reply are included in each section of this report. We would appreciate any additional or ongoing comments on the discussion questions, and any other comments you may wish to add.

Further details about how to respond are given in Chapter 6.

2. Glossary

Automatch　　　　A commercial computer program that allows more than one data collection to be linked together by matching identifying or partially identifying information contained within each collection. The matching process is probabilistic: that is, non-exact matches can be accepted or rejected based on likelihood criteria specified by the user.

Business Objects　A computer program that permits reporting of information contained in many different kinds of data bases. Users can do their own analysis or choose from pre-prepared reports already published within the Business Objects environment. It provides a uniform approach to analysing and reporting from almost any data source. Its inbuilt statistical capabilities are limited when compared with other products such as SAS software.

Data warehouse　A large database or series of databases in which current and historical data are organised according to subject area rather than source and stored in a consistent manner.

Extranet　　　　A protected network facility that functions like the Internet, but services authorised 'outside' users only. Internet is defined below. An extranet can be used for confidential network communications with external people that an organisation deals with but who are not employed by the organisation.

HealthWIZ　　　A computer program published by the Commonwealth Department of Health and Aged Care that provides interactive statistical analysis of a range of health-related data collections.

HIE　　　　　　Health Information Exchange, a data warehouse that will eventually store the majority of data collected and/or used by NSW Health.

HOIST　　　　The Health Outcomes and Information Statistical Toolkit offers access to, and statistical analysis of, a range of data collections via the NSW Department of Health's Intranet network (Health Net). HOIST is a powerful and completely flexible facility designed for use by data analysts who have some familiarity with the SAS programming language.

Internet　　　　A world-wide network of computers that have information stored in a way that can be accessed by any member of the public with suitable computer equipment and computer programs. The NSW Department of Health's Internet site is referred to as Health Web.

Intranet　　　　The same principle as the Internet, except that access to the information is restricted to people within an organisation. The NSW Department of Health's Intranet site is referred to as Health Net.

NGO　　　　　Non-government organisation.

SAS　　　　　A computer program that permits sophisticated statistical analysis of data collections. It also provides data warehousing capabilities to permit multiple data collections to be organised and stored in a consistent way. SAS is the underlying computer software from which the HOIST facility was developed.

Search Engine   A type of Web site on an Internet or Intranet that allows you to enter free text or more sophisticated text searching strategies to help locate a Web site or Web address that has the information you are looking for.

Web address   Every Web site, and every item of information stored in a Web site, has an address so that it can be found by other computers through the Internet or Intranet. Also known as a Universal Resource Locator (URL).

Web browser   A computer program, such as Netscape Navigator or Microsoft Internet Explorer, which is designed for looking at Web sites.

Web page   Information available on a Web site is typically organised into units called Web pages. Every Web page has a Web address (or URL).

Web site   A collection of information stored on a computer that can be accessed using the Internet or Intranet.

3. Introduction

3.1   About PEPHI

The NSW Department of Health has been funded by the Commonwealth Department of Health and Aged Care to develop practical mechanisms and processes for improving reporting of and access to population health information. Many of the improvements build on the existing strategy for population health surveillance in NSW.[1]

Although some of this development will necessarily be specific to NSW data sources and resources, all of the methods, software and other intellectual capital developed as part of this project will be made available nationally and to other states and territories as they are developed.

There have been a number of developments that have contributed to a greater emphasis on developing population health information:

- recognition of the importance of availability and access to information in several NSW strategies including the Government Action Plan for Health, the NSW Department of Health Corporate Plan 1999, Strategic Directions for Health 1998–2003, and the NSW Department of Health Information Management Strategy 1999–2002;

- the National Public Health Information Development Plan,[2] which is a national plan of action to improve information on population health in Australia;

- development of health-specific data warehouses such as the NSW Department of Health's Information Exchange (HIE);

- commencement of a process for developing performance indicators for public health for national reporting through the National Public Health Performance Committee and National Public Health Partnership Joint Taskforce on Performance (POPTOP).

3.2   Existing resources and reporting methods

The main population health information resources used in NSW, and the methods available for accessing them, are shown in Table 1. This table includes resources suggested by respondents to the discussion paper. Many of these resources are used by area health service staff, who may also use additional local information and data resources.

POINTS FOR DISCUSSION IN SECTION 3.2, ASKED OF ORIGINAL RESPONDENTS

1. **Are there other resources that should be added to this list?**

   ♦ Respondents' suggestions were added to Table 1. Suggestions with insufficient information to provide specific references were excluded.

2. **Which of the existing resources and access methods do you find most useful? Why?**

   ♦ National Minimum Dataset on Alcohol and Other Drug Treatment Services (AIHW); NSW methadone treatment data; National Drug Strategy Household Survey; NDARC Illicit Drug Reporting System and other NDARC reports.

Table 1

Main population health information resources in NSW

Resource	Methods of access
Health Outcomes Information and Statistical Toolkit (HOIST) using the SAS computer	SAS statistical analysis software programming language
The Health of the People of NSW —Report of the Chief Health Officer	Public printed book Public Internet Public health system Intranet
NSW Mothers and Babies Report supplement (including the NSW Birth Defects Register Report)	Public printed book–journal Public Internet Public health system Intranet
NSW Health Survey Electronic Report	Public Internet Public health system Intranet
NSW Public Health Bulletin	Public printed journal Public Internet Public health system Intranet
NSW Area Health Service Health Status Profiles	Public health system Intranet
1996 Census Basic Community Profiles	Public health system Intranet
1996 Census Indigenous Profiles	Public health system Intranet
1996 Census Socioeconomic Indices for Areas (SEIFA)	Public health system Intranet
Reports from the NSW Cancer Council's NSW Cancer Registry and Cancer Epidemiology Research Unit	Public printed books Public Internet
Reports from the Australian Institute of Health and Welfare	Public printed books Public Internet
Australian Bureau of Statistics publications	Public printed books Information consultancy
Reports of the Australian School Students Alcohol and Drug Survey	Public Internet Public printed books
National Drug Strategy Household Survey Reports	Public printed books Public Internet
National Centre in HIV epidemiology and clinical research reports on HIV–AIDS, sexually transmitted diseases	Public printed books Public Internet
Communicable Diseases Intelligence reports of the Commonwealth Department of Health and Aged Care	Public printed books Public Internet
National Occupational Health and Safety Commission workers compensation data, work-related fatalities and mesothelioma register: reports and interactive systems analysis	Public printed books Public Internet reports Public Internet interactive
Other suggested resources	**Methods of access**
Australian Council on Healthcare Standards clinical indicators	Printed book Public Internet

