Australian Government



Australian Institute of Health and Welfare

# Creating nationally-consistent health information

Engaging with the national health information committees



# Creating nationally-consistent health information:

## Engaging with the national health information committees

Prepared by National Health Information Standards and Statistics Committee March 2014

> Australian Institute of Health and Welfare Canberra Cat. no. CSI 18

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Board Chair Dr Andrew Refshauge Director David Kalisch

Any enquiries about or comments on this publication should be directed to: NHISSC Secretariat Australian Institute of Health and Welfare GPO Box 570 Canberra ACT 2601 Tel: (02) 6244 1033 Email: NHISSCSec@aihw.gov.au

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### Abbreviations

Australian Commission for Safety and Quality in Health Care
Australian Health Ministers' Advisory Council
Australian Health Protection Principal Committee
Australian Institute of Health and Welfare
Community Care and Population Health Principal Committee
Council of Australian Governments
Data Set Specification
Health Workforce Principal Committee
Hospitals Principal Committee
Independent Hospital Pricing Authority
Joint Standing Committee on Health Informatics Standards
Mental Health/Drug and Alcohol Principal Committee
Mental Health Information Strategy Standing Committee
METeOR and Metadata Unit
National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data
National E-Health Transition Authority
National Health Chief Information Officers Forum
National health data dictionary
National Health Funding Body
National Health Information and Performance Principal Committee
National Health Information Standards and Statistics Committee
National Health Performance Authority
National minimum data set
Standing Committee on Performance and Reporting

## Summary

In a health system dispersed across the states and territories by the Australian Government, strong governance arrangements are needed to ensure that health information, collected under different health administrations, are consistent and therefore accurate and useful for policy, planning and program management.

The National Health Information Agreement, signed in 2011 by all jurisdictions and the national health agencies associated with health information, provides the overarching framework for the governance of national data collections.

Governance mechanisms for many aspects of health information are established under the Standing Council on Health (SCoH), with particular committees vested with delegated authority to endorse national standards and definitions.

This document provides guidance on engaging with the national processes responsible for health information and data standards.

In particular, it describes how those developing data about some aspect of health can obtain assistance with, and/or endorsement of, their data development work.

## Engaging with the national health information committees

## Which are the key national health information committees?

The National Health Information and Performance Principal Committee (NHIPPC) reports to the Australian Health Ministers' Advisory Council (AHMAC) and, through AHMAC, to the Standing Council on Health (SCoH).

NHIPPC has overall responsibility for advising AHMAC on information strategies, and for facilitating collaboration between the Australian Government and states and territories to implement these strategies.

NHIPPC provides advice to AHMAC on needs and priorities for health information. For example, effort has focused on developing measures to monitor the performance of Australia's health system, and on information about the health of Aboriginal and Torres Strait Islander people.

NHIPPC's sub-committee, the National Health Information Standards and Statistics Committee (NHISSC) is responsible for overseeing the development of, and recommending to NHIPPC endorsement of:

- data standards for inclusion in the National health data dictionary (NHDD)
- mandatory national minimum data sets for national implementation
- best practice data set specifications for inclusion in the NHDD.

NHISSC is also responsible for providing advice on the technical aspects of national performance indicator specifications.

The Australian Institute of Health and Welfare (AIHW) was established via the *Australian Institute of Health and Welfare Act 1987* to provide information and statistics on Australia's health and welfare. The AIHW plays a role in developing and maintaining national metadata standards. Australia's repository for national metadata standards for the health, community services and housing assistance information (METeOR) is housed by the AIHW, and the AIHW provides the secretariat for NHISSC. The AIHW works closely with government and non-government organisations to achieve greater adherence to the data standards in administrative data collections, to promote national consistency and comparability of data and reporting.

In addition, the Council of Australian Governments (COAG) has established 4 independent National Health Reform agencies – National Health Performance Authority (NHPA), Independent Hospital Pricing Authority (IHPA), National Health Funding Body (NHFB) and the Australian Commission for Safety and Quality in Health Care (ACSQHC). All of these have important data development, analysis or reporting responsibilities and interact with AHMAC mainly through NHIPPC and its committees.

Various other committees relate to NHIPPC and NHISSC. These are shown in Figure 1.

