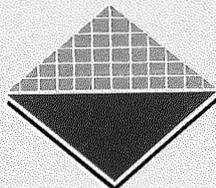


National Health Information Agreement

# PROCEDURE MANUAL

OCTOBER 1994



AUSTRALIAN INSTITUTE OF  
HEALTH & WELFARE

# **National Health Information Agreement**

## **Procedure Manual**

**October 1994**

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# Foreword

Health authorities in Australia now recognise the importance of good information to their policy and planning, management, care provision and monitoring roles. Similarly care providers, academics and researchers are demanding better quality data to assist their care, analysis and research functions.

In Australia it is crucial that data collected by the different health jurisdictions be consistent with uniform definitions, and follow guidelines and standards. This is necessary to allow comparison between those jurisdictions and with other countries, and to enable aggregation of data at the national level.

In May 1993 the Commonwealth, State and Territory health authorities, the Australian Bureau of Statistics, and the Australian Institute of Health and Welfare signed an agreement to improve the quality of and cooperation in the development of national health information. This agreement, the National Health Information Agreement (NHIA), was developed under the auspices of the Australian Health Ministers' Advisory Council (AHMAC), which has continued to support the development of the Agreement and its operation.

The Agreement has been in operation since June 1993 and has demonstrated that, with support, it has the potential to provide much of the infrastructure that the nation needs to provide good quality national health data. This infrastructure includes the National Health Data Dictionary of established definitions and data standards, the National Health Data Collection and Reporting Guidelines, national minimum standard edits and data policy guidelines. The Agreement has also put in place a number of processes to assist the development and management of this infrastructure. These include some processes which were established prior to the Agreement as well as some which have been newly developed.

This Procedure Manual provides explanations and guidance on the structure and procedures established under the National Health Information Agreement. The Procedure Manual will be of value to those involved in developing health data definitions or National Health Information Work Program projects, and also to those with a general interest in national health information. I support the action being taken to improve the quality of our health information and see this Procedure Manual as one further step in this direction.



Peter J Brennan  
Chair of AHMAC

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# Background

The planning and provision of health services and health programs are important and complex undertakings in which governments, government instrumentalities, private organisations, health professionals, academics, community groups and individuals have shared responsibilities.

To meet these responsibilities information is required about health, health services and health service consumers, and about environmental and human factors that may affect health.

To ensure that essential, accurate, reliable and timely information about health and health services, is available nationwide, a coordinated approach and agreed rules are needed to facilitate jurisdictional cooperation, efficient and effective utilisation of financial and intellectual resources.

The Australian Institute of Health and Welfare was established in 1987 as a national health statistics organisation with responsibilities which included development of national information and statistics relating to health and health services.

A forum on national priorities for health statistics, held by the Institute in 1991, recognised a number of deficiencies in Australian health information. To assist in addressing these deficiencies, the forum recommended the development of a national health information agreement between Commonwealth and State health ministers, to improve cooperation on the development, collection and exchange of national health data.

In March 1992 the Australian Health Ministers' Advisory Council (AHMAC) agreed the Institute would convene a Commonwealth-State taskforce to develop a national health information agreement.

Following endorsement of the agreement by AHMAC, the Commonwealth, State and Territory health authorities, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare signed the National Health Information Agreement in May 1993. The Agreement which came into effect from 1 June 1993, is for an initial period of five years (1993-1998).

Although the Agreement has a focus on public sector issues, the need to extend and consolidate links with the private and non-government sectors is recognised. Participation of these sectors in the processes under the Agreement will increase as the processes develop.

The Agreement sets out to ensure that the collection, analysis and dissemination of national health information is undertaken appropriately and efficiently. To achieve this requires agreed uniform definitions, standards and rules of data collection and guidelines for coordination of access, interpretation and publication of national health information.

The National Health Information Agreement provides the processes and structures needed, and the authority through AHMAC endorsement, for implementation of the agreed definitions, standards and guidelines. It is the

authority of the Agreement and AHMAC that legitimises for example, the development of standard, uniform definitions through the National Health Data Committee process, their publication in the National Health Data Dictionary and their implementation in the health data systems.

The Agreement is managed by the National Health Information Management Group, comprised of senior representatives of the signatories to the Agreement.

The effect of the Agreement on health information in Australia is far reaching. As all Commonwealth, State and Territory health authorities are signatories to the Agreement, all public sector health information is covered by the provisions of the Agreement. Similarly through the national statistical agencies, the Australian Institute of Health and Welfare and the Australian Bureau of Statistics, these provisions are also applied to data collected by them from the private and non-government sectors.

The essential process in developing uniform national definitions and standards is one of broad consultation and consensus. This requires consultation not only with health authorities but also health care providers, private sector interests and information specialists.

The Institute has set up a National Health Information Unit with specific responsibility for developing and coordinating national health information policy and infrastructure, coordinating the implementation of the National Health Information Agreement and Work Program—including the National Health Data Dictionary, and the provision of technical and secretariat support to the National Health Information Management Group.

As health information in Australia develops on a national basis it is crucial that the structures established are sufficiently robust to absorb the short-term pressures while remaining sufficiently flexible to reflect changing needs and community requirements. This manual provides a guide to the steps taken in the development so far and the processes in place. There remains considerable work to be done.

# Part 1

# Procedure Manual

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# 1

## National Health Information Agreement

### Background

The National Health Information Agreement (see Part 2 on page 33) aims to ensure that the collection, compilation and interpretation of national information are appropriate and are carried out efficiently. This requires agreement on definitions, standards and rules of collection of information and on guidelines for the coordination of access, interpretation and publication of national health information.

