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Health Information Management in epidemiological research

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President’s Report

Health Information Management in epidemiological research

Angela Randall

First, all of us at the HIMAA National Board would like to extend our warmest congratulations to Associate Professor Johanna Westbrook on her election as an International Fellow to the American College of Medical Informatics. You will read more about Johanna’s award in this issue.

Our roles as Health Information Managers (HIMs) are becoming increasingly diverse and comprehensive. These developments are reflected in articles published in this issue of the Journal, in which a range of research, epidemiological and clinical studies are discussed in relation to Health Information Management, and the involvement of HIMs in health data management is explored.

Management of epidemiological and research data is often the task of a Health Information Manager, and that leads me to consider the concept of data management itself. Data management can be defined as the ability to translate a study design into an effective data collection instrument which is one of the most important aspects of preparing a clinical research protocol. Other aspects of data management particularly relevant to those HIMs interested in a career in research and epidemiological studies, include knowledge of the relevant statutory guidelines on research, a sound knowledge of statistical methods and, increasingly, the issues of privacy legislation — in particular, the impact of new technologies on privacy. Finally, we need to understand the role and responsibilities of human ethics committees in research and epidemiological studies.

Meryl Riley demonstrates the use of the skills described above in her discussion of the methodology used in collecting data related to birth defects and maternal mortality for the Victorian Perinatal Data Collection. Riley demonstrates the need not only for accurate, reliable and timely reporting of data, but also for HIMs in general to enhance their research skills and improve their statistical knowledge for use in the research field. The Victorian Birth Defects Register referred to in this article was established in response to an epidemiological study of congenital anomalies.

Andrew Miller, on the other hand, spells out the need for verifiable source data. Whilst acknowledging the importance of paper-based medical records, he also recognises the exciting possibilities of the electronic environment and its impact on future research capabilities, along with the challenges presented to the gatherers of information (HIMs). In his article, Miller explores the role of the radiation oncologist and the overlap of epidemiological data collecting with those respective gatherers of information.

Quoc Nguyen and Beth Reid employ a comparative study technique to examine the results of a 6-year study of fungaemia, utilising discharge data in two major Sydney hospitals. This article demonstrates not only the involvement but also the ability of a Health Information Manager to research and present the findings in an appropriate journal format. The techniques and skills required for research of this type are achieved through constant work in the research field, and include the ability to calculate the study sample population through statistical calculations.

Michelle Bramley discusses the importance of evaluation in evidence-based policy and planning of health services, and the importance of health classifications of those systems.

As Health Information Managers, we utilise our skills in health classification daily, and find that the resultant product is a usable health database in which many items of service are incorporated into morbidity and mortality data collections ready for use in research and epidemiological studies, health promotion, and the prediction of population health.

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Special Announcement

Major achievement by Associate Professor Johanna Westbrook: election to the American College of Medical Informatics as an International Fellow

Congratulations to Associate Professor Johanna Westbrook PhD, MHA, GradDipAppEpi, BAppSc (Medical Record Administration), who has been elected to the American College of Medical Informatics as an International Fellow.

The Fellowship is the highest recognition possible in the health informatics discipline. Based upon peer election from current College Fellows, no more than two Fellowships are offered in any one year, and there are currently only two other Australian Fellows. This is a wonderful honour as it marks the highest peer recognition possible from the international community, reflecting Johanna’s outstanding research work.

Johanna is currently Deputy Director of the Centre for Health Informatics at the University of New South Wales and is an honorary Associate Professor at the School of Health Information Management at the University of Sydney. Johanna has published over 80 refereed journal articles and has received numerous research grants, the most recent of which is a National Health and Medical Research Council Project Grant of $583 000 for a study investigating the safety and effectiveness of hospital e-prescribing systems.
Getting the most from routinely collected data

Jenny Hargreaves

This issue of the *Health Information Management Journal* has as its theme ‘Health Information Management in epidemiological research’, and all four papers illustrate differing ways in which Health Information Management can contribute to epidemiological endeavours. More than that, though, the papers also convey valuable messages about the importance of appropriate use of routinely collected data, and of understanding and improving the quality of the data and the infrastructures that underpin the data collections. These messages are all important for epidemiological research and other analytical uses of Australia’s routinely collected health data.

Michelle Bramley’s paper (Bramley 2005) provides a comprehensive guide to the evaluation of health classifications, which are core components of health data collection infrastructures. The paper includes useful background information comparing classifications and terminologies, and describes the important attributes of classifications, including their mono-hierarchical structure, comprehensiveness, aggregation of multiple concepts within rubrics, and meaningful coding systems. It also details the features that good classifications should have, covering the administrative, structural, content and usability domains by which classifications can be evaluated. Practical examples of evaluating health classifications include the Anatomical, Therapeutic, Chemical classification with Defined Daily Doses (ATC/DDD) drugs classification that has been submitted for inclusion in the Australian Family of Health Classifications, and is being evaluated against the criteria for inclusion in the Family (AIHW 2005a).

To guide evaluations of classifications, the paper provides useful examples to illustrate the nature of classifications and the characteristics of good classifications. This comprehensive array also provides valuable information for those who use classifications in data analysis work, including epidemiology. In addition to the explanation of mono-hierarchical structures and aggregation of multiple concepts within rubrics, the paper explains the existence of ‘residual’ categories: multiaxial structures; revision processes and mappings between versions; appropriate use of category descriptors; and the importance of definitions, indexes and guidelines that accompany classifications. The paper also urges readers to consider the suitability of classifications to the use proposed for them (for example, in terms of granularity), and their comparability with other classifications used in related domains or internationally. All these are important messages for data analysts.

Andrew Miller’s paper (Miller 2005) is an example of an endeavour that is likely to become more common: optimising interactions between data collections established for clinical purposes (increasingly as electronic health records) and data collected for administrative or epidemiological purposes, with an aim of improving the quality of data for research and monitoring activities.

The paper argues that the epidemiological data collected in relation to radiation oncology are useful to the extent that they are quantified and systematised, but are really only useable if they are also of good quality, accurate and complete. The paper also argues that data compiled in separate clinical systems, such as those used by radiation oncologists, are highly accurate and complete, but suffer from being less quantified and analyst-friendly.

Dr Miller therefore argues that the clinical data systems should be established so that all the data are regarded as and collected as if they were research data, so that data flows can be established between the clinical systems and hospital information systems. He argues that the quality of the clinical data will be enhanced through data ‘ownership’; that is, if the generators of the information also have responsibility for data creation, collection and integrity.

The paper by Quoc Nguyen and Beth Reid (Nguyen and Reid 2005) on sources of data on fungaemia provides a helpful illustration of the importance of understanding the strengths and limitations of routinely collected data, and the way in which work to detail the limitations could be used to improve routinely collected hospital morbidity data. The technique used was to compare two separate data sources. This is a classical method used to evaluate surveillance systems (Centers for Disease Control and Prevention 2001), and considered to be a very useful method when the two data sources are compiled independently, as was the case for this paper. The second data source (considered to be the gold standard for the study) was the pathology data system at the two study hospitals. In a useful addition to the comparison of the data, the relevant medical records were reviewed to assess whether and where the fungaemia was reported.