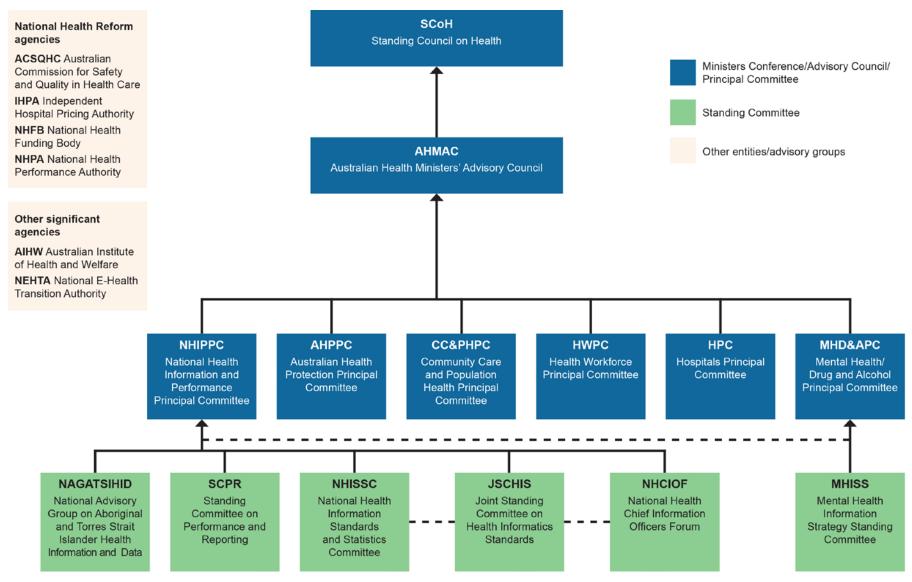


Figure 1: National health information committees

### What does NHISSC do?

NHISSC carries out 2 key roles in the national information governance arrangements in relation to data development. It is the recommending body for:

- data standards that underpin national reporting, including standard definitions of data items (such as a diagnosis or procedure) or standard specifications of data sets (such as a data set describing the operations of public hospitals)
- protocols for statistical and analytical methods that affect the creation or use of health information (such as data confidentialisation and data linkage).

NHISSC's responsibilities also include providing advice on the technical aspects of performance indicator specification including the collection, quality and completeness of the underlying data needed in measuring performance against the indicator.

### What is 'data development'?

'Data development' is the process of building a data set for a specific purpose. For example, one might wish to build a data set that supports research into cancer diagnoses, treatment and outcomes, or one that supports statistical reporting about the operations of hospital emergency departments.

Data development demands a clear understanding of why the data are needed; for example, to underpin the design and evaluation of health policy, or to assess the performance of health services, or to support research into patterns of disease.

It also requires an assessment of the practicalities of collecting the data. Health services are delivered by diverse providers operating in a variety of settings under different public and private sector governance, management and financial arrangements. Building almost any data set will demand the assembly of data from multiple sources. Thus, if valid national data are to be compiled, there must be an understanding of the diverse information systems from which the data are drawn, and there must be an effort to apply or develop common standards for concepts, classifications, terminologies, data values and so forth.

Successful data development requires a variety of expertise typically:

- clinical expertise (relating to diseases and treatments)
- health service expertise (relating to the settings and delivery of services)
- statistical expertise (relating to data collection, quality assessment and analysis)
- informatics expertise (relating to concept formation, definitions and metadata).

For more information about the data development process, see the AIHW publication, *A guide to data development*, available on the AIHW website at < www.aihw.gov.au>.

### Why should I engage with NHISSC?

Over several decades, the national health information committees in various forms have overseen the development of standards for compiling and reporting health information.

• This work – which has been undertaken collaboratively by health information experts, clinicians and others from Australian, state and territory governments and from the

private sector — has generated considerable expertise. It has also created some major infrastructure, including: the *NHDD*, which provides standard definitions of health data items;

- the suite of national minimum data sets, which are the basis for the supply of consistent jurisdictional data that are assembled into national reports on the operation of Australia's health system
- METeOR, an online repository of health and other metadata. For more information see the AIHW's metadata online registry at < meteor.aihw.gov.au>.

Those developing new data sets will find it valuable to engage with NHISSC at an early stage in order to:

- draw on their expertise in conducting data development projects
- ensure that the concepts, classifications, terminologies and so on being developed for the new data set are consistent with those already in place for other data sets, and/or
- seek a recommendation to NHIPPC for endorsement of the new data set as a national standard.