The Agreement is a multilateral agreement, that came into effect on 1 June 1993. The signatories to the Agreement are:

- the Department of Health, Housing, Local Government and Community Services (now the Department of Human Services and Health);
- New South Wales Health;
- Health and Community Services Victoria;
- Queensland Health;
- South Australian Health Commission;
- Health Department of Western Australia;
- Department of Community and Health Services Tasmania;
- Department of Health and Community Services Northern Territory;
- Australian Capital Territory Health (now the ACT Department of Health);
- the Australian Institute of Health and Welfare;
- the Australian Bureau of Statistics.

The Agreement is currently between government authorities only; however, it is intended to extend the Agreement processes to include both private and non-government sectors.

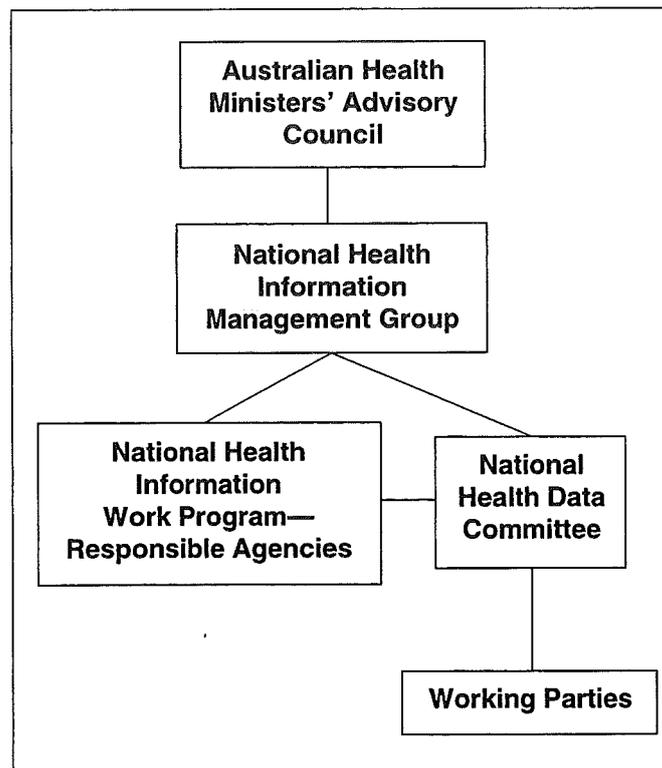
### Aims and objectives

The aim of the Agreement is to improve access to uniform health information by community groups, health professionals, government and non-government organisations. The specific objectives are listed in the Agreement (see 'Aim and objectives' on page 37).

## Authority

The Agreement operates under the auspices of the Australian Health Ministers' Advisory Council (AHMAC). AHMAC is the ultimate authority for resolving issues relating to the Agreement including determination of national priorities, the triennial work program and other management matters.

## Organisational Chart



## 1.1

# National Health Information Management Group

### Function

The Management Group is responsible for:

- overseeing the direction, development, review and implementation of the National Health Information Agreement and the agreed work program;
- making recommendations to AHMAC on national health information priorities, work programs, funding implications and other policy issues;
- negotiating with other groups and individuals for the collection and dissemination of information which will enhance the provision of health care;
- overseeing the role and function of the National Health Data Committee;
- overseeing the review and maintenance of the National Health Data Dictionary.

### Membership

Membership of the Management Group comprises a representative of each of the signatories to the Agreement.

The chairperson is selected for a two-year period from the representatives of State or Territory health authorities on the Management Group on a rotating basis.

The deputy chairperson is the Director of the Australian Institute of Health and Welfare.

The Management Group has an Executive which consists of the Chair, Deputy Chair, Australian Bureau of Statistics, Department of Human Services and Health and a State representative (New South Wales for 1993–95).

### Operating procedures

Management Group meetings are usually held twice yearly, approximately six weeks before scheduled AHMAC meetings in April and November. Matters can be progressed outside meetings by correspondence or teleconference.

The Executive has limited authority to take urgent action on the Management Group's behalf, subject to consultation with other members.

Individual parties meet the cost of their participation in the Management Group.

**Secretariat**

The Institute, through the National Health Information Unit, provides:

- the National Health Information Secretariat;
- support to the Chair;
- technical support;
- coordination of follow-up action.

**Submissions**

Submissions and papers for consideration by the Management Group are to be submitted to the National Health Information Secretariat at the Institute at least 15 working days prior to the Management Group meeting.

**Meetings**

The meeting agenda and accompanying papers are to be despatched by the Secretariat to Management Group members 10 working days prior to the scheduled meeting.

Draft minutes are to be prepared within 10 working days of the meeting and subject to the approval of the Chair, despatched to all Management Group members. Arising from the meeting, a list of items requiring action will be distributed with the meeting minutes.

A report of the meeting agreed to by Management Group members will be provided to National Health Data Committee members and is available to other interested parties.