Comparison of the two data sources showed some miscoding and missed coding, with fewer than half of the pathology database cases including an appropriate fungaemia code, despite evidence of an infection being found in 97% of the relevant medical records. Coding was found to have been affected by the location and nature of the information about the fungaemia in the medical record. The authors indicated a need for improved coding, documentation and coding guidance in this area, and possibly more specific ICD-10-AM codes for recording fungaemias and other fungal infections.

This is an excellent example of a detailed local assessment of the quality of hospital morbidity data with the potential to lead to data quality improvements, at the local and national levels, for an important topic relevant to the safety and quality of hospital care. There has been a range of previous studies of the quality of coded data in Australia (including those cited in the paper) but many have been based on re-extracting data from the medical records (rather than a comparison with an external data source) and they have not usually included information on whether or where the information to be coded was included in the medical record. This paper includes that additional information and therefore could be used to inform data quality improvement, through appropriate changes to guidance on documentation or coding.
The limitations of the codes available for fungal infections described in the paper could also be considered, perhaps through creation of more specific codes. Alternatively, data collection systems could be redesigned to link aetiology and manifestation codes, perhaps allowing them to be paired more meaningfully for purposes such as fungaemia surveillance, and unambiguous interpretation of the codes in downstream applications (such as the Australian Institute of Health and Welfare’s [AIHW’s] National Hospital Morbidity Database).

This article can be linked with the article by Miller, in that it describes a data collection system that is separate from the routinely collected morbidity data, but is regarded as the gold standard. Perhaps in this type of situation, similar to Miller’s suggestion in relation to radiation oncology, there should be investigation of an automated mechanism for pathology results to be added to coded hospital morbidity records, on confirmation that a positive test result represented a clinically significant diagnosis that met the definition of an additional diagnosis.

Merilyn Riley’s paper on birth defects presents a range of interesting statistics on birth defects from the Victorian Birth Defects Register (Riley 2005). However, a major focus is information about the sources and quality of the data, analysis techniques used and appropriate interpretation of the statistics. The paper provides detailed information on the definitions used for the VBDR, the multiple sources of data used, and the methods used to ensure the quality of the data. Data from the multiple sources are linked using demographic data and names of the mother and baby, as possible, and would help to ensure that the multiple sources do not result in over-counts of defects.

The discussion canvasses a range of issues relevant to appropriate analysis and interpretation of the data. Included are impacts of variation in the types of birth defects included, variation in the maximum age of children for whom birth defects can be reported, variation in case ascertainment over time, whether induced abortions before 20 weeks’ gestation are included, whether cases or individual birth defects are being counted, and the time periods chosen for trend analyses. Examples of different statistics resulting from different decisions made in relation to these points provide excellent illustrations of considerations relevant to use of routinely collected data for epidemiological purposes.

Important messages from this paper are that the data should be analysed to suit the question being asked and, to ensure appropriate interstate comparisons, data collation and analysis methods used in other states and territories will also need to be understood. This paper therefore provides plenty of food for thought for the current work to develop a National Minimum Data Set for Congenital Anomalies, being undertaken by the AIHW’s National Perinatal Statistics Unit (AIHW NPSU 2004). This Data Set will aim to improve the usefulness and comparability of data on birth anomalies at the national level.

My own particular interest in this type of work relates to use of the National Hospital Morbidity Database held at the AIHW. This data source is used for a range of epidemiological purposes by the AIHW (for example, in relation to chronic kidney disease [AIHW 2005b], and others (for example, in relation to the use of hospital beds by older people [Gray, Yeo & Duckett 2004]).

Because of the database’s comprehensive coverage of essentially all hospitals in Australia, the generally well established infrastructures for compiling it, and the potential for use of the database in describing the impact of disease, the epidemiology of interventions and aspects of quality of care, it is important that as much as possible is known about the quality of the data. At the national level, there have been some studies of the quality of the data, using techniques that are feasible on the larger scale. For example, the comparability of aspects of additional diagnosis information has been assessed by interstate comparison of the distribution of AR-DRGs with and without complications and comorbidities (Coory & Cornes 2005); the quality of Indigenous status data has been gauged using a mixture of techniques such as patient reinterview study results and analysis of missing data and ratios of separations for Indigenous patients and other patients (AIHW 2005c); and the usefulness of the data for estimating the number of induced abortions in Australia has been examined by comparison of the data with state-based induced abortion registers (AIHW NPSU 2005).

The vast quantity of data contained in the database, covering the wide range of admitted patient activity in Australia, means that detailed knowledge of the quality of all aspects of the data does not exist, and there will be no one source of such information. Efforts at the national level to understand and improve the quality of the data (such as through classification development and other national data development activities) need to be supplemented and informed by investigations and activities at the local level. Hence contributions at the local level like Nguyen and Reid’s paper, and papers such as those by Miller, Riley and Bramley, that are relevant to infrastructure developments for health information, are very welcome.

Finally, I want to add my congratulations to Associate Professor Johanna Westbrook for her election as an International Fellow of the American College of Medical Informatics.

Although many of Professor Westbrook’s recent publications have been concerned with clinicians’ use of online information retrieval systems and other research related to decision support, she has also made valuable contributions over a considerable period to Health Information Management relevant to the assessment of the quality of routinely collected data, and appropriate use of the data in epidemiological analyses. These contributions have included assessment of coding quality for burns (Alechna, Westbrook & Roberts 1998) and appropriate interpretation of complications data in hospital separations data (Westbrook, Rushworth & Rob 1994). They have also included use of Pharmaceutical Benefits Scheme data to assess effects of prescribing restrictions for antiulcer drugs (Westbrook, Duggan & McIntosh 2001) and analysis of hospital morbidity data to assess sub-population use of diagnostic upper gastrointestinal tract endoscopy (Westbrook 2002), and to investigate
the effects of the introduction of paediatric ear, nose and throat (ENT) surgery guidelines on rates of ENT surgery among young people (Rob et al. 2004).

I look forward to Professor Westbrook’s continuing leadership in the use of Australia’s routinely collected data for epidemiological analyses.

References


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A framework for evaluating health classifications

Michelle Bramley

Abstract
Evaluation is important to evidence-based policy and practice in Health Information Management. Health classifications are important components of information systems and should be evaluated to determine their suitability for the task required. This paper provides a framework for evaluating health classifications that are used for statistical and reporting purposes. The framework revises and updates the fundamental principles that make health classifications effective. It also draws on other frameworks, where relevant, to reflect the influence that informatics has had on nosology. Principles are illustrated with examples, topical issues associated with some principles are discussed, and examples of evaluation in practice are provided. Key words: Evaluation framework; health classifications; nosology; health information management

Introduction
Health information is the foundation for the policy, strategic and operational levels of the healthcare industry. Managing and translating health information efficiently is clearly important, and data standards and classifications are mechanisms through which this can be achieved (Gardner 2003; Information and Communications Technology Standards Committee 2004, pp.32-35; National Health Information Management Group 2002; Williams & Rowlands 2003).