NHISSC has established processes for data development projects including:

- registering a data development project on a committee's work program
- auspicing the working group that is undertaking the data development
- checking consistency of the project's recommendations with national standards
- assessing the business case for implementing a data collection
- transmitting a recommendation to the parent (or principal) committee.

Attachment 1 The Appendix provides further information on the health metadata development process.

It is not necessary, however, for those planning to develop a health data set to understand or wrestle with all the details of these processes.

It is more valuable to make early contact with the information committees and to open a conversation about what work is planned and how to begin engagement with the committees.

#### How do I contact NHISSC?

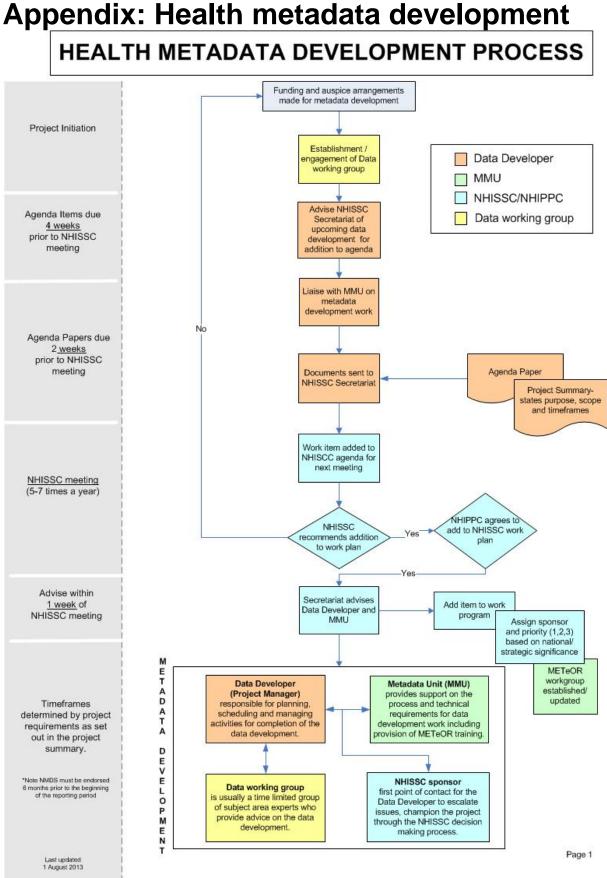
The first point of contact for someone planning to undertake health data development is the NHISSC Secretariat at the AIHW.

The NHISSC Secretariat will ascertain what data development activity you are planning, what information need it will satisfy, who has commissioned or is sponsoring the activity, who is involved in the data development, how far your work has progressed, and what eventual use will be made of your work.

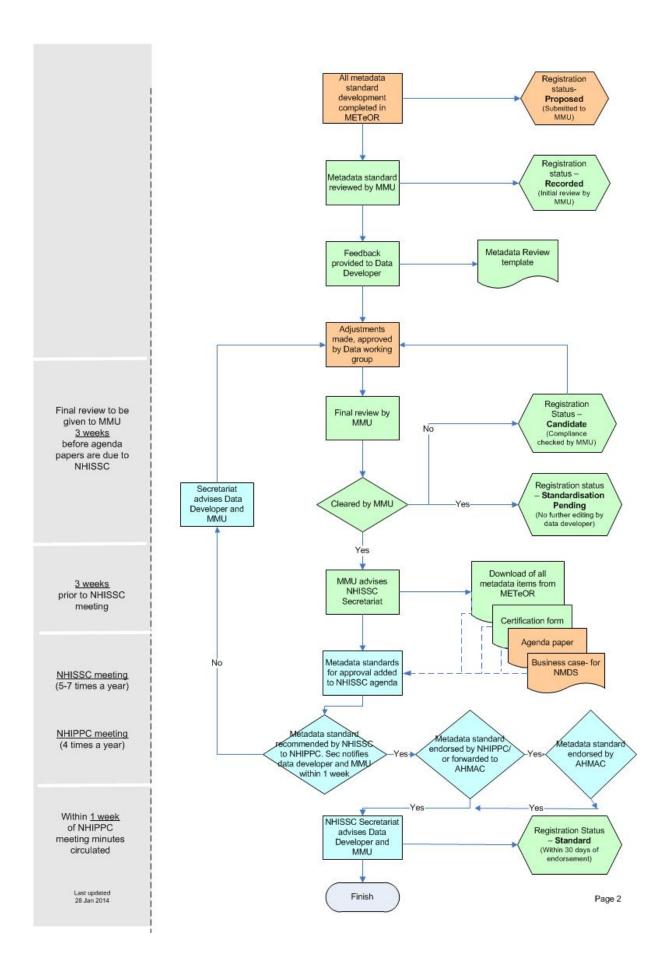
Typically, the Secretariat will suggest that before you make a formal approach to the committee, you arrange a conversation with someone who has experience in developing national collections for the field in which you are working, or an allied field. It might be helpful, for example, to talk with a member of NHISSC who has an interest in and experience of the field in which you are working, or with subject matter and health

