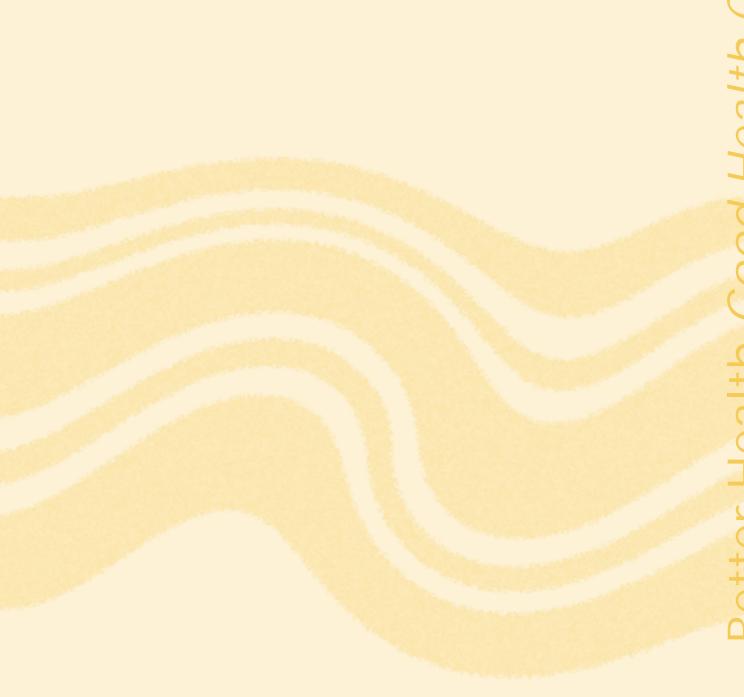
PROGRAM FOR ENHANCED POPULATION HEALTH INFOSTRUCTURE (PEPHI)

Discussion Paper



NSW HEALTH

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For further information please contact:

A/Manager, Program for Enhanced Population Health Infostructure (PEPHI) Epidemiology and Surveillance Branch NSW Health Department Locked Bag 961 NORTH SYDNEY NSW 2059

e-mail: dmusc@doh.health.nsw.gov.au

ph: (02) 9391 9408 fax: (02) 9391 9232

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1 About this Discussion Paper

This paper introduces the NSW Health Department's Program for Enhanced Population Health Infostructure (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 Commonwealth Department of Health and Aged Care's National Health Development Fund.

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 includes 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 an information collection's value, 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 as an immediate priority and will contribute to the infrastructure for later projects to be completed under the Program. Other projects are evolving and, along with advice from the PEPHI Steering Committee, input from interested individuals and organisations will help guide their development. This discussion paper is intended to describe and promote discussion on the proposed developments.

Questions to promote discussion and prompt a structured reply are included in each section of the paper. We would appreciate your comments on the discussion questions and any other comments you may wish to add.

Please respond by 31 December 2000. Further details about how to respond are given in section 6.

2 Glossary

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.

HIE Health Information Exchange, a data warehouse that will eventually

store the majority of data collected and/or used by NSW Health.

HOIST Health Outcomes and Information Statistical Toolkit - offers access to

and statistical analysis of a range of data collections via the NSW Health internal network (intranet). 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 worldwide 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.

Intranet The same principle as the internet, except access to the information is

restricted to people within an organisation.

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, that is designed for looking at web sites.

Web page Information available on a web sites is typically organised into units

called web pages. Every web page has a web address (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 Health Department 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 Health Corporate Plan 1999, Strategic Directions for Health 1998-2003, and the NSW Health Information Management Strategy 1999-2002;
- the National Public Health Information Development Plan, 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 Health Department's Health Information Exchange (HIE); and
- 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 3.1. Many of these are also used by Area Health Service staff, who may also use additional local information and data resources.

Table 3.1. Main population health information resources in NSW

Resource	Methods of access
Health Outcomes Information and Statistical Toolkit	SAS statistical analysis software
(HOIST)	using the SAS computer
	programming language
The Health of the People of NSW – Report of the	Public printed book
Chief Health Officer	Public internet
	Public health system intranet

Table 3.1 (cont). Main population health information resources in NSW

Title	Available as
NSW Mothers and Babies Report (including the	Public printed book/journal
NSW Birth Defects Register Report)	supplement
	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 Socio-Economic Indices for Areas	Public health system intranet
(SEIFA)	·
Reports from the NSW Cancer Registry (produced by	Public printed books
the NSW Cancer Council)	Public internet
Reports from the Australian Institute of Health and	Public printed books
Welfare (AIHW)	Public internet
Australian Bureau of Statistics publications	Public printed books
	Information consultancy
Reports of the Australian School Students Alcohol and	Public internet
Drug (ASSAD) Survey	Public printed books
National Drug Strategy Household Survey Reports	Public printed books
	Public internet
National Centre in HIV epidemiology and clinical	Public printed books
research reports on HIV/AIDS, sexually transmitted	Public internet
diseases	
Communicable Diseases Intelligence reports of the	Public printed books
Commonwealth Department of Health and Aged Care	Public internet

Discussion points for Section 3.2

- 1. Are there other resources that should be added to this list?
- 2. Which of the existing resources and access methods do you find most useful? Why?

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 3.2.