Table 1

Main population health information resources in NSW, continued

Resource	Methods of access
Centre for Health Economics Research and Evaluation	Public printed books Public Internet
Commonwealth Department of Health and Aged Care: General Practice in Australia, Medicare Statistics	Printed book Public Internet
Family Medicine Research Centre SAND–BEACH project	
Health Insurance Commission (HIC) Internet-based statistical analyses and static reports; Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), Australian Childhood Immunisation Register (ACIR), Practice Incentives Program (PIP)	Public Internet
Health Services Research Group (University of Newcastle)	Public Internet
HealthWIZ interactive analysis and reporting facility	Public CD-ROM
National Coronial Information System (anticipated)	
National Drug and Alcohol Research Centre reports such as drug overdose deaths for NSW, annual survey of Injecting Drug Users etc	
National Health Priority Area Reports of the Commonwealth Department of Health and Aged Care	Public printed books Public Internet
National Injury Surveillance Unit (Research Centre for Injury Studies, Flinders University) publications	Public Internet Public printed books
National Survey of Mental Health and Wellbeing Reports	Printed books
NSW Bureau of Crime Statistics and Research Bulletins	
NSW Corrections Health 2001 Inmates Health Survey	
NSW Dust Diseases Board reports	Public printed books Public Internet
NSW Hospital Comparisons Book	Printed book Public Internet
NSW Pap Test Registry–Cervical Screening program and BreastScreen program profiles	
NSW Schools Fitness and Physical Activity Survey 1997 report	Printed book
Quality Framework Indicators for NSW	Printed report
Women's Health Australia—The Australian Longitudinal Study on Women's Health	Public Internet
WorkCover NSW Statistical Bulletins	Public printed books Public Internet

The Internet is most useful for accessing data, particularly if a site permits access to specific and relevant information (for example data for a particular year of interest).

♦ Public Internet access minimises delay in receiving the information and is useful if information can be selectively downloaded. Drawbacks can be out-of-date information, slowness of downloads, reports that are too big to download.

♦ NSW Mothers and Babies Reports, Area Health Status Profiles, National Drug Strategy Household Survey Reports—for demographic profiles.

♦ AIHW and ABS Internet sites best for big picture information.

♦ NSW Department of Health Intranet–Internet (quicker).

♦ Basic population health data for service planning.

♦ AIHW, ABS and Commonwealth Department of Health and Aged Care reports for a national view.

♦ ABS census data and HOIST for small data, printed and Web sources.

♦ HealthWIZ, AIHW, ABS, and NSW Department of Health data because of range and accuracy.

♦ *NSW Public Health Bulletin* for emerging issues, Report of the Chief Health Officer for recent data on health priorities, AIHW reports for health determinants, and ABS publications for a wide variety of information.

♦ HOIST and CDATA96.

♦ Report of the Chief Health Officer and the NSW Health Survey Electronic Report for easy access to summary information.

♦ HOIST, CHO Report, NSW Health Survey Report, *NSW Public Health Bulletin*, ABS Reports.

♦ ABS data is easy to access, reliable, and timely

♦ NSW Area Health Status Profiles for sexually transmitted infections.

♦ National Centre for HIV Epidemiology and Clinical Research.

♦ The Internet is easy to use and convenient, flexible and accessible.

♦ Books and journals often have better quality graphics.

♦ AIHW, National Health Priority Area Reports, and Centre for Health Economics Research and Evaluation reports are useful for a national perspective on health needs and services and development and evaluation of health policies and programs.

♦ ABS Census (including SEIFA socioeconomic indices), NSW Health Survey, Report of the Chief Health Officer, and NSW Cancer Council reports are useful for state and local perspectives on health service development needs.

♦ HOIST mortality and inpatient data for ad hoc analysis requirements.

♦ HOIST brings together health and population information.

♦ CHO Report to compare area health services and define indicators.

♦ *NSW Public Health Bulletin* for communicable disease reports.

♦ Note that the Area Health Service Profiles contain inaccuracies and do not always agree with information in the CHO Report.

♦ The South Western Sydney Area Health Service Epidemiology Profile is excellent.

♦ Census data for planning local services, especially at the local government area and postcode level.

♦ HIC data provides private sector general practice patterns.

♦ All.

3.3   Data collections

The main data collections that can be used for population health analysis and reporting and which are available or which may become available in NSW are listed in Table 2, which includes collections suggested by respondents to the discussion paper.

POINTS FOR DISCUSSION IN SECTION 3.3, ASKED OF ORIGINAL RESPONDENTS

3. **Are there other collections that might be useful? What are they and why?**

    ♦ Respondents' suggestions were added to Table 2.

4. **Can you suggest any modifications to these collections that would improve their usefulness for population health reporting?**

    ♦ A metadata facility for easily obtaining information about each collection; purpose, methodology, available outputs.

    ♦ Improve coverage of survey data, facilitate sharing of data between jurisdictions and provide a basis for establishing agreed minimum survey data requirements.

    ♦ Promote probabilistic record linkage of program-based administrative collections.

    ♦ Standardisation of the instruments used to measure socioeconomic status or disadvantage in all population-based health surveys.

    ♦ Evaluate data collections for usefulness, for example, measurement of readmissions or emergency department presentation following inappropriate earlier discharge.

    ♦ Involve a health economist in reviewing data collections to evaluate how data collections could be made more useful for isolating cost-intensive factors and causes.

    ♦ Suggested additions to NSW Health Survey:

        ♦ Duration of exclusive breastfeeding

        ♦ Food security

        ♦ Use of nutrient fortified foods

        ♦ Levels of physical activity across various age groups within the population

    ♦ Increase data linkage.

    ♦ More validation studies of the collections.

    ♦ Reporting of Mothers & Babies, Health Status Profiles, and National Drug Strategy Household Survey reports at the LGA level would be more useful.

    ♦ Population counts by age by sex by indigenous status plus socioeconomic status at the Census Collection District level would be useful in the Far West Area for health planning.

    ♦ More local level data with indigenous status for smaller and remote areas.

    ♦ Need community demographic and health profiles at LGA and sub-LGA level for service planning particularly for co-location of Ambulance Services and Multi-Purpose Services.

    ♦ Linkage of the NSW Neonatal and Paediatric Emergency Transport Service collection to NICUS or the MDC.

    ♦ Extend the EDDC to more hospitals, particularly those in rural areas.

Table 2

Main data collections available for population health information analysis and reporting in NSW

NSW Health Surveys

NSW Inpatient Statistics Collection (ISC)

NSW Emergency Department Data Collection (EDDC): Only collected at larger hospitals.