informatics (metadata) staff of the AIHW. The AIHW maintains the data dictionary and is custodian of the national standards contained in the minimum data sets.

The next step is to prepare a paper for the committee setting out the context and content of the planned data development. The paper should be sponsored by a member of NHISSC and submitted through the NHISSC Secretariat using the attached template for NHISSC papers.



6 Creating nationally-consistent health information



The health metadata development process applies to all metadata including:

- data elements (the basic unit of identifiable and definable data, essentially analogous to data items)
- data set specifications (sets of data elements that are collected for a specific purpose)
- national minimum data sets (nationally mandated data collections for all states and territories) in the health sector.

The data development process is described under the NHISSC governance process including timelines, other committees and necessary forms.

## Funding and auspice arrangements made for metadata development

If applicable, external funding and auspice arrangements should be made as soon as possible. If any part of the project is dependent on the AHMAC-cost-shared budget, the budget bid must be submitted by end of the calendar year for funding in the following financial year.

#### Establishment/engagement of data working group

Interested parties are brought together to form the data working group (usually a time limited group) to develop, discuss and provide subject matter endorsement of the data development project. This group may be coordinated by the lead data developer.

## Advise NHISSC of upcoming data development for addition to agenda

NHISSC must consider a data development project before it is accepted on the Work Program. The data developer must advise the NHISSC Secretariat 4 weeks before the meeting date about an upcoming item for the agenda.

#### Advise MMU of metadata development work

The lead data developer should advise the AIHW's METeOR and Metadata Unit (MMU) of the proposed item of data development on the next NHISSC agenda. This will assist MMU in allocating resources against the work program.

#### **Documents sent to NHISSC Secretariat**

Agenda paper: 3 weeks before the NHISSC meeting, an agenda paper (using the attached NHISSC standard template) is to be forwarded by the data developer to the NHISSC Secretariat for distribution to NHISSC. The agenda paper should provide the background to the project and give reasons for the data development.

Project summary: 3 weeks before the NHISSC meeting, a project summary (using the attached NHISSC standard template) is to be forwarded by the data developer to the NHISSC Secretariat for distribution to NHISSC. This should be developed in consultation

with the Data working group, with assistance from MMU as necessary. The project summary must include project scope, timeframes and the composition of the data working group.

In the agenda paper, clearly identify any funding that has already been allocated, external, AHMAC and so forth, and where possible identify a NHISSC member that may be suitable to champion the project.

Note, for the collection of new data items in an NMDS to take effect on 1 July for the reporting year, the dataset must be endorsed by December of the preceding year (for example, by the end of December 2013 for the reporting year 2014–15). This allows each of the agencies agreeing to collect and submit the data to organise, test and implement the changes to their business processes and systems. Data developers should therefore aim to have all new data development activities submitted to NHISSC for approval in time to seek endorsement at the November NHIPPC meeting.

## Work item added to the NHISSC agenda for next meeting

The NHISSC Secretariat adds the data development project to the agenda of the next NHISSC meeting. NHISSC meetings are held approximately every 2 months. NHIPPC meets 4 times a year, with its last meeting in November. NHISSC meetings are usually 4–6 weeks prior to the NHIPPC meetings.

#### NHISSC accepts metadata work

The data development project is discussed at the NHISSC meeting. If the metadata work/project is accepted by NHISSC it will be:

- forwarded to NHIPPC seeking its approval to add the work/project to NHISSC's Work Program
- assigned a priority code based on a number of factors, including its national or strategic significance and accordance to strategic needs and emerging priorities
- assigned a project sponsor; that is, a representative of NHISSC who is responsible for guiding the project through the Committee's decision-making process. The sponsor champions the project through the committee decision-making process including recommending the finalised project for NHISSC approval and subsequent NHIPPC endorsement. The project manager, who undertakes the work, must keep the sponsor informed of the progress of the data development. The project manager must also prepare progress reports, as requested by the sponsor, for reporting back to the Committee.