## 1.2

### **National Health Information Management Group —establishment and operation of working groups**

<b>Terms of reference</b>	To be set by the Management Group, and will include milestones and reporting deadlines.
<b>Membership</b>	To be specified by the Management Group.
<b>Convenor</b>	To be specified by the Management Group.
<b>Role and responsibilities of the convenor</b>	<p>The convenor will be responsible for the operation of the working group, its progress and reporting including:</p> <ul style="list-style-type: none"><li>• arranging for working group meetings or other operational issues;</li><li>• maintaining records of meetings and their distribution to Working Group members and the National Health Information Secretariat;</li><li>• meeting the working group's work plan, consultation and reporting requirements mentioned above.</li></ul>
<b>Work plan</b>	Each working group will develop and submit to the National Health Information Secretariat for endorsement by the Management Group Executive, a work plan that outlines the proposed program within each group's terms of reference.
<b>Consultation requirements</b>	Each working group will set up agreed consultation with all other parties to ensure the national nature of the project is maintained (to this end the convenor may invite participation from representatives of other health interests including the health professions, private sector and non-government organisations).
<b>Reporting requirements</b>	Progress reports are to be provided to Management Group meetings within the agreed time frame—these are to be received by the National Health Information Secretariat no later than 15 working days before Management Group meetings.

**Financial  
arrangements**

Individual parties involved in working groups must meet the cost of their participation.

## 1.3

### National Health Information Work Program

The National Health Information Work Program is a rolling triennial work program of national health information projects, agreed to by the Management Group and endorsed by the Australian Health Ministers' Advisory Council. Inclusion of a project in the Work Program indicates that work is either currently under way on that project or will be commenced within the time frame of the Work Program.

The Work Program also provides a detailed program for the coming year, details of individual activities and specifies the agency responsible for project coordination and management.

#### Criteria for including projects in the Work Program

The project must meet the following criteria:

- the project must be concerned with health information activities that
  - meet agreed national priorities
  - have a national focus or national implications;
- the agency responsible for project coordination and management, i.e. the Responsible Agency, must be a signatory to the Agreement or the project must be coordinated and managed in conjunction with a signatory to the Agreement;
- the Responsible Agency must have available or be able to draw on financial resources and expertise sufficient to undertake and complete the project.

#### Procedure for including projects in the Work Program

All project proposals are to be submitted in a standard format through the National Health Information Secretariat to the Management Group by the intended Responsible Agency.

Private and non-government organisations may submit project proposals of national significance either through a signatory to the Agreement or through the National Health Information Secretariat.

#### Project funding

The cost of implementing agreed activities will usually be met by the signatories as a component of their own work programs. Reciprocal arrangements may be made between signatories to meet specific needs for additional collections, specific analyses or the provision of additional expertise.

In special circumstances, requests to AHMAC for financial assistance may be directed to the Management Group through the National Health Information Secretariat.

The Work Program will take account of the resource constraints of the signatories.

### **Project reporting**

Each project plan will provide an overall program for the coming year, including details of the specific outputs and milestones expected within the time frame allocated.

Each Responsible Agency is required to address the issues from a national rather than a Commonwealth or State perspective by consulting broadly and using national data definitions and standards as defined in the National Health Data Dictionary.

A six-monthly report on the progress of each project will be prepared by the Responsible Agency for the Management Group and forwarded to the National Health Information Secretariat.

### **Publication of the Work Program**

The complete triennial Work Program will be provided to Responsible Agencies and revised with new inclusions each financial year.

A summary Work Program listing the projects for the current year, major outputs and responsible agencies will be published annually by the National Health Information Secretariat.

### **Roles and responsibilities of responsible agencies**

A Responsible Agency will:

- undertake the responsibility for the development and implementation of the designated project set out in the National Health Information Work Program;
- submit to the Management Group, for endorsement, a project work plan that specifies the proposed sources of funds, budget, project specific resources and expertise needed and available, and project milestones and time frames;
- set up agreed consultative links with all other parties to ensure the national nature of the project is maintained (to this end responsible agencies may invite representatives of other health interests, including the health professions, private sector and non-government organisations to

participate in National Health Information Work Program activities):

- the nature and frequency of these links are to be set out in the project work plan;
- plans for liaising and cooperating with relevant existing projects should be considered when specifying these links;
- ensure that different levels of users, and where applicable consumers, are represented on the project;
- define the link with the Institute on National Health Data Dictionary definitional development;
- where applicable, develop a time line for National Health Data Dictionary development activity in cooperation with the Institute:
  - submit progress reports and draft definitions to the Institute in accordance with the agreed time line;
- report six monthly, or as requested, to the Management Group on the progress of the project, including financial reports on expenditure of any joint funds;
- ensure that all National Health Data Dictionary inputs incorporate appropriate quality-of-care indicators that are consistent with those developed in the hospital outcome and health service outcome projects.

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## 2

# National Health Data Committee

### Function

The National Health Data Committee has the responsibility to:

- maintain the development and revision of the National Health Data Dictionary and national minimum data sets in all areas of health, including institutional health care;
- receive, consider and comment on all draft National Health Data Dictionary input;
- take a pro-active role in national definition development while retaining its emphasis on the primary function of coordination of National Health Data Dictionary inputs;
- ensure that the authors of draft inputs to the National Health Data Dictionary have undertaken sufficient national consultation and that the definitions are acceptable for national implementation;
- receive, consider, comment on and endorse inputs to the National Health Data Dictionary modules, and recommend these to the Management Group;
- develop the conceptual basis of the National Health Data Dictionary in light of the scope of the National Health Information Work Program;
- determine the manner in which the National Health Data Dictionary and its revisions are disseminated;
- consult on and determine the expansion of the National Health Data Dictionary to other areas of health;
- recommend and review from time to time, the scope of data and items collected in Management Group designated minimum data sets.

The Committee may facilitate entry to the National Health Information Work Program of those definitional developments that meet or have the potential to meet the specified criteria for inclusion on the work program (see section 1.3 on page 11).