NSW Central Cancer Registry (cancer incidence and deaths)

NSW Midwives Data Collection (MDC)

NSW Birth Defect Register (BDR)

NSW Notifiable Diseases Database (NDD)

NSW HIV–AIDS Register

Save our Kids Smiles (SOKS) oral health collection

Police Record of Death (PROD)

Medicare and Pharmaceutical Benefits Scheme data

Australian Childhood Immunisation Register (ACIR)

NSW Environmental Protection Authority air monitoring collections

National Occupational Health and Safety Commission Mesothelioma Register

Sydney and Hunter Water Corporations water quality collections

NSW Department of Analytical Laboratories data collections

National Coronial Information System

ABS cause of death data collection

ABS census information and estimated resident populations

ABS National Health Survey and National Nutrition Survey

ABS National Survey of Mental Health and Wellbeing

Other suggested data collections	Why?
Illicit Drug Reporting System (NDARC) National Drug Strategy Household Survey Methadone client data	National drug strategy
Aged Care Assessment Program data collection Home and Community Care (HACC) data collection	Aged population: Health conditions experienced by aged people needing assistance to remain at home, particularly when dependency measures become available on the minimum data standard
Bureau of Meteorology–National Climate Centre data	Environmental health, such as the Australian Ozone report
Australian Radiation Protection and Nuclear Safety Agency (ARPANSA) ultraviolet radiation level data	Environmental health–skin cancer. ARPANSA is part of the Commonwealth Health and Aged Care portfolio
The Australian and New Zealand Dialysis and Transplant Registry	See reports published by ANZDTR (Disney et al.)
BEACH GP Study	Not stated
Commonwealth Enhanced Primary Care initiatives data	Not stated
Neonatal Intensive Care Unit Study (NICUS)	Outcomes for newborns' requiring intensive care
Neonatal & Paediatric Emergency Transport Service	Linking neonatal transport to outcomes and the maternal population base.
Occupational health collections: National Occupational Health and Safety Commission, WorkCover NSW, NSW Dust Diseases board	Planning health services for industrial areas, research into occupational health problems

Table 2

Main data collections available for population health information analysis and reporting in NSW, continued.

Other suggested data collections	Why?
Australian Council on Healthcare Standards (ACHS) Clinical Indicators	Health system improvement potential
NSW Oral Health Information System	Dental health
ABS Surveys of Disability, Ageing and Carers	Disability status
ABS National Aboriginal and Torres Strait Islander Survey	Health of indigenous people
The Australian Longitudinal Study on Women's Health (University of Newcastle)	Longitudinal data on women's health. Useful for rural–urban comparisons.
NSW Mental Health information system	Anticipated
NSW Community Health information system	Anticipated
Relevant overseas collections	If data is not available locally
NSW Roads and Transport Authority	Road injury risk factors
NSW Department of Community Services (DOCS)	Child protection and domestic violence
Commonwealth Department of Family and Community Services (formerly Social Security)–Centrelink	Rent assistance by postcode as a marker of poverty. Disability support pensioners and health care card holders by Local Government Area.
Health Insurance Commission (HIC) Medicare Benefits Scheme (MBS), Pharmaceutical Benefits Scheme (PBS) data	Prescriptions for illnesses associated with aging, infirmity and disability. Family planning: abortions, pap tests, chlamydial infections General practice services
NSW Department of Juvenile Justice	Economic and health deprivation
NSW Bureau of Crime Statistics and Research	Economic and health deprivation. Violence–safety by Local Government Area.
NSW Department of Community Services	Economic and health deprivation
NSW Attorney General's Department	Economic and health deprivation
NSW Department of Corrective Services	Economic and health deprivation
NSW Pap Test Registry	Useful for comparing Family Planning Association benchmarks
NSW BreastScreen program	Not stated
National Diabetes Register	Insulin dependent diabetes only.
NSW Environmental Protection Authority Register of contaminated and unhealthy land	Spatial environmental information
AIHW Supported Accommodation Assistance Program Data Collection	Emergency accommodation for persons in danger of becoming homeless
NSW Department of Transport Household Travel Survey	Exercise–activity patterns, effects of public infrastructure developments.
CARDIAB—cardiovascular disease and diabetes management database collected by some divisions of general practice	Registration and management of patients with cardiovascular disease and diabetes
Environmental: algal levels, blood lead levels, environmental lead levels, pollen levels, meteorological data	Not stated
NSW Ambulance Service	Local health needs–service–access issues

- Greater feedback to people collecting the data to demonstrate usefulness and quality.
- Increase the sample size of the NSW Health Survey to provide LGA level estimates
- Conduct an Aboriginal Health Survey every three to four years.
- Reduce the frequency of the NSW Health Survey and the number of questions.
- The NSW Health Survey should provide information on incidence and prevalence of priority diseases.
- ISC should count the number of patients, not the number of episodes. May be possible with universal patient identifiers.
- Link ISC and EDDC.
- Collect language spoken at home, Aboriginality and risk factor information in the Cancer Registry.
- Collect pregnancy–childbirth-related depressive conditions in the MDC.
- Link ISC and MDC.
- Add Medicare Benefits Schedule, Pharmaceutical Benefits Scheme and ACIR data to HOIST.
- Extend focus of some collections, such as mental health not mental disease, community knowledge and empowerment. Collection systems for unobtrusive tracking of GP practice and other health professional behaviours such as smoking cessation advice.
- Ensure data collections are sufficient to enable sub-group analyses and comparisons over time, between areas and across groups.
- Rank collections as to their reliability—checked with appropriate analytical tools.
- Downloadable data from Web sites for own spreadsheet analysis.
- Publish data at the area health service and local government area level where possible.
- Improve the quality of Emergency Department data through funding Emergency Departments to improve the management of the data collection process.
- Include place of death and occupation for victims of suicide.
- Australian Bureau of Statistics National Health Survey and Census data need to be more accessible.
- ABS Survey of Mental Health and Wellbeing measured mental *ill-health*, but more measurement of mental *health* is required; how do people perceive their mental health, happiness, self worth, self esteem? How do people achieve mental health and how do they maintain mental health during adverse situations? Questions that could be added to the NSW Health Survey include (from Medical Outcomes Trust Short Form-36):

  In the past four weeks:
  Did you feel full of life?
  Have you felt calm and peaceful?
  Did you have a lot of energy?
  Have you been a happy person?

- Reduce the number of data collections and data items.
- More accessible data, such as the downloadable spreadsheets available from the Australian Institute of Health and Welfare.
- Report the quality, accuracy and timeliness of the data collections to permit appropriate interpretation and use of collections.
- Better timeliness of data.
- Trauma, suicide, domestic violence, and child abuse.
- Link Ambulance and Emergency Department data collections.