Table 3.2. 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) 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 NSW Health Information Exchange (HIE)
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NSW Notifiable Diseases Database (NDD) NSW HIV/AIDS Register
NSW HIV/AIDS Register
NSW Health Information Exchange (HIE)
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 census information and estimated resident populations
ABS National Health Survey and National Nutrition Survey
ABS National Survey of Mental Health and Wellbeing

Discussion points for Section 3.3

- 3. Are there other collections that might be useful? What are they and why?
- 4. Can you suggest any modifications to these collections that would improve their usefulness for population health reporting?
- 5. Are any new data collections or data sources needed to fill important information gaps?

4 Information access options

Apart from publishing printed documents, NSW Health has an *internet* web site available to the general public at web address: http://www.health.nsw.gov.au/ and a separate *intranet* site available only to people working within the NSW public health system at address: 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 which 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.

Discussion points for Section 4.1

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

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 which can be accessed using web browsers through specially developed web sites. Examples of these systems can be found at web addresses: http://www.nahdo.org/nahdo/databases/memberinets1.htm.

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 computer mouse to submit the analysis, and the web 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 web browser for display.

Discussion points for Section 4.2

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

4.3 Sophisticated statistical analysis and reporting

The Health Outcomes and Information Statistical Toolkit (HOIST) was developed by the Epidemiology and Surveillance Branch of NSW 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 which is most useful to data analysts and researchers skilled in the use of statistical computer programs.

Discussion points for Section 4.3

- 9. Is there a demand for improving access to information using the HOIST facility?
- 10. What are the barriers to making more use of the HOIST facility and what are the best ways to reduce these?

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 Health intranet site at address: 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; or
- visiting a library and obtaining assistance from a librarian.

Discussion points for Section 4.4

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

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.

Discussion points for Section 5.1

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

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; and
- promotion and facilitation of population health research in NSW using the wide range of data already available.

Discussion points for Section 5.2

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

5.3 Main strategies

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

1. Expansion of *internet*-based publication programmes.

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 non-health sectors and of 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 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 non-health sectors.

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.

Discussion points for Section 5.3

- 14. Do you think these strategies are adequate to meet the goals of PEPHI (see section 5.1?
- 15. If not, what other strategies could be used?

5.4 Projects proposed under the Program

Table 5.1 describes current information gaps in NSW and proposed projects to address them.

Table 5.1. Information gaps, proposed projects under PEPHI, and their goals

Information gap	Project	Goal met (see section 5.1)			
Infrastructure projects					
Training and capacity building for staff of NSW Health and	Develop HOIST training course and materials	3			
public health services	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	Marketing of available population health information	1,2,3			
information	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 eg 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			

Table 5.1 (cont). Information gaps, proposed projects under PEPHI, and their goals

Information gap	Project	Goal met (see section 5.1)
Expanded publication program	m	
Easy access to a range 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 info	ormation 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 (PROD) 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 Infectious disease and outbreak case management monitoring and reporting system	1,2,3

Information gaps, proposed projects under PEPHI, and their goals Table 5.1 (cont).

Information gap	Project	Goal met (see section 5.1)			
Intranet-based interactive information facilities (cont)					
Enhanced access to	NSW Health Surveys and other population-	1,2,3			
information available from the	based survey information facility.				
NSW Health Surveys					
Easy and flexible access to	Mortality information facility	1,2,3			
information on causes of death					
Easy and flexible access to	Morbidity information facility	1,2,3			
information on causes of					
morbidity					

Discussion points for Section 5.4

- 16. What other important information gaps are there?
- 17. What other important projects should be considered for inclusion in PEPHI?
- 18. Do the projects listed adequately meet the goals of PEPHI (see section 5.1)?

6 How to respond to this document

We welcome and invite comments on this Discussion Paper. Please provide comments by Friday, 31 December 2000 to:

David Muscatello A/Manager PEPHI Epidemiology and Surveillance Branch NSW Health Department Locked Bag 961 NORTH SYDNEY NSW 2059

Phone: 02 9391 9408 Facsimile: 02 9391 9232

e-mail: dmusc@doh.health.nsw.gov.au

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 for Section 3.2

- 1. Are there other resources that should be added to this list?
- 2. Which of the existing resources and access methods do you find most useful? Why?

Discussion points for Section 3.3

- 3. Are there other collections that might be useful? What are they and why?
- 4. Can you suggest any modifications to these collections that would improve their usefulness for population health reporting?
- 5. Are any new data collections or data sources needed to fill important information gaps?

Discussion points for Section 4.1

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

Discussion points for Section 4.2

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

Discussion points for Section 4.3

- 9. Is there a demand for improving access to information using the HOIST facility?
- 10. What are the barriers to making more use of the HOIST facility and what are the best ways to reduce these?

Discussion points for Section 4.4

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

Discussion points for Section 5.1

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

Discussion points for Section 5.2

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

Discussion points for Section 5.3

- 14. Do you think these strategies are adequate to meet the goals of PEPHI (see section 5.1)?
- 15. If not, what other strategies could be used?

Discussion points for Section 5.4

- 16. What other important information gaps are there?
- 17. What other important projects should be considered for inclusion in PEPHI?
- 18. Do the projects listed adequately meet the goals of PEPHI (see section 5.1)?

7 References

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