## NHISSC Secretariat advises data developer and MMU

Within 1 week following the NHISSC meeting, the NHISSC Secretariat advises the data developer and MMU whether the metadata work was accepted by NHISSC for recommendation to NHIPPC. The NHISSC Secretariat will advise the data developer and MMU when endorsement is given by NHIPPC.

METeOR workgroup established/updated: MMU will organise for a METeOR workgroup to be set up or for an existing workgroup to be updated or reactivated, as appropriate. A METeOR workgroup is essentially a dedicated workspace on METeOR where new metadata content is created and stored. MMU can also provide METeOR training for data developers if required.

### Metadata development

This is the period in which all of the actual data development work occurs. Timeframes for this work is determined by the project requirements set out in the Project Summary, including the number of new and/or revised data elements and an intended date of implementation. A National minimum data set (NMDS) must be finalised and endorsed 6 months before the standard is to be applied. Establishing both the NHISSC meeting at which approval will be sought and the subsequent NHIPPC meeting at which endorsement will be sought will help establish timelines for the data development project.

The data developer (project manager) works with the AIHW's MMU and the Data working group to develop the metadata items that will be stored in the national metadata registry system, METeOR. (METeOR holds data from other Registration Authorities such as Housing, Community Services, IPA, NHPA and so forth.) Data collected for national reporting purposes must be defined in a standardised way. The standard adopted for health data is the International Organization for Standardization's metadata registry standard (ISO/CEN 11179:2003).

MMU is involved throughout the data development process and provides a valuable resource for data developers. MMU provides support to the data developer regarding the process of data development and the technical requirements for data development. MMU is also able to provide METeOR and Metadata development training to the data development group.

The metadata development phase of the development process for projects that make use of clinical information should also include both National E-Health Transition Authority (NEHTA) and clinical representatives to ensure that opportunities for alignment of clinical and statistical standards are leveraged and clinical workflow impacts are minimised.

The NHISSC project summary template and the business case template include 2 sections outlining 'Opportunities for leveraging and aligning with existing clinical data standards' and 'Risks and potential clinical workflow impacts' to help cover off the need to better leverage clinical information and reduce the risk of clinical workflow impacts.

The Data working group comprises members with expertise in the subject area of the data development project. It may be a time-limited group set up specifically to do a piece of data development or it may be an existing group that is used to assist in the data development process. The Data working group provides advice to the data developer on subject-specific matters related to the data development. In some cases the Data working group will want to endorse metadata before it is submitted for NHISSC approval and NHIPPC endorsement.

The NHISSC sponsor is a member of NHISSC who is responsible for supporting the data development project. The sponsor will monitor the progress of the work, ensure that there is appropriate jurisdictional consultation and report regularly on the progress of the project to NHISSC. The sponsor is the first point of contact for the data developer to escalate issues and champions the project through the data development approval process with NHISSC.

## Metadata standard development completed in METeOR

All metadata standard development is completed, with all of the metadata is documented METeOR and discussions have been held between the data developer and the working group to reach agreed data standards.

The registration status (in METeOR) of the draft metadata is changed to 'Proposed' by the data developer, indicating that the metadata is ready to be reviewed by MMU.

#### Metadata standards are reviewed by MMU

MMU undertake a comprehensive review of all new and revised metadata standards and provide written feedback to the data developer.

Once the technical review has been completed by MMU, the registration status (in METeOR) of the draft metadata is changed to 'Recorded' by MMU. The registration status will remain at 'Recorded' while subsequent reviews are undertaken by MMU.

Where a metadata change affects any national minimum data sets (mandatory national collections), MMU advises the relevant data stewards of the pending changes and notifies the NHISSC Secretariat of the potential effect on other standards in the registry. The Secretariat notifies the project manager of potential effects on the change(s) on the registry.

### Feedback provided to data developer

Technical review feedback is provided to the data developer by MMU on the standard metadata review template.

### Adjustments made, approved by Data working group

The data developer receives written feedback from MMU and incorporates MMU's comments and makes changes to the draft metadata, where applicable. Any feedback from MMU that the data developer does not agree with can be documented on the metadata review template and discussed further with MMU. Once adjustments have been made to the metadata on METeOR there may or may not be a need for the data working group to review the changes.