5. **Are any new data collections or data sources needed to fill important information gaps?**

- Law enforcement, family and community services, aged care, unemployment and socioeconomic status etc data.
- Ambulatory care and ED data for small and remote health services.
- Suicide attempts, especially lone young men in motor-vehicle accidents.
- Target populations such as Indigenous people, young people, older people, pregnant women, non-English speaking people, particularly at the area health service and smaller area level.
- New uses of administrative by-product data: measuring performance and for developing performance indicators, and developing National Minimum Datasets for defining 'what' and 'who received what' from health and community service providers. Develop administrative data for health and community care service providers for providing more data for the National Health Performance Framework.
- Health promoting environments (such as schools, homes and the workplace) to fill a gap identified in the National Public Health Information Development Plan. Need information on existence, maintenance and effectiveness of these.
- ABS General Social Survey 2002, ABS Indigenous General Social Survey 2002, National Biomedical Risk Factor Survey (2004?)
- Economic costings and evaluations (here or overseas) for strategies used by NSW Health.
- GP, hospital–nursing home–hostel bed availability per capita.
- Mental health and illicit drug use information at area health service or local government area level.
- Home care information.
- GP treatment data for priority diseases.
- Education.
- Social capital.
- Disability.
- Chronic conditions.
- Mental health.
- Quality of life, disability, social health (for example: learning disabilities, literacy levels).

4. Information access options

Apart from publishing printed documents, the NSW Department of Health has an Internet Web site (Health Web) that is available to the general public at www.health.nsw.gov.au; and a separate Intranet site (Health Net) that is available only to people working within the NSW public health system at http://internal.health.nsw.gov.au. These are currently used by the Public Health Division as a primary means of publication of population health information.

4.1   Published reports

The development of Internet and Intranet technology means that information that was previously only available through expensive and time consuming publication and printing processes can now be published rapidly through the Internet or Intranet. It also means that much larger volumes of information can be created at very low marginal cost and stored for later retrieval if and when needed. The challenge of this increased volume, flexibility, and timeliness is to make the information readily accessible and easy to find for those who want to use it.

The availability of special computer programs, such as Acrobat Reader, make it possible to store entire books on Web sites in a way that can be printed directly onto a computer printer. This means that books and other publications can be freely and quickly distributed.

It is also important to recognise that some people are unable to obtain information through the Internet or Intranet, and information still needs to be made available in printed form.

POINTS FOR DISCUSSION IN SECTION 4.1, ASKED OF ORIGINAL RESPONDENTS

6.   **Is it important to continue publishing reports of population health information rather than relying on interactive facilities? Why?**

*'Yes' responses (39)***:**
- Equity of information access.
- For people and organisations who do not have sufficient resources–equipment (for example, people living–working in rural and remote areas, community organisations).
- Many staff of rural area health services do not have access to the Intranet.
- Published reports are important for historical information, consistency and reliability.
- Explanatory text and interpretation of statistics is important.
- There needs to be a recognised catalogue for Internet publications.
- Bound publications are more mobile, easier to check, facilitate comparison of pages and are neat.
- Printed publications for advertising, promoting and how to use electronic information.
- Printed publications are useful when electronic access is interrupted.
- Some reports are too big to be downloaded.
- Cheaper for many users.

- But printed reports should only include important and summary information.
- Hard copies contribute to culture change.
- Allows rapid response to queries.
- But can reduce the number of printed copies required if available electronically.
- Difficulty of citing Internet publications.
- Lack of access to colour printers.
- Visual scanning, scoping and overview is easier.
- Better for people who are not familiar with electronic or health data.
- Published reports have a longer shelf life
- Using computers to read information can lead to eye-strain.
- Paper copies provide a low technology backup.
- For those who do not have the skills to use electronic facilities.

'No' responses (2):
- Electronic access is easier if the facility is user-friendly.

4.2   Easy to use interactive analysis and reporting

A further advantage of Internet and Intranet technology is the capacity to develop interactive data analysis and reporting systems that can be accessed using Web browsers through specially developed Web sites. Examples of these systems can be found at the Web addresses: http://wonder.cdc.gov and www.nahdo.org/nahdo/databases/memberinets1.htm.

- Other examples suggested by respondents:
- National Occupational Health and Safety Commission: http://nohsc.info.au.com.

These systems allow you to specify the details of an analysis using your Web browser. You then click on a button on the Web browser with your mouse to submit the analysis, and the browser sends the specifications to the Web site's computer where the analysis is completed. The Web site computer then returns the results of the analysis to your browser for display.

POINTS FOR DISCUSSION IN SECTION 4.2, ASKED OF ORIGINAL RESPONDENTS

7. **Is there a demand for an easy to use interactive analysis and reporting system based on Internet–Intranet technology? Who would find it useful?**

'Yes' responses (32):
- Flexibility in obtaining specific information.
- Simple tables would be available quickly and cheaply.
- For health professionals and policy makers who need a variety of views of the data.
- For health planners, researchers, educators and students.
- For program managers, health service managers, health promotion staff, and policy and planning staff.
- Useful to staff in any human services area.
- For staff with limited SAS skills.

- For population health professionals.
- For divisions of general practice, and general practitioners.
- Cost-effective.
- For needs assessments or for justifying decisions.
- Non-government organisations need up-to-date information to support funding proposals.
- For priority setting.
- Researchers.
- Will save time for people who currently have to do data requests.
- For public health.
- For general public.
- Planning and evaluation by divisions of general practice.
- Useful for data availability with area health services.

'No' responses (1):
- Many people are not able to formulate appropriate analyses; a selection of static reports for downloading are better.

8. **What considerations should be taken into account when developing such a facility?**
- A few well-structured tables can answer the majority of questions.
- Uncomplicated datasets.
- Statistical limitations due to small sample sizes.
- Appropriate, adequate and clear metadata.
- Protecting confidentiality.
- Easy to use and access—take into account limited technical expertise of users
- Who will it be available to?
- Flexibility.
- Should not require special statistical skill.
- Training in use and interpretation of results.
- Include caveats and expected interpretations of the data.
- Really simple—user-friendly—intuitive.
- Small area analyses misleading unless shrunken Bayesian estimates are used.
- Extensive piloting required to prevent teething problems.
- Limited scope initially to assess usefulness.
- Market–publicise the facility.
- Ensure wide availability.
- Available on the Intranet because many area staff do not have Internet access.
- Availability of area, LGA and even town–postcode level analyses.
- Compatibility of variables across data collections.
- Develop a plan that includes cost, complexity of analysis, database capacity, running time, and correct interpretation.
- Reliability.
- Multiple ways of accessing the same data, such as social and economic viewpoints.