Health classifications are systems that categorise terms used in healthcare and order them in a logical and methodical way (Hoffman & Chamie 1999). They are primarily used for statistical and reporting purposes, but may be used for other reasons, such as health services planning and funding. The most widely used statistical classification in healthcare is the International Statistical Classification of Diseases and Related Health Problems (ICD), now in its 10th revision (World Health Organization 1992a). The ICD is used internationally to classify morbidity and mortality data. The ICD-10-AM, an Australian modification of the ICD (National Centre for Classification in Health 2004), is used nationally and internationally to classify diseases and procedures in in-patient settings. Another statistical classification used in Australia to classify general practice data for the BEACH™ data collection is the International Classification of Primary Care 2nd edition–Plus (ICPC-2 PLUS) (Family Medicine Research Centre 1998). Strictly speaking, the ICPC-2 PLUS is not a classification, but an electronic interface terminology.2 Each term is uniquely identified and then classified to a category of a statistical classification, the International Classification of Primary Care, 2nd edition (WONCA 1998).

Not every domain in the Australian healthcare sector classifies its work, and nursing is a good example. There is no classification used on a systematic basis in Australia to identify what nurses do, why they do it and how well they do it (Hovenga 2002). While classifications do exist to capture this data, they need to be evaluated to determine how useful they are in an Australian setting (Hovenga 2002). In fact, all classifications should be evaluated before implementation to determine their suitability for the task required and the domain they are intended to serve.

This paper provides a framework for evaluating health classifications that are used for statistical and reporting purposes. The framework revises and updates the fundamental principles that make health classifications effective, as described in two seminal nosological papers (Hoffman & Chamie 1999; Price 1982). It also draws on other frameworks, where relevant, to reflect the influence that informatics has had on nosology. The principles are illustrated with examples, using the language of nosology to enhance understanding of the terms. Topical issues associated with some principles are discussed, and examples of evaluation in practice are provided. The examples and discussion have been shaped from my previous work for the National Centre for Classification in Health (NCCH), the Australian centre of expertise in health classification theory. The centre creates and maintains classifications and standards that uniformly describe health concepts such as diseases, injuries, contextual factors and clinical interventions.

Health classifications versus clinical terminologies
Health classifications differ from clinical terminologies in purpose, structure and output. Even though both manage clinical information, they manage it in different ways. Classifications are useful tools for aggregated statistical data analysis at all management levels, whereas terminologies are useful for operational decision making (for example, concept re-use in clinical decision support, point-of-care analysis) and semantically interoperable messaging. The once clear distinction between classifications and terminologies is becoming ‘blurred’ by the advent of electronic health records. The NCCH now frames health classifications as ‘aggregate terminologies’—a ‘functional subtype’ of clinical terminologies (Scott 2003). This framework, then, is also relevant to aggregate terminologies that are used for statistical and reporting purposes because

1 The BEACH™ project collects data and reports information about general practice patients—their problems and treatments. It is conducted by the General Practice Statistics and Classification Unit, a collaborating unit of the Family Medical Research Centre, The University of Sydney, and the Australian Institute of Health and Welfare.<http://www.fmrc.org.au/beach.htm>


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they are conceptually equivalent to health classifications.

Before outlining the taxonomic principles of health classifications, it may be useful to define the key characteristics that distinguish health classifications from clinical terminologies: mono-hierarchies, comprehensiveness, aggregation, and meaningful coding systems.

**Mono-hierarchies**

Classifications are mono-hierarchical, that is, a concept appears at only one place in the hierarchy. Terminologies, particularly concept-oriented terminologies, tend to be multi-hierarchical, meaning a concept can appear at several places in the hierarchy.

**Example: mono-hierarchies**

Influenza illustrates this concept. Influenza is an infectious disease. Influenza is also a disease of the respiratory system. In a terminology, influenza can appear in two (or more) places in the hierarchy to reflect the different parent–child relationships. In a classification, it can appear in only one place in the hierarchy. Placing a concept in only one place in the hierarchy is necessary for statistical analysis of data. 

Rogers (2003) explains why: ‘Without the single parent rule, any statistical analysis of data could end up counting individual patients [in this example, the statistical unit] several times. If you are trying to pigeon-hole patients for the purposes of statistical aggregation, you have to be sure that each patient ends up in only one pigeon hole and you may need complex rules for deciding which pigeon hole a patient ultimately goes into if there is more than one reasonable choice’.  

**Comprehensiveness**

Classifications are comprehensive (or exhaustive) and this feature is enabled through the use of ‘other’ and ‘unspecified’ (or residual) categories. All concepts within a domain can be classified at any one point in time. Terminologies (generally) do not have residual categories.

**Example: comprehensiveness**

A general practitioner (GP) sees a patient and records the patient’s signs and symptoms in the clinical record. Using ICPC-2, the GP can assign a code to every documented symptom and sign. Some concepts will be assigned to specific codes. The remaining concepts will be assigned to residual categories. Thus, all relevant information relating to the patient’s illness can be coded at that point in time.

**Aggregation**

Classifications tend to aggregate several unique concepts under one code. Only certain concepts are separately identified by their own unique code; these concepts are important to distinguish for public health purposes, research or statistical reporting. Terminologies discriminate and allocate a unique code to each and every unique concept.

The residual categories in classifications allow the aggregation of several distinct concepts under one code. Aggregation is necessary and useful for the reporting of data at all management levels. At the operational level, however, the ability to retrieve specific terms from an information system that stores data by codes tends to be lost when concepts are classified to a residual category.

**Example: aggregation**

In ICD-10-AM, more than thirty unique concepts are indexed to N83.8 Other non-inflammatory disorders of the ovary, fallopian tube and broad ligament. ‘Broad ligation laceration syndrome’ is one of these concepts. When a clinical researcher asks you to identify the number of cases of broad ligament laceration syndrome treated in the facility over the past three years, the original clinical records must be retrieved for each instance of N83.8 to determine which records contain this term and thus meet the search criterion.

Terminologies work more efficiently than classifications in terms of data retrieval at the operational level because they allocate a unique identifier to each concept. It is primarily for this reason that terminologies are more suitable for decision support systems and point-of-care analysis. Whether terminologies are useful at the reporting level is open to debate. 

Bowman (2005) states that terminologies are ‘inadequate’ for aggregation because of their immense size, considerable granularity, complex hierarchies, and lack of reporting rules (p.1). 

Roberts et al. (2004) note that ‘In reporting, there are as yet few if any predetermined groupings to use for national or international data extraction and interpretation’ (p.30). It seems then, that it is yet to be demonstrated whether terminologies can function as classifications in respect of aggregation and reporting.

**Meaningful coding systems**

Classifications apply coding systems which generally reflect the hierarchical structure of the classification. In this sense, the codes have meaning and are best understood in the context of their relationship to other codes in the classification. In terminologies, the coding system does not (generally) reflect the hierarchical structure. In this sense, the codes are meaningless.

**Example: meaningful coding systems**

In ICD-10-AM, the codes are an essential part of the system and aid in understanding the structure of the classification. Users can get a sense of where they are in the classification from the coding system.