### Final review by MMU

A final technical review of the metadata is undertaken by MMU. Advice of the requirement for a final review is to be provided to MMU 3 weeks before agenda papers are due to the NHISSC Secretariat.

### **Cleared by MMU**

If MMU's final review finds further problems with the metadata:

• MMU will provide further feedback to the data developer.

• The registration status (in METeOR) of the draft metadata is changed to 'Candidate' by MMU, indicating that compliance has been checked by MMU and additional review feedback has been provided.

Once the final changes are made to the metadata by the data developer, an additional review is undertaken by MMU, after which the draft metadata will be cleared and its registration status changed to 'Standardisation pending'.

No further editing of the metadata can be done by the data developer from this point. The metadata is now ready to be submitted to NHISSC for approval and subsequent NHIPPC endorsement.

#### **MMU advises NHISSC Secretariat**

Once the draft metadata is cleared and ready for committee endorsement, MMU will advise the NHISSC Secretariat. This will be done 3 weeks prior to the NHISSC meeting.

The following documents will be prepared by MMU:

- A download of the relevant metadata items from METeOR: Where a new or changed data item is to be registered as a standard in the National Health Metadata Registry (METeOR) all of the accompanying affected metadata items must be included in the download.
- Certificate of compliance: The AIHW must assure NHISSC that the metadata items that are to be registered in the NHDD conform to the applicable metadata registry standard. The certificate of compliance provides this assurance. A certification form will be completed by MMU and will accompany the metadata items being considered by the NHISSC for inclusion as national standards in the NHDD.

The following documents will be prepared by the data developer:

- NHISSC agenda paper: Using the standard NHISSC template, an agenda paper will include the background of the data development, any development issues that may have arisen and details of the metadata that is being submitted for standardisation.
- Business case (template attached at page 19): This is required when an NMDS is being submitted to NHISSC for approval. The business case must outline the costs of implementation and ongoing collection. It must also contain a statement from each of the jurisdictional agencies agreeing to collect and submit the data, confirming that they will supply the data in a form that complies with the national standards for the collection as stated in the NMDS.

## Metadata standards for approval added to NHISSC agenda

The 4 documents listed in the previous section are sent to the NHISSC Secretariat and the metadata being submitted for approval is added to the NHISSC agenda.

### Metadata standard approved by NHISSC

The project sponsor presents the agenda paper and metadata for approval by NHISSC. If NHISSC approves the draft metadata it is then ready for submission for endorsement by the relevant committee. (Generally this will be NHIPPC.)

If NHISSC requires further changes to the draft metadata before it can be submitted for committee endorsement, the NHISSC Secretariat will advise MMU and the data developer. Depending on the extent of the required changes, MMU will either implement NHISSC's suggestions in consultation with the data developer or change the draft metadata's registration status to 'candidate' so the developer can make any changes necessary.

### Metadata standard endorsed by NHIPPC

Following NHISSC approval of the metadata, the NHISSC Secretariat will seek NHIPPC's endorsement of the proposed metadata standard. In some instances, NHIPPC may decide to seek AHMAC endorsement.

## NHISSC Secretariat advises data developer and MMU of committee endorsement

MMU (the Registry administrator) is advised by the NHISSC Secretariat that the draft metadata has been endorsed as a standard by the relevant committee. MMU then updates the Register.

The registration status (in METeOR) of the new metadata items is changed to 'Standard' by MMU, with a date of effect corresponding with the date of the committee meeting that endorsed the new standard. MMU changes the registration status of the previous standards to 'Superseded'. Any national minimum data sets (NMDS) (mandatory national collections) that are affected by the changes are also changed to 'Superseded' and replaced by the new standard. These new NMDS standards generally come into effect at the beginning of the next financial year (for example, 1 July 2014).

The NHDD is updated, if necessary, to reflect the new or revised NMDS/data set specifications (DSS). Updates to the dictionary are generally released every 6 months, and a complete revised edition of the dictionary is released every 2 years.

On completion of the project, the NHISSC Secretariat will send an AHMAC budget acquittal form to the contact officer for the acquittal of funds. Acquittals are required in December and June of each financial year.

#### NHISSC agenda paper template sample

#### **National Health Information Standards and Statistics Committee**

Meeting no: [meeting number] Meeting date: [meeting date]

Purpose: [insert purpose e.g. for decision/discussion, for information/update, report from committee/agency, referral from AHMAC/NHIPPC]

#### [agenda paper number] – [insert title]

#### **RECOMMENDED ACTION**

That NHISSC members:

1.