- ♦ Statistical accuracy.
- ♦ Avoid ambiguity.
- ♦ Avoid jargon, or explain if used.
- ♦ Clear statement of limitations.
- ♦ Monitor access and output.
- ♦ Quick response (avoid unnecessary graphics).
- ♦ Up-to-date data available.
- ♦ Range of functions: graphs, tables etc.
- ♦ Do not permit small area comparisons at less than area level, because there is danger of misinterpretation.
- ♦ Take into account the diversity of user skills in manipulating and interpreting data.
- ♦ Quality of presentations (tables, graphs, maps).
- ♦ Provide a central resource for conducting analyses instead—to ensure that work done is meaningful.

4.3 Sophisticated statistical analysis and reporting

The Health Outcomes and Information Statistical Toolkit (HOIST) was developed by the Epidemiology and Surveillance Branch of the NSW Department of Health to provide a facility for analysing and displaying population health information. It is currently available to authorised users within the NSW public health system, and provides access to a range of data collections and tools for analysing the collections. The facility was developed using SAS statistical analysis software, and requires a basic knowledge of the SAS programming language to use. It is, therefore, a facility that is most useful to data analysts and researchers skilled in the use of statistical computer programs.

POINTS FOR DISCUSSION IN SECTION 4.3, ASKED OF ORIGINAL RESPONDENTS

9. **Is there a demand for improving access to information using the HOIST facility?**

- ♦ 'Yes' responses from organisations within the NSW public health system: 12
- ♦ 'No' responses from organisations within the NSW public health system: 4
- ♦ 'Yes' responses from organisations outside the NSW public health system: 11
- ♦ 'No' responses from organisations outside the NSW public health system: 2

10. **What are the barriers to making more use of the HOIST facility and what are the best ways to reduce these?**

- ♦ Not available to relevant academic institutions, other government departments, non-government organisations, and divisions of general practice. These organisations work with NSW Health, but do not have access to useful information.
- ♦ Not available to postgraduate students within teaching hospitals of area health services.
- ♦ Difficult to access.
- ♦ Requires SAS programming skills.

- Lack of training.
- Make data available for use with SPSS or STATA, or Microsoft Access.
- Confidentiality and misinterpretations with small numbers in small and remote areas.
- SAS courses are expensive, especially with airfares and accommodation.
- Cost of SAS licenses.
- Offer access and training to Ambulance Service staff.
- Reduce HOIST demand through implementing interactive facilities (as in Section 4.2).
- Many staff in rural areas do not have access to PCs.
- Not available outside the public health system.
- SAS licenses are is too expensive, for rural areas and non-government organisations.
- SAS is not user-friendly.
- Privacy and confidentiality considerations.
- Develop partnerships with non-government organisations to develop mutually beneficial information systems.
- Lack of publicity on its existence.
- Lack of relevance of SAS training to HOIST usage.
- Difficult to understand the variations in data collected, definitions used, and changes over time.
- Facilitate local area analysis with sample SAS programs and documentation.
- Facilitate calculation of standard indicators and presentations of them.
- Provide on-line or telephone support to area data analysts.
- Lack of access to computers.

4.4 Facilities for locating population health information

Potential tools to assist the location of information, include:

- incorporating links to population health information into the NSW Clinical Information Access Project (CIAP) located on the NSW Department of Health Intranet site at http://internal.health.nsw.gov.au:2001;

- publishing a regular bulletin of NSW population health information or incorporating more advice about available information into the *NSW Public Health Bulletin*;

- indexing the information in a medical or health bibliography database such as Medline or Healthstar;

- establishing an indexed Intranet–Internet facility that would provide you with a structured method of locating the information you are looking for. Similar to a Search Engine, but leads you through a set of structured criteria that help identify what information is available for the topic you are interested in;

- a more conventional Internet–Intranet text Search Engine which lets you enter free text to locate the information you are interested in;

- informally browsing a Web site to find information;

- browsing a catalogue of publications on a Web site;

- obtaining a printed catalogue of information;

- visiting a library and obtaining assistance from a librarian.

POINTS FOR DISCUSSION IN SECTION 4.4, ASKED OF ORIGINAL RESPONDENTS

11. What methods would you prefer for locating population health information? Why?

- Structured Web-based indexed facility using standard thesaurus–terminology (14).

- CIAP (many managers and clinicians are familiar with it, and its available at small hospitals) (11).

- Text-based Web search engines (8).

- Web-based publication catalogue browsing (6).

- Publish regular information bulletins to advertise developments (4).

- Medline or Healthstar style indexes (3).

- Informal browsing of a Web site (3).

- A variety of methods depending on personal preference, needs and skills, and availability of resources (3).

- Greater use of the *NSW Public Health Bulletin* as a cost-effective vehicle for delivering information or advertising available information and facilities (2).

- Web portal with a variety of methods: search, most recent reports and bulletins etc. (1).

- An electronic population health information gateway, NSW and nationally (1).

- Don't use the NSW Health Web's Circular search facility as a model; it doesn't work (1).

- Static reports are better because the Web is unpredictable (1).

- Intra-government access to the NSW Department of Health Intranet (1).

- Make more information available to local, university, TAFE and secondary school libraries to reduce the number of information requests to public health units (2).

- Bibliographic style database (like Medline) (1).

- Printed catalogue (1).

Suggestions were made about the desirable characteristics of any method of searching:

- User friendly.

- Brief but comprehensive description of the item.

- Brief description of the main data variables.

- Name of author–database coordinator included.

5. Proposed developments

5.1 Goals of PEPHI

The proposed developments have three main goals addressing a three-tiered audience:

1. Enhanced access to useful population health information for health professionals working outside the public health system, administrators, planners and policy analysts working in non-health sectors, students, and the general public.

2. Enhanced access to useful population health information for public health system staff at all levels.

3. Enhanced access for data analysts and researchers to population health data and to relevant analytical techniques and facilities.

POINTS FOR DISCUSSION IN SECTION 5.1, ASKED OF ORIGINAL RESPONDENTS

12. Are there any groups whose population health information needs are not met by these goals and who are they?

- Note the National Indigenous Health Information Plan.
- Are academics included?
- Other government departments and institutions.
- General public who want fact sheets and short information bulletins.
- Area Health Advisory Council members.
- University of Sydney campus at Broken Hill.
- Royal Flying Doctor Service.
- Non-government organisations.
- Health-funded non-government organisations.
- Ethnic groups, Aboriginal health and women's health.
- Sexual health?
- Area high-level health service managers–decision makers who prefer information presented in a sophisticated manner and who are likely to be uninterested in using interactive analysis systems.
- Area lower level managers, program staff and related but non-health agencies who have trouble formulating data requests and who do not have the resources or expertise to obtain the data.
- Add academics and researchers to Group 1.
- Medical colleges, divisions of general practice and general practitioners.
- Local level area health staff and managers, especially in rural communities where resources are very limited.
- The goals should be more outcome-oriented rather than process-oriented, such as 'monitoring population health trends', 'identifying emergent issues and new priorities', 'monitoring effectiveness of area health services in promoting, maintaining and enhancing population health'.