- O61.0 Failed medical induction of labour
- O is used in the obstetrics chapter to identify conditions affecting pregnancy or occurring in childbirth or the peripartum period. The codes in block O60–O75 describe complications of labour and delivery.

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3 Residual categories are further explained in the following section. — Aggregation.

4 Codes are attached to concepts to help manage the data electronically. Codes can be either alphabetical or numerical, or alphanumeric.
The Systematized Nomenclature of Medicine — Clinical Terms (SNOMED-CT) (College of American Pathologists n.d.) is a concept-oriented reference terminology. In SNOMED-CT, concepts and terms and their relationship to each other are the primary focus. Users rarely see the codes; they are simply a management tool to enable computerised identification and retrieval. In this example, the concept identifiers (Conceptid) are the codes; they are randomly assigned to concepts and convey no meaning.

- Influenza (Conceptid 6142004)
- Influenzal pneumonia (Conceptid 39932903)
- Influenzal laryngitis (Conceptid 19463902)
- Influenzal pharyngitis (Conceptid 19452905)

(Source: Scott 2004)

Meaningful coding systems arose out of necessity to keep the hierarchical structure and format simple for users in a predominantly manual environment (Roberts et al. 2004). In the evaluation framework, some examples demonstrate the tensions that exist in maintaining a classification’s structure and its clinical relevance. An electronic environment may offer solutions to some of the problems that arise with meaningful coding systems (Roberts & Chalmers 2002).

Evaluation framework

Health classifications can be evaluated by the characteristics that define a ‘good’ classification (Hoffman & Chamie 1999). These taxonomic principles are explained below and are themselves grouped into administrative, structural, content and usability principles.

1. Administrative principles

1.1 Purpose and scope (coverage)

A health classification must have its objectives, purpose and scope (or coverage) clearly stated so that its relevance to the domain it serves, or to other domains, can be measured (Hoffman & Chamie 1999).

Example 1.1a

A classification of chiropractic interventions may not be suitable for use by physiotherapists who specialise in manual therapy (manipulation and mobilisation). There may be some common interventions, but generally, physiotherapy interventions are different from chiropractic interventions, because of theoretical and philosophical differences between the two disciplines (Canadian Physiotherapy Association 1994).

Example 1.1b

Procedure classifications generally have a broad scope because they need to encompass all types of procedures performed in healthcare: diagnostic, therapeutic and preventive interventions; and invasive, non-invasive and cognitive interventions. They also need to be applicable to all clinicians, across all healthcare settings (Innes et al. 1997; National Committee on Vital and Health Statistics Subcommittee on Medical Classification Systems 1993).

1.2 Custodianship

The custodian is the organisation or body responsible for the development and maintenance of a health classification. They should be readily identified and their responsibilities clearly outlined (Hoffman & Chamie 1999).

1.3 Maintenance/updating

1.3.1 Maintenance plans

Health classifications must remain credible and relevant to users and so must be maintained and updated over time. The custodian must have a plan for regular updating and maintenance (Hoffman & Chamie 1999; Price 1982), which clearly documents the criteria against which a submission for change can be made. The plan should be well publicised and allow for all users and producers of statistical data to contribute to the process within an appropriate time frame (Hoffman & Chamie 1999).

Example 1.3.1

The NCCH updates the ICD-10-AM every 2 years. There is a public submission process advertised on its website <http://www3.fhs.usyd.edu.au/ncch/4.7.1.htm> which allows all stakeholders to participate in the update process. Similarly, the Australian Government Department of Health and Ageing updates the Australian Refined Diagnosis Related Groups (AR-DRGs) classification in line with updates to the ICD-10-AM and has a public submission process <http://www.health.gov.au/internet/wcms/publishing.nsf/Content/Casemix-1>. The ICD has a ten year update cycle, though it is now more than 10 years since ICD-10 was introduced (1992). Plans to introduce ICD-11 have been extended to 2011 (Ustun 2004), primarily because the World Health Organization now has a mechanism through which the ICD is regularly updated — the WHO Update Reference Committee (National Centre for Classification in Health 2005).

Because stability is crucial to statistical analysis, the impact of any updates needs to be considered by all stakeholders (Hoffman & Chamie 1999). In Australia, there are diverging views on what constitutes ‘regular’ updating. Clinical coders, and the bodies responsible for maintaining classifications, prefer updates once a year or biennially so that the classification remains current, particularly in relation to surgical procedures. Researchers, policy analysts and those who maintain health information systems prefer a more stable classification with less frequent updates and suggest a timeframe of 3 to 5 years.

1.3.2 Concept permanence

Classification follows clinical research and discovery. As more is learnt about the nature of diseases and the efficacy of interventions, the better able we are to describe, define (or redefine), and classify them appropriately. Thus, the classification of clinical concepts can change over time.
Concept permanence relates to the maintenance of the meaning of concepts. The meaning of a concept in a health classification should be permanent and never deleted (International Organization for Standardization 2000). The terms representing the concept may change (even its preferred term or category descriptor), however, the concept’s meaning should remain the same. Concepts can be retired or invalidated, but not deleted.

The principle of concept permanence does not refer purely to concepts, but to the codes as well. When a concept is denoted as inactive or is superseded, the code linked to the concept should not be re-used. The meaning of a code should also be permanent because of its link to a concept.

Example 1.3.2

This example nicely illustrates the tensions that can arise between adhering to the principles of classification development and maintaining a clinically relevant classification. The changes to the rubrics classifying diabetes mellitus in ICD-10-AM (E10-E14) in the second and third editions were significant and timely. The NCCH replaced an outdated classification with a new classification that reflects the changes to clinical knowledge. Importantly, the changes made were based on the World Health Organization’s (WHO) recommendations for reclassifying diabetes mellitus (World Health Organization 1999). In making the changes it was necessary to delete existing codes and concepts and re-introduce the same codes with different descriptors (that is, overriding the concept permanence principle and introducing concept changes). The NCCH managed this change effectively by clearly identifying all concept changes in their mappings between editions. They ensured that the ability to compare data over time was not compromised by communicating these changes to stakeholders. Stakeholders could then interpret these changes with relevance to their work. This example also illustrates a flaw in the structure of the ICD-10. The alphanumerical coding system reflects the hierarchy and, in most instances, does not allow for major restructuring of sections of the classification between revisions. Another problem is the long time lapse between revisions of the classification (currently more than 10 years).

1.3.3 Tracking changes over time

Mechanisms for tracking changes to health classifications over time should exist (Hoffman & Chamie 1999; Price 1982). These include version control and mapping.

Each update, revision or edition of a health classification should be clearly described and differentiated from previous versions. Documentation explaining the changes made, and listing the time frames in which they were made, should be readily available to all stakeholders (Hoffman & Chamie 1999).

Example 1.3.3a

The NCCH has developed the ICD-10-AM Chronicle, an electronic reference tool, with the aim of enhancing understanding about what changes were made, when they were made and why (National Centre for Classification in Health, n.d.).

Example 1.3.3b

With every update, the custodian should perform (or validate) mapping to help researchers compare data over time.