**BACKGROUND** [insert background]

#### ISSUES

[insert issues]

Sponsor/Member Agency: [insert name of agency responsible for submitting the paper or sponsoring the work item covered in the paper]

#### Date: [insert date paper is cleared by the agency]

Attachment list [delete if not required] Attachment A: [title with date/version no.]

#### NHISSC project summary form

Name of project/activity	
Auspice organisation or agency (i.e. the 'authority' of the project and the organisation or agency with whom the NHISSC will communicate on a formal basis)	
NHISSC sponsor	
<b>Purpose</b> (i.e. aim of project/activity and/or reasons for undertaking project)	
Benefit/Outcome to be achieved	
(Please specify the benefits that are expected as a result of the NHISSC undertaking the work)	
<b>Scope</b> (i.e. the types of persons, services or issues to which the data development activity relates)	
<b>Brief Description</b> (2–3 lines only)	
Group/committee undertaking data development activity/project	Name of group/committee: Name of contact person: Contact persons e-mail address: Contact persons mailing address:

Relationship with AHMAC or other government priorities	Does the project relate to work required to support AHMAC- sponsored projects/strategies, the National Health Priority Action areas, the National Health Information Development Priorities, the Australian Healthcare Agreements, the National Health Performance Committee indicators, or as part of the ongoing program of NMDS review YES/NO If Yes, please specify which priority		
<b>Consultative mechanisms</b> (i.e. details of consultative arrangements in place to ensure product of activity/project is supported by the relevant stakeholders, including jurisdictional Departments) Please attach a membership list for any working groups involved			
Related projects/data collections	If Yes, please specify?		
Timeframes / dependencies	Is there any urgency associated with the project or another deadline that must be met? Please specify Is any other project or work program dependent on completion of this project Please specify		
Project/Activity Timeframe	Beginning: End: Any other key milestones:		

<b>Funding source for the project</b> (i.e. who is paying for the data development activity, who will be paying for the ongoing maintenance)	
Metadata items	Does the project intend using any existing metadata items that are endorsed as national standards for example current metadata items included in the <i>National health data dictionary, National community</i> <i>services data dictionary</i> or the <i>National housing assistance data dictionary</i> ? If Yes, please specify?
	Is it intended to include these metadata items in the submission, with or without modification? Specify which ones will be modified Any further comment?
Estimated number of metadata items that may be submitted to the NHISSC for consideration as national data standards?	

#### **Business case template sample**

Specific requirements for a business case for a new national minimum data set or a significant change to an existing national minimum data set

Background					
Includes:	- origins and rationale for the proposal				
	- development process undertaken to date				
	<ul> <li>details of national consultation, including details of experts and/or others involved with or consulted during development</li> </ul>				
	- degree of consensus reached on submitted data elements				
	- results of any pilot testing completed or proposed pilot testing arrangements.				
Detailed purpose and objectives					
Includes:	es: - how the information will be used				
	- the likely benefits at the national level (and the likelihood that they will be realised)				
	- if they deem appropriate, the States and Territories to advise on the likely				
	benefits at the jurisdiction level (and the likelihood that they will be realised).				

#### Details of the NMDS:

Includes: - scope;

- data elements
- statistical units
- start date
- national reporting arrangements
- other attributes as specified in the *National Health Data Dictionary*.

#### Implementation issues

Includes: - any plans and timetables for staggered or phased implementation

- feasibility of collection
- notes on likely late or non-participation by jurisdictions
- notes on effects of these on the NMDS
- impact on time series reporting.

#### **Cost implications**

See Attachment A

Note: When completing the costing template include costs to hospitals in addition to direct outlays.

#### **Commitment statement**

Final, binding comments from the states and territories on their willingness and ability to implement the NMDS according to the format and timetable proposed.

### Attachment A to the business case template

Components of the costing	Initial costs	First subsequent year	Second subsequent year	Third subsequent year
Set up and related costs				
Information system costs (including data capture, storage, submission to data repositories, changes to repositories and extraction of data)				
Additional staff numbers or impacts on existing staff				
Training costs				
New documentation and forms or changes to documentation and forms				
Other costs (please specify)				
TOTAL				

This document provides guidance on engaging with the national processes responsible for health information and data standards. It has been developed to ensure data collected are consistent, accurate and useful for policy, planning and program management.