5.2   BENEFITS OF PEPHI

The proposed benefits of an expanded population health information program include:

- ♦ provision of more detail and improved timeliness of information;
- ♦ promotion of a population-based perspective in health policy development and services planning and delivery;
- ♦ promotion and facilitation of population health research in NSW using the wide range of data already available.

POINTS FOR DISCUSSION IN SECTION 5.2, ASKED OF ORIGINAL RESPONDENTS

13. Can you suggest any additional benefits of an expanded population health information program?

- ♦ Potential reduction in costs due to reduction in duplication of data collection.
- ♦ Improved responsiveness to the health-related needs of the population.
- ♦ Help NGOs to provide informed comment on government policy, better inform decision-making and use resources more efficiently.
- ♦ Improved access to a wider range of users.
- ♦ Will provide tools for action.
- ♦ Improvement in health literacy in the public.
- ♦ Better timeliness of data.
- ♦ The information gap is greatest in the smallest health services—scope for greatest benefit.
- ♦ Feedback cycle to clinicians who collect data will improve quality.
- ♦ Better equity in the provision of health services through population-based allocations.
- ♦ Evidence-based health service planning, decision-making, and policy development.
- ♦ Better use of existing information.
- ♦ More informed decisions by health managers.
- ♦ More standardised data collection.
- ♦ Use of reliable data by groups outside the public health system.
- ♦ Consistency of information.
- ♦ Efficient and effective distribution of health information.
- ♦ Avoids duplication and inconsistency of information.
- ♦ Promotion of population health approach among clinicians, if done correctly.
- ♦ Capacity building in the health system workforce in use of population health information.
- ♦ Improve use of population health information by non-health agencies.
- ♦ Better use of data for planning and evaluation.
- ♦ Improved health outcomes and satisfaction with the health system based on utilisation of population health information to assist best practice in health care.
- ♦ Time saving when searching for information.
- ♦ Greater involvement of general practitioners in primary health care planning and delivery.

- Better data for cluster–outbreak investigations.
- Accessible and relevant local level information—especially for rural communities.
- May provide facilities that rural area health services cannot provide because of small scale.

5.3 Main strategies

The proposed goals of PEPHI will be met using the following three main strategies:

1. EXPANSION OF INTERNET-BASED PUBLICATION PROGRAMS

Until now, the Internet–Intranet versions of publications such as the *Report of the Chief Health Officer* have mirrored the printed editions, which have been necessarily limited in their scope and detail. This strategy aims to dramatically expand the current publication program by using electronic publishing on the Internet and Intranet to provide a wider range of health indicators, and to provide more information at the area health service and smaller geographic levels.

This strategy is intended to meet the majority of information needs of staff of the NSW health system, health professionals in the private sector, administrators and planners in sectors other than health, the general public, and students. Attention will be given to developing material that can be easily understood by each of these audiences and is easily accessible. Methods for easily producing printed reports from material drawn from Internet–Intranet resources will also be investigated.

2. DEVELOPMENT OF A RANGE OF INTRANET-BASED INTERACTIVE ANALYSIS AND REPORTING FACILITIES

These facilities will be aimed at providing more flexible access to information for staff working in the public health system. Depending on future development of the NSW Department of Health Intranet, access to these facilities may become available to health professionals working outside the public health system and to administrators, planners and policy analysts working in sectors other than health.

3. ENHANCEMENT OF THE HEALTH OUTCOMES AND INFORMATION STATISTICAL TOOLKIT (HOIST) FACILITY

The aim of this strategy is to promote easier access to data collections for skilled analysts and researchers and to provide infrastructure for the first two strategies above. The intention is that HOIST will draw as much of its data as possible from the Health Information Exchange (HIE), which will take over the majority of the data acquisition and management tasks which have been performed by HOIST in the past.

POINTS FOR DISCUSSION IN SECTION 5.3, ASKED OF ORIGINAL RESPONDENTS

14. Do you think these strategies are adequate to meet the goals of PEPHI (see section 5.1)?

- 'Yes' responses (2).
- 'No' responses (7).
- 'The potential is there'.
- 'The strategies are too general'.
- Include general practitioners through their college and divisions of general practice.

♦ But not for the general public, who need printed information.

15. If not, what other strategies could be used?

♦ Incorporate ongoing quality and usefulness management by consumer evaluation, which leads to responsive developments.

♦ Data should be current, reliable, and available for small areas or by language group.

♦ The Council on the Ageing (NSW) has trouble obtaining relevant data.

♦ Facilitate a consultancy service or help desk of data experts–statisticians.

♦ Extend Intranet access to non-government organisations, health professionals outside the public health system, and divisions of general practice.

♦ Extend HOIST access to approved applicants from outside the public health system.

♦ Extend Intranet access to academics and postgraduate students outside the health system.

♦ A dual report format for the general public, students and private health professionals: A very detailed area health service report with small area breakdowns complemented by a summary overview report for those with a less detailed interest.

♦ Offer education to users and other information facilitators such as librarians.

♦ Greater linkage of health status, health service usage, outcomes, and other available data sources to better describe population health.

♦ Ensure availability of the statistical information to a wide range of stakeholders.

♦ Consider combining Internet and Intranet facilities into a single secure Internet site and use Public Key Infrastructure (PKI) to provide secure access to authorised individuals and organisations.

♦ Ensure the HIE leads to better access to more local data.

♦ Greater use of small area analysis tools such as HealthWIZ.

♦ Ensure the facilities are useful for planning, surveillance, policy development at local, area, and state levels.

♦ Ensure the information is always up-to-date.

♦ Continual promotion, training and evaluation so that it goes beyond the 'cogniscenti'.

♦ Balance 'hard' data with 'soft' data; that is, don't forget the subjective side of things.

♦ Be more inclusive of other disciplines outside health professionals—avoid 'us' and 'them'.

♦ More community involvement, realignment of health services and build better health policy (from Ottawa Charter).

♦ Extend CIAP access to non-government organisations.

♦ A scoping paper to develop an understanding of information skills and costs of upskilling.

♦ Ensure information resources are publicised to all stakeholders and training is provided where necessary.

♦ HOIST data should be accessible and usable by analysts and researchers who may not be skilled in SAS programming. Establish a minimum standard for SAS programming skills in the health system.