## **Membership**

The membership of the National Health Data Committee comprises representatives of each signatory of the Agreement, the Australian Private Hospitals' Association, the Department of Veterans' Affairs and others designated by the Management Group. The National Health Data Committee may co-opt other individuals to provide expert advice. The Committee is chaired by the Australian Institute of Health and Welfare.

The Committee Executive consists of the Chair and a representative from each of the Australian Bureau of Statistics, the Department of Human Services and Health, the larger states (Victoria for 1994-97) and the smaller states (Queensland for 1994-97).

## **Operating procedures**

The National Health Data Committee establishes its work program at the beginning of each calendar year, and usually meets four times each year.

When a consensus decision cannot be reached, the matter will be referred to the Institute and the Australian Bureau of Statistics for a recommendation to the Management Group for final decision. AHMAC is the final arbiter of all contentious decisions.

The individual parties meet the cost of their participation in the Committee.

## **Secretariat**

The Institute, through the National Health Information Unit, provides:

- the National Health Data Committee Secretariat;
- support to the Chair;
- technical support;
- coordination of follow-up action.

## **Submissions**

All papers for consideration by the Committee are to be submitted through the National Health Information Secretariat at least 15 working days prior to the next meeting date. All dictionary and minimum data set proposals are to be submitted in a standard format.

Those private and other non-government organisations not represented on the Committee should submit proposals for definitional development through a member of the Committee or through the National Health Information Secretariat initially.

## **Meetings**

The National Health Data Committee meeting agenda and accompanying papers are to be despatched by the Secretariat to Committee members ten days prior to the scheduled meeting. The agenda should specify the action required for each item, e.g. decision, discussion, for information.

Draft minutes are to be prepared within 10 working days of the meeting and circulated to Committee members for comment.

Arising from the meeting, a list of items requiring action will be distributed with the minutes.

Minutes will be provided to members of the Management Group.

## **Annual time lines**

The Committee conducts the review of the National Health Data Dictionary on an annual basis, ensuring decisions are made and definitions finalised to allow nine months lead-up before implementation.

The Committee operates a review, development and publication cycle based on the calendar year. Work to be conducted is agreed each February and proceeds from March through to August.

Recommendations are prepared in September for consideration at the October meeting. Agreed definitions are submitted to the National Health Information Management Group for endorsement in November, allowing nine months to implementation on 1 July the following year.

## 2.1

# National Health Data Committee —establishment and operation of working groups

### Terms of reference

The National Health Data Committee will establish terms of reference for each working group, setting out:

- the context of the task of the working group;
- issue(s) to be addressed;
- the task of that working group;
- the extent and level of consultation considered necessary;
- milestones and reporting deadlines.

### Convenor

The convenor is appointed by the Committee.

### Membership

The membership may be specified by or agreed to by the Committee after consultation with the convenor.

### Roles and responsibilities of the convenor

The convenor is responsible for the operation of the working group including:

- arranging for working group meetings (ideally held via teleconference), agenda and other operational issues;
- ensuring adequate consultation, both in terms of extent and level;
- maintaining records of meetings and their distribution to working group members and the National Health Information Secretariat;
- meeting the group's work plan, consultation and reporting requirements mentioned in the terms of reference above.

### Work plan

The Committee shall develop each working group's agenda. Each working group will develop and submit to the National Health Information Secretariat a program outline including terms of reference, work plan, milestones, time lines and reporting time frames.

### Consultation requirements

Each working group will set up consultation, where appropriate, with all other parties to ensure the

national nature of the project is maintained and the views of different levels of users, suppliers and consumers are considered. The convenor may invite representatives of other health interests including the health professions, private sector and non-government organisations to participate in working group activities.

**Reporting requirements**

Progress and meeting reports are to be provided to each meeting of the Committee—these are to be received by the National Health Information Secretariat no later than 15 working days before the Committee meeting.

**Financial arrangements**

Individual parties will meet the cost of their participation. Assistance in meeting travel expenses for an invited clinician or expert who is not in government employment or not entitled to reimbursement of costs may be provided at the discretion of the Committee. Travel under these circumstances must be approved by the Chair of the National Health Data Committee and coordinated through the National Health Information Secretariat.

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# 3

## National Health Data Dictionary

The National Health Data Dictionary is a set of data items and definitions. It is intended to facilitate the collection of uniform data in order to more accurately describe and compare health services throughout Australia. The National Health Data Dictionary is the authoritative source of health data definitions.

### Principles to guide development of National Health Data Dictionary definitions

National Health Data Dictionary definitions should:

- conform to the concepts of:
  - uniformity*—the same definition consistent among multiple providers and among multiple collectors. It is assumed that there will continue to be multiple systems for recording, processing and using the data items; but when a data item is recorded and later abstracted, it will always conform to its definitions;
  - utility*—a data item/definition is included in the National Health Data Dictionary only after determination that the data item definition has demonstrated utility for many user groups. Items which are of limited utility or which are useful only to limited user groups are excluded;
- employ existing concepts:
  - the Agreement states that data standards adopted by the Australian Bureau of Statistics and authoritative international organisations (such as Open Systems Connection (OSI) and European Standardisation Committee/Technical Committee for Medical Informatics (CEN/TC 251)) will be employed wherever possible and variations made explicit when this is not possible.
- follow the fundamental principles endorsed by the National Health Information Management Group:
  - a definition that is developed for national purposes, i.e. to be published in the National Health Data Dictionary, should reflect or describe the every day practice of the service providers. Any immediate policy or legislative requirements should be taken into account with the creation of additional data items or flags.