Mapping is the process of identifying equivalent concepts or terms in related health classifications or terminologies, or in different ones. It is performed to provide researchers, data analysts, governments and other authoritative bodies with information about the comparability between different health classifications or to demonstrate the relationships between changes introduced in updated versions or editions of a single health classification. The ability to compare data over time (tracking data) between different versions or editions of a classification is essential for epidemiologists and other researchers conducting longitudinal studies. It is also helpful to compare different health classifications to enable the translation of data from one health classification to another.

Mapping is a complex activity. Concepts infrequently match on a one-to-one basis. More often, there is some loss of meaning. Whether this loss of meaning is important will depend on the purpose of the mapping. For example, a mapping performed for the purpose of identifying the changes made to a parent classification and its country-specific modification (for example, ICPC-2 PLUS to ICPC-2) may require less precision than mapping performed between a terminology and a classification for the purpose of funding healthcare services (Bowman 2005). The effectiveness of any mapping must therefore be evaluated and will be dependent on a number of variables. Such variables include: reasons why the mapping was performed, the expertise of the mapper, criteria or rating scale applied (the degree to which the health classifications are comparable), and electronic tools used to assist the mapping process.

Example 1.3.3c

The Unified Medical Language System (UMLS) is a ‘terminology mapping, translation and maintenance system on which broad-based information retrieval and domain modelling can be based’ (Campbell, Oliver and Shortliffe 1998: p.15). In essence, it is a terminology interoperability effort which helps health professionals and researchers retrieve and use biomedical information from different sources (e.g. MeSH headings). ICPC-2 has been incorporated into the UMLS to provide a mechanism through which ICPC-2 can be related to other classifications and terminologies included in the UMLS (Family Medicine Research Centre 2005).

2. Structural principles

2.1 Hierarchical organisation/theoretical framework

Health classifications should have a clinically logical, hierarchical organisation built upon a theoretical framework. The framework should clearly and simply define the principles of this organisation to enhance understanding by all users (Hoffman & Chamie 1999). The hierarchical organisation should facilitate data retrieval at different levels of specificity by enabling aggregation of data from subcategories to categories (‘roll up/roll down’) (Price 1982).
2.2 Expansion

'The only good classification is a living classification' (Bowker & Star 1999: p. 326). Health classifications need to be responsive to changes in clinical practice and new technology if they are to maintain their relevance. They also need to maintain their uniformity with related classifications (Roberts and Chalmers 2002). The structure of a health classification should be flexible to allow for expansion (Price 1982). The addition of new concepts into the hierarchy should not be flexible to allow for expansion (Price 1982). The structure of a health classification should need to be responsive to changes in clinical practice and new technology if they are to maintain their relevance.

Example 2.2

The International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001) has linked a meaningful, alphanumeric coding system to concepts. There are at least five digits between each category to allow for expansion. Within categories, there is capacity to expand to ten digits for first, third and fourth level items, and one hundred digits for second level items.

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>b</td>
<td>Body functions (a key component of the ICF)</td>
</tr>
<tr>
<td>b2</td>
<td>Sensory functions and pain (first-level item – one digit)</td>
</tr>
<tr>
<td>b210</td>
<td>Seeing functions (second-level item – two digits)</td>
</tr>
</tbody>
</table>

2.3 Comprehensiveness

A health classification must be comprehensive (i.e., exhaustive) to support the domain it serves (Hoffman & Chamie 1999). ‘Other’ or ‘unspecified’ categories (residual categories) must be provided so that all possible concepts within a domain can be classified somewhere, at any given point in time. Classifications, in this sense, have sensitivity at the expense of specificity.

Example 2.3

Current Procedural Terminology (CPT) (American Medical Association 1999a) is a mandated national code set used in the United States for coding, reporting and reimbursement of medical procedures and services performed by physicians in all settings. Although it is a terminology, one of the features it shares with classifications is the residual codes which are used in each section to identify a service or procedure that is not listed in the current edition. In the surgery section, the following are examples of residual codes:

- 21499 Unlisted musculoskeletal procedure, head
- 55899 Unlisted procedure, male genital system
- 64999 Unlisted procedure, nervous system

In the US, users are required to submit a special report when these codes are applied (American Medical Association 1999a: p. 51). The report provides a detailed description about the procedure and justification for its use to enable authorities to determine an appropriate payment. Information provided in the report may also be used to inform future updates.

Residual categories are essential to the purpose of a health classification. Nonetheless, they should be kept to a minimum because of the inability to retrieve specific data from these categories without reference to the original source. Management of residual categories through systematic analysis of the data should be performed regularly to determine whether the data demonstrate the need for a concept to have its own unique identifier. Analysis can also determine if concepts are being correctly classified to residual categories, which in itself implies that: (a) there may be a need to improve the index, or (b) there may be a need to improve clinical documentation.

3. Content principles

3.1 Mutual exclusivity

Categories or subcategories must be mutually exclusive (Hoffman & Chamie 1999). There must be only one code for any given concept with adequate indexing and guidelines to denote the boundaries. There cannot be two (or more) different codes for the same
concept. If there are, then the classification is said to have redundancy (needless repetition). The main problems with redundancy are data retrieval and statistical counts, particularly if data managers are unaware of the redundancy.

Example 3.1

Recall Roger’s (2003) explanation for why statistical classifications need to be mono-hierarchical and apply that here: each statistical unit should only be counted once. Mono-hierarchies are one mechanism used by classification developers to facilitate mutual exclusivity. Terminologies, because of their multi-hierarchical structures, have problems with mutual exclusivity. SNOMED is a multiaxial system; codes can be built by combining elements from each relevant axis. In an earlier version, SNOMED III, Evans et al. (1994) found that appendicitis could be expressed in seventeen different ways. The following are three examples:

- D5-46210 Appendicitis, NOS
- D5-46100 Appendicitis, NOS
- G-A231 Acute
- M-41000 Acute inflammation, NOS
- G-C006 In
- T-59200 Appendix, NOS

In SNOMED III there were limited mechanisms for determining the equivalence of concepts built in this way, and hence the problems with data retrieval. Data managers needed to ‘anticipate virtually all permutations and combinations of expression to ensure complete retrieval’ (Chute 2000: p. 300). These problems with equivalency and redundancy are being addressed in SNOMED-CT through automated means, such as description logics (Spackman & Campbell 1998), and manual review and analysis (Sable, Nash & Wang 2001).

Example 3.2b is another illustration of the tension between practicality and principles. International classifications serve as a lingua franca; in the case of the ICD it is a common language for morbidity and mortality data. In interpreting this principle, be aware that in order to satisfy an international community and be a practical epidemiological tool, there has to be some ambiguity in some of an international classification’s descriptors and definitions (Bowker & Star 1999).

3.3 Relevant and standardised terminology used in descriptors

Standardised use of language that is accepted and in common usage, and relevant to the domain and scope should be used to describe each category or subcategory (Price 1982). In the case of health classifications, descriptors should be clinically relevant.