- Critically appraise the inadequacies and problems with HOIST data collections and consequent enhancement of the data collections.
- Consult relevant staff and organisations for topic-specific data.
- It is too optimistic to think that area level needs can be met through electronic means.
- Need to train, support and encourage clinicians and other decision-makers to access and use population health data, otherwise impact will be limited.
- Ensure printed information is available to the general public.
- If the goals include the general public, non-government organisations etc, then include representatives of these on steering or working groups. Can utilise rural health councils, peak consumer NGOs, local government, tertiary education bodies. They will help ensure information is relevant and understandable. They may also help in marketing strategies. Note the Government Action Plan is evaluating type and dissemination of health information to the wider community.
- Develop better links with other government departments and local government.
- How can the isolated role of information officers in (rural) area health services be supported (EPISIG isn't relevant to many of these)?
- Training has to be targeted towards different competency levels.

5.4 Projects proposed under the Program

Table 3 describes current information gaps in NSW and proposed projects to address them.

POINTS FOR DISCUSSION IN SECTION 5.4, ASKED OF ORIGINAL RESPONDENTS

16. What other important information gaps are there?

- Social determinants of health.
- Administrative or process (for example, waiting times) factors.
- Circumstances of attendance to emergency departments.
- Re-admissions or re-presentation following inappropriate earlier discharge.
- Occupational health and safety information.
- A greater selection of indicators for area health services to choose from for performance agreements.
- Biomedical risk factors.
- Health of non-English speaking people and rural populations.
- Developing the capacity of the population health workforce to design, implement, and evaluate strategies in response to sub-optimal population outcomes.
- Community health.
- Indicator evaluation and validation.
- Sexual health.
- Clear guidelines, protocols and procedures within the NSW Department of Health for publishing Web-based documents or facilities with no printed counterparts.

Table 3

Information gaps and opportunities and proposed projects under PEPHI

Information gap–opportunity	Project	Goal met (see section 5.1)
Infrastructure projects		
Training and capacity building for staff of NSW Health and public health services	Develop HOIST training course and materials	3
	Establish a training fund for the development of skills for accessing, comprehending and using population health information among staff at the Departmental and area health service levels, particularly in rural areas.	2
Awareness and ease of finding available population health information	Marketing of available population health information	1,2,3
	Development of a single and efficient point of access to population health information through the public health system Intranet	2
Standards for analysing and presenting information for small geographic areas that protects personal privacy while providing a high level of detail	Small area data analysis and presentation best practice standards	1,2,3
Information that can be understood and interpreted by a wide range of audiences and skill levels	Develop and implement standards for displaying graphs so that they can be understood and interpreted by a wide range of audiences	1,2,3
Longitudinal–follow-up–long-term outcome information on health care	Interim procedures (pending statewide implementation of universal patient identifiers) for improved record linkage of datasets—for example, inpatient data to itself and to death certificates, midwives data collection and cancer registry data.	1,2,3
Comprehensive information on environmental health issues	Establish data access and reporting mechanisms for a wide range of environmental health information (air and water quality, food safety)	1,2,3
Information on childhood immunisation status and primary health care utilisation.	Under the national Medicare agreements, establish routine transfer of aggregate data from the Health Insurance Commission (HIC) derived from the Australian Childhood Immunisation Register (ACIR), Medicare and Pharmaceutical Benefits Scheme databases.	1,2

Information gap–opportunity	Project	Goal met (see section 5.1)
Expanded publication program		
Easy access to a renge of key national and state health performance indicators	An annual Internet-based publication program for: • National health performance indicators developed by the National Health Performance Committee and the National Public Health Partnership Joint Working Party on Performance (POPTOP) • Healthy People 2000-2005 indicators (key population health indicators for NSW) • NSW Aboriginal and Torres Strait Islander Health Performance Indicators (to be developed)	1,2,3
Information on morbidity associated with chronic and complex health problems	Develop methods for the reporting of chronic and complex health problems for inclusion in the Intranet-based *Report of the Chief Health Officer* (to monitor the progress of the Government's Plan of Action in response to Health Council recommendations)	1,2,3
Information on burden of disease and disability-adjusted life expectancy due to disease	Establish reporting of burden of disease and disability adjusted life expectancy for the Intranet-based *Report of the Chief Health Officer.*	1,2,3
A wide range of area health service and smaller geographic level population health information	Replicate a selection of indicators included in the Intranet-based *Report of the Chief Health Officer* at the area health service and smaller geographic levels.	1,2,3
Intranet-based interactive information facilities		
Emergency Department information and timely illicit drug morbidity information	Emergency Department information facility (including self-harm and drug overdose reporting)	1,2,3
Timely information on suicide, illicit drug-related, and other preventable deaths	Police Record of Death information facility (including suicide and drug death reporting)	1,2,3
Timely information on injury causes and morbidity	Injury information facility	1,2,3
Improved timeliness and flexibility for notifiable disease reporting and outbreak investigations	Notifiable disease information facility	1,2,3
	Infectious disease and outbreak case management monitoring and reporting system	2
Enhanced access to information available from the NSW Health Surveys	NSW Health Surveys and other population-based survey information facility.	1,2,3
Easy and flexible access to information on causes of death	Mortality information facility	1,2,3
Easy and flexible access to information on causes of morbidity	Morbidity information facility	1,2,3

- Patient visits to GPs (being addressed to some extent by the Health Insurance Commission).
- Mental, emotional and social wellbeing (including that of Aboriginal people).
- Ambulance data, crime data, school data (particularly counselling–mental health issues).
- Mental health problems in the population that are not seen by mental health workers.

17. What other important projects should be considered for inclusion in PEPHI?

- Public health information marketing and promotion (see National Public Health Information Development Plan) to government and the community.
- Improving the use of administrative data (see comments under Section 3.3)
- An infrastructure to support the development of public health information, to provide a systematic, co-ordinated approach to the collection and management of public health information at all levels in Australia is required. Development of a body which has well-defined mechanisms for making decisions affecting national public health information and can represent the information needs of the public health sector and can act as an advocate for a population perspective in national and international health information forums.
- Information on consumer-based consumer focused education and training would also be useful.
- Information facilities for obtaining local cancer screening participation rates.
- NSW performance against national cancer screening performance indicators.
- Ambulance Service needs local mortality and morbidity patterns and identification of environmental and other health risks at the local level—to support identification of key health problems in communities.
- Evaluating HealthWIZ for information analysis and dissemination.
- Development of consistent disease definitions for population health reporting according to ICD codes, that are adopted by different organisations. Implement a working group of clinical experts, epidemiologists, medical coders, and data analysts.
- Determine the value of and recommendations for use of secondary diagnoses in the ISC.
- Incorporate more datasets such as the HIV–AIDS register and the Australian Childhood Immunisation Register into HOIST, plus any other relevant collections that are not currently included.
- Explore application of interrupted time series methods and new methods that can be applied to health services research; possibly consult an international expert under PEPHI.
- Make community health information system data available for analysis when possible.
- A frequently asked questions (FAQ) Web site.
- Market HOIST to all areas of the public health system (for example, Ambulance Service)—and back it up with ease of access, support, and training.
- Establish protocols and procedures for publishing Web-based publications and information facilities, needs to cover health privacy and confidentiality, and procedures for expediting the publishing approval process.