## **Criteria for recommending inputs to the National Health Data Dictionary**

The following criteria are used by the National Health Data Committee as a guide to determining the eligibility of a set of definitions that are put forward for acceptance into the National Health Data Dictionary. In order for an input to be recommended for acceptance into the National Health Data Dictionary, the input should:

- comply with the Committee's principles for National Health Data Dictionary definition development (see above);
- follow the recommended standard data definition format (see below);
- contain the recommended minimum content for National Health Data Dictionary definitions (see below);
- be accompanied by evidence that the input was developed:
  - using a national consultation process involving all relevant jurisdictions where possible;
  - with consensus from the parties to that process;
  - with all jurisdictions, where possible, having agreed to or endorsing the definitions;
- give an indication of the degree to which the definitions have been implemented or have been agreed to be implemented by the constituency;
- show evidence of pilot testing for all new data constructs and definitions being recommended for introduction for the first time. Results of pilot testing should be incorporated into the proposals. Where inputs have been developed from well-established data collections, evidence of the cost-effectiveness, feasibility of collection and utility of the proposed definitions should be included in the proposal;
- include a recommended process for implementation, review and future development of the definitions. A process for supporting the ongoing review, maintenance and development of the input needs to be developed.

It is advisable to submit draft data definitions to the Committee as part of the consultation process. All draft data definition development for incorporation into the National Health Data Dictionary must be submitted by the responsible agency or National Health Data Dictionary working party to the Committee, unless advised otherwise.

## Recommended format for National Health Data Dictionary definitions

The format of National Health Data Dictionary data definitions must include the following elements:

- *Term or item name*—name of the concept that is being defined;
- *Variable Number*—allocated by the National Health Information Unit;
- *Definition*—the recommended definition of the term or item;
- *Guide for use*—deals with any 'notes' that may accompany a definition to give additional information, explain or enhance interpretation;
- *Classification/coding*—specifies how the item is to be classified and reported, e.g. 1 = Yes, 2 = No, Australian Standard Classification of Occupation (ASCO) six-digit code. Consultation with the National Coding Centre may be appropriate.
- *Effective from*—date the definition becomes effective in the National Health Data Dictionary.
- *Effective to*—date on which the definition ceased to be part of the National Health Data Dictionary. This is the opposite of 'Effective from'. This definition will remain in the National Health Data Dictionary as it will have been valid for a period of time. This is separate from items that have been superseded, i.e. the definition has changed, not ceased.
- *National minimum data set*—the national minimum data set/s in which this definition is employed.
- *Justification*—grounds for the creation and utility of the definition;
- *Source of definition*— specifies the name of the lead agency or working group responsible for developing/revising the definition;
- *Related to/used with*—specifies the related definitions to assist in ensuring consistency across the National Health Data Dictionary when terms or items are updated or revised;
- *Comment*—explanatory notes regarding the formation or the definition. Describe the current situation and the reasons for decisions taken. Give examples of how the definition is to be applied, this will help implementation and collection of the item. If applicable, give an indication of issues for resolution in future revision of the item.

The above are compulsory elements of a National Health Data Dictionary definition. It may be relevant to include more detail such as an acceptable abbreviated form of a term or item name; synonym(s) that are in current use; obsolete or superseded terms; or references to related entries, i.e. 'Used with'.

**Recommended minimum format for National Health Data Dictionary input proposals**

1. Introduction and background
  - rationale
  - process employed to create the module
  - review mechanism and proposed time line
  - contact names for comments and support
2. Objectives, uses and users
  - scope
  - about the module and the data that will be collected
  - relationship to the rest of the dictionary
  - forecast of future development
3. The conceptual basis
4. Terminology
  - definitions that stand alone and do not have data collected against them
5. Definitions
  - organised by the conceptual basis
6. References
7. Index

**Publication of the National Health Data Dictionary**

Processes for publication of the National Health Data Dictionary will include:

- the National Health Information Unit estimating, in consultation with each Responsible Agency, a timetable for publication each calendar year;
- the National Health Information Unit and Responsible Agency, when referring the final component document to the Committee, agreeing to:
  - an estimated date of receipt of the final (Management Group endorsed) document
  - the format of the document including:
    - table of contents
    - item format
    - preferred media—e.g. 3.5 inch floppy diskette and word processing package;

- compiling a mailing list for distribution of the document by the National Health Information Unit.

**Responsibilities  
of the National  
Health  
Information Unit**

The responsibilities of the National Health Information Unit include:

- documenting progress of the publication process;
- editing the component document;
- inputting the document into the National Health Data Dictionary database;
- overseeing printing and arranging distribution of the document.

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## 4

# National minimum data sets

National minimum data sets are those subsets of National Health Data Dictionary data items which will be collected nationally in a forthcoming collection period. A proposed national minimum data set collection should be recommended to the National Health Data Committee separately from a National Health Data Dictionary proposal. This may occur concurrently with a National Health Data Dictionary proposal or at a later date.

Preparation and submission of a national minimum data set to the Committee must follow the same procedure as specified for National Health Data Dictionary inputs.

Scope and timing of the collection must be considered. It may not need to be collected by all agencies annually, but by sample or survey at appropriate intervals, e.g. three years may be adequate to meet the purpose of a national minimum data set.