Example 3.3a

Semantics are important. In healthcare, a patient’s life may depend on the clarity of meaning in communication between clinicians. O’Rourke (1997) nicely illustrates the importance of meaning when he discusses issues that patients have with some of the descriptors that practitioners use to describe certain conditions. He cites hypertension as one example in which the descriptor does not accurately reflect the condition and hence causes false perceptions in the public’s mind. It is generally believed that tension equates to stress. Therefore ‘hypertension’ becomes a stress-related condition, and so stress is the important risk factor, rather than high blood pressure. O’Rourke goes on to say that high blood pressure, a more precise descriptor, is slowly becoming the preferred term. Public education should result, if more clinicians use the preferred term. Nosologists need to be sensitive to the nuances of language and the changes that occur over time in the way language is used within a domain.

Descriptors for procedures or interventions should be setting and provider neutral; they should not reflect the clinician who performed the procedure or indicate where the procedure was performed (Innes et al. 1997; National Committee on Vital and Health Statistics Subcommittee on Medical Classification Systems 1993). One logic behind this principle is redundancy; such additional information is captured elsewhere in
the information system. Another is to enable comparability across different clinicians and sites.

**Example 3.3b**

In the first edition of ICD-10-AM, the procedure codes for allied health interventions were included as a separate chapter and identified the clinician who performed the procedure. For example:
- 95254-00 [2095] Education/counselling, speech pathology
- 95054-00 [2056] Education and information, social work

This was the first attempt to classify allied health interventions consistently and include them in a national procedure classification (Innes and Bramley 1997). Some guiding principles had to be overlooked because of the timeframes for consultation, publication and implementation. In the second edition of ICD-10-AM, the codes were restructured on the basis of provider neutrality and integrated into the existing chapters of the classification, thus removing any duplication of interventions (Bramley and Innes 1998). The timeframe between publication of the first and second editions allowed the NCCH to work constructively with the allied health professions to produce a classification that followed guiding principles and met the needs of key stakeholders.

3.4 Semantic and conceptual scope of descriptors

Category or subcategory descriptors should have a meaning (semantic scope) that corresponds to the idea (conceptual scope) being classified. When the meaning does not correspond to the idea, there is a concept mismatch.

**Example 3.4a**

If a category descriptor for an object producing an injury is 'furniture' then all subcategories should be items of furniture. If carpet was classified to this category, then the conceptual scope of the category would need to be changed to something more representative, like 'furniture and floor coverings'. When a category descriptor states 'cough', expectations are that all subcategories are instances of 'cough', such as 'chesty cough', 'dry cough' or 'chronic cough'. If 'does not cough' is included as a subcategory, then there is a concept mismatch. The category descriptor is essentially saying the patient has a cough, and statistically, the count reflects the numbers of patients who had a cough at a particular point in time. It is illogical, then, to include in those statistics a patient that does not have a cough.

The International Classification of External Causes of Injury (ICECI Coordination and Maintenance Group 2004) is a multiaxial classification that captures data about the circumstances of an injury (external cause, mechanism of injury, place of occurrence, et cetera). Injury surveillance activities and injury prevention programs aim to reduce death and illness. To be effective, these initiatives require those statistics a patient that does not have a cough.

**Example 3.4b**

The Australian Classification of Health Interventions (ACHI) (National Centre for Classification in Health 2004) classifies surgical procedures and other clinical interventions. One principle in developing procedure classifications is to avoid including diagnostic information in the category or subcategory descriptors. The descriptor should correspond with the procedure being performed, rather than the disease being treated, for example 'transplantation of liver' or 'lobectomy of lung'. Having said that, there are instances where the diagnostic information is inextricable from the procedure, for example 'haemorhorhoidectomy', or warranted, such as 'excision of pilonidal sinus'.

3.5 Unique categories for important concepts

Concepts that have particular importance within a domain should have their own unique category in a statistical classification (Hoffman & Chamie 1999). These concepts are important for public health purposes, research or statistical reporting and so should be easily distinguishable.

Who determines which concepts are uniquely distinguished from others? In developing and maintaining health classifications, many 'voices' are taken into account, not just those of the developers. The influential voices are not purely based on clinical research and discovery. Political reasoning can dominate, as can technological, social, religious, legal, moral and ethical reasoning (Bowker & Star 1999). Balancing the needs of all stakeholders means compromise. In any process involving consensus, it is the strongest voices that have the most influence and will be heard above other voices who will generally be silenced (Bowker & Star 1999).

**Example 3.5**

Consider that in 1977, homosexuality was classified as a mental disorder in ICD-9. The guidelines clearly stated that it was to be coded to this category 'whether or not it is considered as a mental disorder' (World Health Organization 1977: p.196). The fact that homosexuality was considered a pathology then was probably underpinned by strong political, legal, social, moral and religious voices. Opinion must have been divided though and hence the inclusion of the guidelines.

By 1992, the term is absent in the ICD-10 because of: the strongest voices being now a reflection of the changing social norms; the emerging influence of gay and lesbian advocacy groups; and empirical data showing little support for its pathological classification (Herek 2005; Narain and Chandran 2002; Smith, Bartlett & King 2004; Stakelbeck & Frank 2003; Wu 1998).
4. Usability principles

4.1 Definitions and instructional notes

The categories or subcategories in a health classification must be well defined and supported by definitions and explanatory notes (Hoffman & Chamie 1999; Price 1982).

Example 4.1

The Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition – Text Revision (DSM) (American Psychiatric Association 2000) is more than a classification, as its name suggests. The manual is used extensively by mental health clinicians, primarily as a diagnostic tool, but also as a statistical, research and educational tool, and is applicable in all healthcare settings. ICD-9-CM is the statistical classification applied and there are mappings to ICD-10 codes. The categories in DSM are differentiated on diagnostic criteria and other defining attributes of a disorder. They are extensively defined, and support the practical use of the manual.

4.2 Indexes/thesauri

Indexes or thesauri are essential to provide users with easy access to the desired term and its classification. They should contain all terms relevant to the domain the health classification serves, including synonyms (Hoffman & Chamie 1999).

Example 4.2

The ICPC-2 PLUS is an electronic interface terminology, with links to its parent classification, the ICPC-2. To describe it very simply, it is an electronic index of terms used in general practice. Terms are managed in a database which is routinely updated from user feedback. Each term is given a unique identifier which is then linked to its relevant category in ICPC-2. The end product is a clever electronic solution to two problems: (1) it overcomes the lack of specificity in the ICPC-2 for clinical research purposes; and (2) it simplifies the work of GPs when classifying or retrieving morbidity data. A demonstrator model of the ICPC-2 PLUS can be viewed on the Family Medicine Research Centre’s website: <http://www.fmrc.org.au/icpc2plus/demonstrator.htm>.

Indexes are also essential tools for maintaining classifications. They aid in reducing redundancy and detecting misclassifications.

4.3 Guidelines/training materials

Guidelines or rules on how the classification is to be used should be available to all users. Training materials should also be provided, particularly when revisions or updates are introduced (Hoffman & Chamie 1999).