- On-line support for HOIST users.
- A resource for helping users understand the limitations and assumptions of quantitative information.
- A Web-based resource for social and qualitative data.
- Work with other branches of NSW Health to improve data capture, quality, and timeliness of data collections.

18. **Do the projects listed adequately meet the goals of PEPHI (see section 5.1)**

Due to the complexity of responses to this question, yes–no responses were not counted. However, constructive comments were noted below.

- Greater access to HOIST–Intranet facilities required outside the public health system.
- No, it is only just the beginning. Needs to more clearly specify the state, area and metro–rural relevance.
- FlowInfo is a good model for improving dissemination of data—look into it.
- HealthWIZ should be considered for improving information access.
- Would be a great boost for information use in area health services.
- Market HOIST to all areas of the public health system (for example, Ambulance Service)—and back it up with ease of access, support, and training.
- Need to provide interactive analysis facilities through the public Internet to satisfy Goal 1.

6. How to respond to this report

We welcome and invite continuing comments on PEPHI. Please provide comments at any time to:

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The discussion points are repeated below. Where possible, please structure your comments according to the discussion points, although we welcome additional comments and suggestions.

DISCUSSION POINTS

- Are there other resources that should be added to Table 1?

- Which of the existing resources and access methods listed in Table 1 do you find most useful? Why?

- Are there other data collections, apart from those listed in Table 2, which might be useful? What are they and why?

- Can you suggest any modifications to these collections that would improve their usefulness for population health reporting?

- Are any new data collections or data sources needed to fill important information gaps?

- Is it important to continue publishing reports of population health information rather than relying on interactive facilities? Why?

- Is there a demand for an easy to use interactive analysis and reporting system based on Internet–Intranet technology? Who would find it useful?

- What considerations should be taken into account when developing such a facility?

- Is there a demand for improving access to information using the HOIST facility?

- What are the barriers to making more use of the HOIST facility and what are the best ways to reduce these?

- What methods would you prefer for locating population health information? Why?

- Are there any groups whose population health information needs are not met by these goals and who are they?

- Can you suggest any additional benefits of an expanded population health information program?

- Do you think the three strategies: expansion of Internet-based publication programs; development of a range of Intranet-based interactive analysis and

reporting facilities; and enhancement of the Health Outcomes and Information Statistical Toolkit (HOIST), are adequate to meet the goals of PEPHI?

- If not, what other strategies could be used?
- What other important information gaps are there in NSW?
- What other important projects, apart from those listed in Table 3, should be considered for inclusion in PEPHI?
- Do the projects listed in Table 3 adequately meet the goals of PEPHI?

References

1. Public Health Division. *Strategy for Population Health Surveillance in New South Wales*. Sydney: NSW Department of Health, 1997.
2. Australian Institute of Health and Welfare. *National Public Health Information Development Plan*. Canberra: Australian Institute of Health and Welfare, 1999.

Distribution and number of responses received

Category of organisation	Distribution method	Responses received
NSW area health services	Mailed to: chief executive officers, directors of public health units, public affairs officers, directors of health promotion units, directors of nursing, coordinators of multicultural health, coordinators of Aboriginal health, coordinators of mental health	22
NSW Department of Health	Advertised in *This Week in Health*, the Director-General's weekly email newsletter, Departmental Internet and Intranet, and the *NSW Public Health Bulletin*	4
Peak non-government organisations, NSW divisions of general practitioners, medical and nursing colleges and associations	Mail-out	13
Commonwealth Government	Mailed to: Department of Health and Aged Care, Australian Institute of Health and Welfare, Australian Bureau of Statistics, Health Insurance Commission	9
Other relevant NSW State Government departments and authorities	Mailed to those likely to have an interest in health issues	3
University public health faculties in NSW	Mail-out	4
Total responses		**55**

List of organisations–units responding

Thank you to all those individuals and organisations that responded. The following units may have provided individual rather than organisational responses.

Organisation	Units
Australian Bureau of Statistics	Health Section
Australian Institute of Health and Welfare	Population Health Unit
Central Coast Area Health Service	Mental Health, Health Service Development Unit
Central Sydney Area Health Service	NSW Perinatal Services Network (University of Sydney), Division of Population Health
Central Sydney Area Health Service	
Commonwealth Department of Health and Aged Care	Drug Strategy and Population Health Social Marketing Branch, Population Health Division, Primary Prevention Section, Chronic Diseases Section, Cancer Screening Section, Injury Prevention Section, Primary Prevention and Early Detection Branch, Population Health Information Development
Corrections Health Service (NSW)	
Council on the Ageing (NSW)	
Far West Area Health Service	Health Service Planning, Research and Surveillance
FPA Health (formerly Family Planning Association of NSW)	
Goulburn Correctional Centre	Public Health Nurse
Greater Murray Area Health Service	
Health Insurance Commission	Information Management Division
Illawarra Area Health Service	Mental Health Service
Macarthur Division of General Practice	
Macarthur Health Service	
Macquarie Area Health Service	Population Health Unit
Mid Western Area Health Service	Public Health Unit
New England Area Health Service	Chief Executive Officer
Northern Rivers Area Health Service	Health Promotion Unit
NSW Agriculture	
NSW Ambulance Service	Corporate Services
NSW Cancer Council	Pap Test Register, Cancer Epidemiology Research Unit
NSW Department of Community Services	Strategic Policy and Planning
NSW Department of Education and Training	Drug Education Unit, Student Services and Equity Programs
NSW Department of Health	Health Services Policy Branch, Epidemiology and Surveillance Branch, Environmental Health Branch
Organisation	**Units**
NSW Nurses Association	

Public Health Association of Australia	NSW Branch
Royal Australian and New Zealand College of Opthalmologists	
Royal Australian College of General Practitioners	
Royal Australian College of Surgeons	
South Eastern Sydney Area Health Service	Chief Executive Officer, Public Health Unit
South Western Sydney Area Health Service	Chief Executive Officer
The Australian Council on Healthcare Standards	Performance and Outcomes Service
University of Newcastle	Centre for Clinical Epidemiology and Biostatistics
University of Sydney	Department of Public Health and Community Medicine, Effective Healthcare Australia
Wentworth Area Health Service	
Western Sydney Area Health Service	Health Promotion, Mental Health Service
Western Sydney Division of General Practice	