### **Recommended format for national minimum data set data items**

The format of national minimum data set items must include the following elements:

- *Term or item name*—name of the concept that is to be collected (as given in the National Health Data Dictionary);
- *Variable number*—allocated by the National Health Information Unit and specified in the National Health Data Dictionary;
- *Scope*—indication of the range or extent of the definition or data item, for example, all health occupations/professions; nursing profession; general hospitals/psychiatric hospitals;
- *Level of enumeration*—specify the level that is being counted, i.e. the individual, the establishment, the health system;
- *Effective in the national minimum data set from*—the date on which the definition is included in the specified national minimum data set;

- *Effective in the National Minimum Data Set to*—the date on which the definition ceased to be part of the specified national minimum data set;
- *Justification*—grounds for the utility of the data item within the specified national minimum data set;
- *Timing*—when an item is to be collected, e.g. on admission, on separation or on 30 June.
- *Related to/used with*—specifies the related definitions to assist in ensuring consistency across the specified national minimum data set when items are updated or revised.
- *Comment*—explanatory notes regarding the item that have not been covered in the other elements of the item definition.

## 5

# Committee members (at October 1994)

### National Health Information Management Group

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# **Part 2**

# **National Health Information Agreement**

AGREEMENT  
BETWEEN  
THE HEALTH AUTHORITIES OF  
THE COMMONWEALTH OF AUSTRALIA,  
THE STATES AND TERRITORIES OF AUSTRALIA  
AND  
THE AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE  
AND  
THE AUSTRALIAN BUREAU OF STATISTICS

Concerning the establishment of structures and processes through which the Commonwealth, State and Territory health and statistical authorities will develop agreed programs to improve, maintain and share national health information.

# Preamble

The planning and provision of health services and health programs are important and complex undertakings in which governments, government instrumentalities, private organisations, health professionals, academics, community groups and individuals have shared responsibilities.

The national health system operates within finite resources that cannot be expected to increase significantly in real terms. The system is required to meet increasing demands and changing needs and is experiencing major technological advances. Health and statistical authorities are committed to micro economic and structural reform and to being responsible and accountable for their expenditure and impact.

Information is required about health services and health service consumers; and about environmental and human factors that may affect health. To ensure that essential, accurate, reliable and timely information is available nationwide for and about the health system a coordinated approach and agreed rules are needed to facilitate jurisdictional cooperation, efficient and effective utilisation of financial and intellectual resources.

Much health service information is generated by health professionals and health administrators in the conduct of their normal activities. Consistent with sound management and commercial practice and protection of individual privacy, the use of this information should be optimised. Collections should be rationalised to eliminate duplication and minimise the need for special collections. Some health status information is available from these sources, but significant health related data are collected by groups such as the Australian Bureau of Statistics, Worksafe, National Heart Foundation and environmental protection authorities.

As governments provide or finance almost 70 per cent of all health services, and largely fund the training of health professionals, they are major producers and users of health information. Therefore, the Agreement will cover government authorities initially but efforts will be made to involve other sectors in the processes and possibly in the Agreement itself.

This Agreement is to ensure that the collection, compilation and interpretation of national information are appropriate and are carried out efficiently. This will require agreement on definitions, standards and rules of collection of information and on guidelines for the co-ordination of access, interpretation and publication of national health information.

The Australian community will be the beneficiaries of this Agreement as the result of better and more timely information, more appropriate provision of services, improved health outcomes and improved efficiency.

For the purposes of this Agreement, 'health information' is data or derived information, indices, computer software, publications in any medium, concerned with:

- the health status and risks of individuals and populations; and
- the provision of health and illness care services, health promotion and disease prevention programs including information on the uses, costs and outcomes of services and programs, and the resources required to provide the services and programs.

## 2

# Aim and objectives

The aim is to improve access to uniform health information by community groups, health professionals, government and non-government organisations. Specifically, the objectives are to:

- promote the collection, compilation, analysis and dissemination of relevant, timely, accurate and reliable health information concerned with the full range of health services and of a range of population parameters (including health status and risks), in accordance with nationally agreed protocols and standards;
- develop and agree on projects to improve, maintain and share national health information;
- cooperate in the provision of resources necessary to address national health information development priorities efficiently and effectively;
- provide the information required to research, monitor and improve health and the delivery of health services;
- provide the information required to facilitate nationally agreed projects which promote the development and reform of the health care system in accordance with the priorities of the Australian Health Ministers' Advisory Council; and
- promote the extension of the range of national health information and encourage other groups and individuals in government and non-government sectors to participate by making available information that they hold.

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## 3

## Context

This section describes the context and underlying principles within which the Agreement will operate.

### 3.1

#### Collection of national health information

- 3.1.1 Health information under this Agreement will be gathered and maintained nationally with the approval of the Australian Health Ministers' Advisory Council.
- 3.1.2 National collections will use data from surveys of the Australian population as well as data contributed by the Parties, their agents or by other parties. The level of data contributed to national collections, being at an appropriate level of aggregation or unit record, will be agreed for each collection.
- 3.1.3 National data linkage will be allowed only in accordance with agreed privacy and ethical guidelines and for such purposes as longitudinal studies of individuals and/or the study of sequential or concurrent events.
- 3.1.4 Responsibility for the quality and completeness of contributed data will remain with the Party providing the data.

### 3.2

#### Rights and privileges

- 3.2.1 Unless in the public domain, data provided by a Party remains the sole property of that individual Party and therefore release, publication or other use of the data by any other party or group will be within any arrangements set by the providing party.
- 3.2.2 When publishing or releasing any national health information each Party shall acknowledge the authorship as advised by the provider of the data.
- 3.2.3 Users of the information will be expected to respect the custodial role and ownership rights of collecting parties and no Party shall be obliged to supply any information or to identify its origin if by so doing it would

jeopardise that Party's continuing access to the information.