Example 4.3

Volume 5 of the ICD-10-AM is the Australian Coding Standards. The aim of the volume is to achieve consistency in coding through guidelines on the use of the classification. The standards are written with the assumption that users have had training in the application of the classification, are trained in the abstraction of clinical data from clinical records, and familiar with the ICD conventions (National Centre for Classification in Health 2004). The Australian Institute of Health and Welfare has developed an Australian user guide for the International Classification of Functioning, Disability and Health (ICF) (Australian Institute of Health and Welfare 2003). Practical advice is also included for those preparing to implement the ICF.

4.4 Suitability/acceptability/appropriateness

Health classifications should be well matched to the users' work processes and information flow to enable integration (Price 1982). In this sense, health classifications can be described in terms of their specificity. The level of detail should match that of the domain it serves (International Organization for Standardization 2000).

Example 4.4a

The ICD-10-AM works well in acute care settings because of its specificity. However, the five-volume classification in its manual format is said to be too detailed for use in general practice (Britt, Beaton & Miller 1995; Parnanen, Kumpusalo & Takala 2000).

Health classifications can also be described in terms of their granularity. The term is often confused with specificity, generally because granular classifications allow more specificity. In informatics, the term ‘granularity’ is defined as ‘the degree of modularity of a system. More granularity implies more flexibility in customising a system because there are smaller increments (granules) from which to choose’ (Answers.com 2005).

Example 4.4b

The Canadian Classification of Interventions (CCI) is more granular than the Australian Classification of Health Interventions (ACHI) because the CCI has a flexible structure; it allows codes to be built by taking an element from each axis (or module or table). The codes in the ACHI are predefined; elements cannot be added to them for greater specificity.

Health classifications should not be too complex or difficult to use, nor should they require more detailed information than is available to the user (Price 1982).

Example 4.4c

The NCCH has worked collaboratively with the AIHW National Injury Surveillance Unit to include a greater level of detail in the external causes chapter of the ICD-10-AM. Guidance for some changes has been drawn from the International Classification of External Causes of Injury (ICECI). Their rationale is that this specificity is necessary to make the external cause codes more useful for injury prevention and control (Harrison 2001). The effects of this increased specificity on usability need to be measured. It is uncertain whether this high level of detail is currently captured in in-patient records and is able to be coded. Schmertmann & Wil-
liamson (2001) reviewed NSW injury data from 1995-1999 and found that residual categories were overrepresented in the data set. They could not determine whether this was because of poor source information or inadequacies of the ICD’s theoretical framework (p.103). Before any more specificity is added to this chapter, research needs to be undertaken to determine whether there is enough detail in the source information to satisfy the specificity. Only then will we know if these changes have indeed led to ‘some major gaps in [injury] information ... being filled’ (Harrison 2001).

4.5 Compatibility/comparability
A health classification should be compatible or comparable with other similar health classifications in use, both nationally and internationally.

Example 4.5
Recall that mapping is a mechanism used for maintenance of a health classification. Mapping also measures comparability between health classifications. Mappings between different health classifications can demonstrate the quality of the relationship through the number of one-to-one mappings, representing minimal loss of detail. However, the quality of the relationship will always be dependent on the purpose of the mapping. ICPC-2 is mapped to the ICD-10 to demonstrate the compatibility, and facilitate linkage, between the two classifications (Lamberts & Wood 2002; Okkes et al. 2002; Wood et al. 1992). The mappings are useful for conversion of data from ICPC-2 to ICD-10 and vice versa (Britt, Beaton & Miller 1995), and thus provide a connection or common language between primary care services and acute care services.

4.6 Subsets
If a health classification serves a wide domain, then mechanisms should exist to enable the production of a subset of the classification for a specific sector within that domain, or perhaps for other domains that deem the classification suitable for their purposes.

Example 4.6
The Nursing Interventions Classification (Iowa Intervention Project 2000) covers all nursing domains but, because of its broad scope, may not be suitable for use by community nurses working in community-based healthcare settings. A subset that includes only the interventions appropriate to their domain may be less cumbersome and more useable than the larger classification. ICD-10-AM is the mandated classification for use in Australian acute and community-based mental health services. In community health centres, there are limited numbers of trained coding staff, so it is more likely that clinicians will code and report the data. To support clinicians in this task, the NCCH developed the ICD-10-AM Mental Health Manual (National Centre for Classification in Health 2002), a subset of the ICD-10-AM, Third Edition, as a diagnostic and coding tool. The manual is similar in theory to the DSM, however, the diagnostic criteria and other defining attributes of a disorder are based on a number of WHO publications that are all subsets of the ICD-10 (World Health Organization 1992b; 1996a; 1996b; 1997). Other features distinguishing this manual from the DSM are the inclusion of mental health interventions, and diagnostic instruments to supplement the diagnostic guidelines.

4.7 Adaptable to an electronic environment
Health classifications should be adaptable to an electronic environment to broaden their usability (Hoffman & Chamie 1999). Database management of health classifications can streamline the production, maintenance, updating, mapping and exchange processes. Subsets can be more easily created from databases.

Practical examples of evaluating health classifications
Evaluation is performed to determine the ‘merit, value or worth of things’ (Scriven 1991: p. 1). It is a rigorous process that employs both quantitative and qualitative research methodologies and should be performed at all stages of an information system’s life cycle: planning, development, implementation, and operation. Evaluation enables informed decisions to be made based on scientific facts and thus is harmonious with evidence-based policy and practice in Health Information Management (Leys 2003; Rigby 2001). Health classifications are essential components of information systems. The following evaluations are all good examples of evaluation in practice. Some build on a theoretical framework, while others apply components of it. They each have different purposes and objectives.

The Australian Institute of Health and Welfare (AIHW) evaluates health classifications for inclusion in the Australian Family of Health and Related Classifications. Their aim is to endorse national classifications for specific purposes within particular health settings. As the Australian WHO Collaborating Centre for the Family of Classifications, the AIHW has aligned this work with the principles of the WHO’s family of international classifications and the United Nation’s family of international economic and social classifications (Australian Institute of Health and Welfare 2002). The AIHW General Practice Statistics and Classification Unit recently lodged a submission for inclusion of the Anatomical, Therapeutic, Chemical classification system with Defined Daily Doses (ATC/DDD) and the relevant documents can be viewed online at: <http://www.aihw.gov.au/committees/ctwg/submissions/submissions.cfm>.

When the decision was made to implement ICD-10 in Australia, the next task was to determine the most appropriate procedure classification to be used in conjunction with the ICD-10 (Bramley 1994). Four candidates were assessed for their taxonomic quality and usability:

- 3M Health Information Systems ICD Procedure Coding System (ICD-10-PCS) (USA);
- Office of Population Censuses and Surveys Classification of Surgical Operations and Procedures, fourth revision (OPCS-4) (UK);
- Commonwealth Medicare Benefits Schedule (MBS) (Australia); and

A rating system for each criterion was created in order to make a fair comparison. CPT was the best performer, MBS was the worst. The result for MBS was not surprising because it is not a classification, and it was perhaps unfair to include it in the assessment. However, the Australian Government saw merit in developing an Australian procedure classification based on the MBS, and the rest is history (Innes et al. 1997). In hindsight, the decision to create an Australian procedure classification was the best choice. The OPCS-4 was, and remains, outdated, and its use in the United Kingdom is under review (National Health Service Information Authority 2004). The ICD-10-PCS has not yet been implemented in the United States, and the future of the CPT is not certain as debate goes on (and on) about the value of having only one procedure classification for the US5 (American Medical Association 1999b; Bowman 2005; Libicki & Brahmakulam 2004; National Committee on Vital and Health Statistics Subcommittee on Medical Classification Systems 1993; Rode 2005; Slee 2000).