- 3.2.4 All information contributed by Parties to this Agreement will be provided in good faith as to its accuracy and any legal or other liability arising from the use of any information supplied to national collections shall be the responsibility of the publishing Party.

### **3.3**

#### **Access to national health information**

- 3.3.1 Any transfer or storage of data for national collections will be in a manner that prevents unauthorised access.
- 3.3.2 Unpublished national health information may be made available according to agreed privacy and ethical considerations and by agreement with the providers of the information.

### **3.4**

#### **Privacy**

- 3.4.1 All parties will respect the rights to privacy of any person or organisation named or otherwise identified in any information resource.

### **3.5**

#### **Standards for national health information**

The Parties will agree and comply with definitions and standards for national information collections, including completeness and timeliness standards.

## **4 Operation of the Agreement**

The Agreement is a multilateral agreement between the Parties and operates under the auspices of the Australian Health Ministers' Advisory Council.

### **4.1 Ownership and release of information**

- 4.1.1 The owner of the information is the collecting authority. Owners also may have custodial roles in respect of information they receive from and manage for other parties.
- 4.1.2 Information will be made available nationally to all levels of the health system according to ethical and privacy considerations discussed elsewhere in this document.
- 4.1.3 The owner may specify conditions regarding the use, release and publication of information and such other considerations as are reasonable and necessary. Release of otherwise unpublished information to any party requires the approval of the owner or to be within the conditions specified.

### **4.2 Collection of Information**

- 4.2.1 Agreed definitions and standards will be applied rigorously to ensure that information is capable of national comparison.
- 4.2.2 Information will be collected in such a way that it is timely and of high quality.
- 4.2.3 National data which is not collected by national survey will generally be collated by the Australian Institute of Health and Welfare and will be provided by the Parties following assessment of quality and in a form which meets the requirements of the particular collection.

## 4.3

### **Maintenance of Information**

Information will be collected and maintained by the Parties to the Agreement who will release it in a way consistent with agreed national protocols, definitions and standards.

## 4.4

### **Privacy**

- 4.4.1 Information will be collected, disseminated, used and secured in such a way as to protect the privacy and confidentiality of any individual and/or organisation to whom it may refer. In particular, all State and Commonwealth privacy, confidentiality, quality and freedom of information policy and legislation and established ethical guidelines and practices will be complied with in any formal or informal arrangements made under this Agreement.
- 4.4.2 The concerns of individuals who are members of minority or small community groups regarding privacy are acknowledged and advice on such concerns will be sought from State and/or other authorities.
- 4.4.3 When individual data sets are too small for protection of privacy and/or reliable interpretation linked or other data sets may be used to contribute derived data.

## 4.5

### **Funding for national health information**

- 4.5.1 The costs of implementing agreed activities will generally be met by the Parties as a component of their own work programs. However, reciprocal arrangements may be made between the Parties to meet specific needs for additional collections, specific analyses or provision of additional expertise.
- 4.5.2 Proposals for alternative resourcing may be developed where national benefit can be identified. Thus, funding may be sought under the Agreement where work on specific health information issues imposes additional costs on a signatory, where there are economies of scale to be gained, or where joint action of the Parties contributes to meeting the objectives of the Agreement.

- 4.5.3 The parties will agree on the distribution of any income generated.
- 4.5.4 The cost recovery policy of each of the contributing Parties will be made explicit in respect of agreed Work Program activities.

## **4.6**

### **National Health Information Work Program**

- 4.6.1 There will be a rolling triennial work program agreed by the Australian Health Ministers' Advisory Council.
- 4.6.2 The Work Program will take account of the resource constraints of the Parties.
- 4.6.3 The Work Program will outline the projects which will be undertaken over the next three years. It will include a detailed program for the coming year providing details of the specific projects and the agencies responsible for coordination and management of each project.
- 4.6.4 A six monthly report on the progress of each project will be prepared by the agency responsible and circulated to the Parties by the Australian Institute of Health and Welfare.

## **4.7**

### **Standards for information**

- 4.7.1 All Parties agree to cooperate in the improvement of health information standards.
- 4.7.2 The National Health Data Dictionary will be the authoritative source of data definitions.
- 4.7.3 Data standards adopted by Australian Bureau of Statistics and authoritative international organisations will be employed wherever possible and variations made explicit when this is not possible.

## **4.8**

### **Extension of the collections**

Every attempt will be made to involve other sectors collecting and using health information in the processes of this Agreement.

## **4.9**

### **Duration of the Agreement**

The Agreement will operate for a period of five years and after review, for a further period as agreed by all the Parties.

## **4.10**

### **Variation to the Agreement**

4.10.1 The Agreement may be amended at any time by agreement between all the Parties.

4.10.2 Additional parties may become Parties to the Agreement if all existing Parties agree.

4.10.3 A party proposing to withdraw should give six months notice. If a Party withdraws, the Agreement will continue to operate in respect of all other Parties.

## **4.11**

### **Termination of the Agreement**

The Agreement may be terminated at any time by agreement in writing of the remaining Parties.

## 5

# Management of the Agreement

- 5.0.1 This Agreement will operate under the auspices of the Australian Health Ministers' Advisory Council (AHMAC). The AHMAC will be the ultimate authority for resolving issues relating to the Agreement including determination of national priorities, the triennial work program and other management matters.
- 5.0.2 Each of the Parties will provide a representative on the Management Group which will:
- oversee the direction, development, review and implementation of the Agreement and the agreed work program;
  - make recommendations to the AHMAC on national priorities, work programs, funding implications and other policy issues;
  - negotiate with other groups and individuals for the collection and dissemination of information which will enhance the provision of health care; and
  - oversee the review and maintenance of the National Health Data Dictionary.
- 5.0.3 The Management Group will select an inaugural chairperson and deputy chairperson for a two year period. The positions will then rotate to other Parties.
- 5.0.4 The Australian Institute of Health and Welfare will provide secretariat assistance to the Management Group and support to the chair of the group.
- 5.0.5 The individual Parties will meet the cost of their participation in the operation and management of the Agreement.

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## **6 Responsibilities of parties to the Agreement**

Specific responsibilities of the parties to the Agreement are:

### **6.1 The Australian Bureau of Statistics (ABS)**

The ABS will be responsible for:

- 6.1.1 providing representation on the Management Group overseeing the Agreement;
- 6.1.2 acting as the responsible agency for specific Work Program areas as agreed;
- 6.1.3 collecting, compiling, analysing and disseminating statistics and related information for which they have specific responsibility;
- 6.1.4 developing statistical standards; and
- 6.1.5 providing specialist advice in relation to statistics.

### **6.2 The Australian Institute of Health and Welfare (AIHW)**

The AIHW will be responsible for:

- 6.2.1 providing representation on the management group overseeing the Agreement;
- 6.2.2 acting as the responsible agency for specific Work Program projects as agreed;
- 6.2.3 convening and providing secretariat assistance to the Management Group overseeing the Agreement;
- 6.2.4 in consultation with the ABS, developing specialised statistical standards and classifications relevant to health and health services;

- 6.2.5 providing information and specialist advice on activities and collections for which it has responsibility;
- 6.2.6 ensuring that information collected, maintained and collated by the AIHW is consistent with the national protocols, definitions and standards contained in the National Health Data Dictionary and other guidelines endorsed by the AHMAC;
- 6.2.7 maintaining the information collected by the AIHW under the aegis of the Agreement in such a way that it can be readily made available to approved individuals, groups and authorities for purposes which require access to national health information kept under the terms of the Agreement;
- 6.2.8 ensuring that information held by the AIHW is maintained in such a way as to ensure that the privacy provisions of the Agreement are observed;
- 6.2.9 undertaking specific research, using national data, to improve the efficiency and effectiveness of the health care system;
- 6.2.10 assisting other Parties to the Agreement in using and interpreting national health information; and
- 6.2.11 ensuring that the National Health Data Dictionary and other quality control standards to encourage accuracy and consistency in the collection and reporting of health information are maintained and enhanced as agreed by the AHMAC.

## 6.3

### **The Commonwealth Department of Health, Housing, Local Government and Community Services (HHLGCS)**

HHLGCS will be responsible for:

- 6.3.1 providing representation on the management group overseeing the Agreement;
- 6.3.2 acting as the responsible agency for specific Work Program projects as agreed;

- 6.3.3 maintaining and providing information in accordance with agreed purposes and data sets;
- 6.3.4 ensuring that information collected, maintained and collated by the HHLGCS is consistent with the national protocols, definitions and standards contained in the National Health Data Dictionary and other guidelines endorsed by the AHMAC;
- 6.3.5 maintaining the information collected by the HHLGCS under the aegis of the Agreement in such a way that it can be readily made available to approved individuals, groups and authorities for purposes which require access to national health information kept under the terms of the Agreement; and
- 6.3.6 ensuring that information held by the HHLGCS is maintained in such a way as to ensure that the privacy provisions of the Agreement are observed.

## **6.4**

### **State/Territory Health Authorities (SHAs)**

Each SHA will be responsible for:

- 6.4.1 providing representation on the management group overseeing the Agreement;
- 6.4.2 act as responsible agency for specific Work Program projects as agreed;
- 6.4.3 maintaining and providing information in accordance with agreed purposes and data sets;
- 6.4.4 ensuring that information collected, maintained and collated by the SHA is consistent with the national protocols, definitions and standards contained in the National Health Data Dictionary and other guidelines endorsed by the AHMAC;
- 6.4.5 maintaining the information collected by the SHA under the aegis of the Agreement in such a way that it can be readily made available to approved individuals, groups and authorities for purposes which require access to national health information kept under the terms of the Agreement; and

6.4.6 ensuring that information is maintained by the SHIA in such a way as to ensure that the privacy provisions of the Agreement are observed.

# 7

## Date of commencement of the Agreement

The Agreement will commence on 1 June 1993.

In witness whereof this Agreement has been made the day of May 1993 and signed.

SIGNED for and on behalf of the Commonwealth Department of Health Housing Local Government and Community Services by

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Secretary of the Department, in the presence of

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SIGNED for and on behalf of the New South Wales Health Department by

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Director - General, in the presence of

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SIGNED for and on behalf of Health and Community Services Victoria by

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Director - General, in the presence of

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SIGNED for and on behalf of Queensland Health by

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Director-General, in the presence of

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SIGNED for and on behalf of the South Australian Health Commission by

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Chairman, in the presence of

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SIGNED for and on behalf of the Health Department of Western Australia by

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Commissioner, in the presence of

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SIGNED for and on behalf of the Department of Community and Health Services, Tasmania by

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Secretary, in the presence of

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SIGNED for and on behalf of the Department of Health and Community Services Northern Territory by

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Secretary, in the presence of

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SIGNED for and on behalf of ACT Health by

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Chief Executive, in the presence of

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SIGNED for and on behalf of the Australian Institute  
of Health and Welfare by

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acting Director in the presence of

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SIGNED for and on behalf of the Australian Bureau of  
Statistics by

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Australian Statistician, in the presence of

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