A study conducted in the Netherlands (Van Achterberg et al. 2005) transcribed nursing diagnoses to the International Classification of Functioning, Disability and Health (ICF) to evaluate the fit between that classification and hospital-based nursing practice. Van Achterberg et al. (2005) found that the classification was useful to nursing practice in acute care settings, and because human functioning is at the heart of nursing care, they recommended its use in this domain (p.440). They found that aggregated levels of the classification were a better match with nursing diagnoses, than the more detailed levels, and that the principal focus was on the body functions and activities components of the classification. Negative points raised in the study were that some aspects of nursing observations were found to be missing from the classification. Nurses also had problems finding terms because of a lack of familiarity with the structure of the classification and the language used to describe the terms. For these reasons, the authors recommended that nurses participate in future revisions of the ICF and that the classification be introduced into nursing curricula (Van Achterberg et al. 2005).

The substantial task of determining a suitable classification for general practice in Australia was undertaken by the General Practice Coding Jury (2000), and supported by government funding through the General Practice Computing Group (GPCG). Bearing in mind developments in electronic health records, the scope of this evaluation included terminologies as well as classifications. Each criterion was prioritised and ranked and systems were compared on that basis. The Jury’s recommendation was to adopt the ICD-10-AM in the interim (on a 5 year short-term basis), with a view to ultimately implementing SNOMED-CT, if further assessments supported such a move (General Practice Coding Jury 2000: p.4).

The Jury’s recommendations were not adopted because there was no widespread support for them among key stakeholders (General Practice Computing Group 2002: p.2). One response in particular was a critique of the methodologies applied by the Jury (Britt & Miller 2000). The Australian Government commissioned an independent review to make recommendations on the best way to proceed. The GPCG has decided to implement one of those recommendations, which is to develop a vocabulary for general practice, for the areas of diagnosis and problems (General Practice Computing Group 2002: p.2).

Not all evaluations achieve their goals, as can be seen in the Jury’s evaluation. It is wise to bear in mind that evaluations are innately political, primarily because of the vested interests of various stakeholders (Leys 2003).

Conclusion

Evaluation is important to evidence-based policy and practice in Health Information Management. Health classifications are important components of information systems and should be evaluated. My aim in writing this paper was to provide a revised and updated framework for evaluating health classifications that are used for statistical and reporting purposes. Additional guidance has been provided, particularly to novices, by illustrating the criteria with examples from the field, and using the language of nosology in context to enhance understanding of these terms. Examples of evaluation in practice have also been included.

The principles listed in this framework are not intended to be exhaustive, nor will each criterion be relevant to every evaluation. Rather, these criteria can be used as building blocks on which to base an evaluation, because each evaluation will differ in purpose and objectives. One important point to bear in mind is that the basic principles on which this framework was built will change as classifications, and their relationship with terminologies and information technology, develop over time.

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References


5 In the US, two procedure classifications are used to code clinical procedures. ICD-9-CM is used for in-patient services. CPT is used in both ambulatory and in-patient settings. Both systems are used for payment (National Committee on Vital and Health Statistics Subcommittee on Medical Classification Systems 1993: pp.8-9).

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New informatics-based work flow paradigms in radiation oncology: the potential impact on epidemiological cancer research

Andrew Miller

Abstract
Epidemiological research is worthless without verifiable source data. Much of this data is common to the clinical environment. Currently, substantial resources are allocated to data management bureaucracies in attempts to ensure data accuracy. These bureaucracies developed in the era of paper records, but in the present health information climate, the ability to share electronic data presents exciting possibilities, while placing new responsibilities on the gatherers of information and challenging them to develop new work flow paradigms. Radiation oncologists have a pivotal role to play in the processing of oncological data for future epidemiological research because of the substantial overlap in data requirements.

Key Words: Radiation oncology; informatics; epidemiology; database management system

Introduction
Radiation oncologists are medical specialists who manage cancer patients and employ radiation therapy as their main treatment modality. It is estimated that 50% of the patients who are identified in annual cancer incidence records will receive radiation therapy at some time after their diagnosis; indeed, service planning is often based on this estimate (Delaney et al. 2005).

The speed of infiltration of information technologies into radiation oncology has been astounding. So rapid has it been been that while most departments are equipped with an advanced Oncology Information System (OIS), few are fully aware of the improvements that can be achieved by a wider implementation that includes the radiation oncologist's work flow. Coupled with this under-appreciation is the dearth of experienced implementation services, and the reticence of oncology administrators to provide the substantial resources required to achieve meaningful implementation.

This paper describes the potential role that radiation oncologists can play in ensuring that data for epidemiological research is accurate and complete. The impact of the OIS in changing work flow will be discussed in another paper.

Discussion
Current data collection paradigms
There is an unfortunate dichotomy in the handling and status of current oncological data. In many centres a single source of data (interaction with a patient) results in dual systems of data flow. This dichotomy results from historical methods of data collection in the paper era which persist into the electronic era.

The first data flow system consists of 'normal' clinical data which is transmitted within a free text format; that is, data that is classified in accordance with strictly defined categories, such as the National Cancer Institute's Common Toxicity Criteria. This format is highly explicit, invariable, highly mutable, easy to analyse, highly structured, systematised and often validated. To collect and collate this type of oncological data for research, many departments developed substantial data 'management' bureaucracies. These systems exist in parallel with and largely duplicate or parasitise the paper-based process of routine clinical data collection.

While routine data is usually recorded by clinicians and other staff in a text format, when specialised data collection is required, an additional process follows which requires that the identical data be quantised according to well recognised and validated categories (e.g., ICD-0 diagnostic codes, AJCC/UICC staging codes, NCI CTC 99 side effect criteria, RTOG/EORTC acute toxicity categories, LENT/SOMA scoring). Many of these categories are now also used in routine practice.

While the source of data is identical (the patient) and the content is identical, the 'research' collection is more structured than the 'normal' clinical data. Frequently these categorisations are scored by clinicians and then transferred to an electronic database by data managers within the bureaucracy. Moreover, it is not unknown for data managers to attempt to extract the quantised data from routine notes. Thus a single clinical interaction results in two essentially contextually identical but differently structured entries.

Difficulties in the recording of data within the two systems can be seen when a clinician might, for example, report in the clinical notes that a patient has 'mild to moderate skin reaction'. However, when entering this as trial data, the entry systems will require that the assessment of this patient's skin (as a quantised RTOG Acute Skin Reaction) be '1' (meaning faint erythema, a mild reaction) or '2' (meaning bright erythema, dry desquamation; a moderate reaction), as there is no '1.5 — mild to moderate' choice.

At sites where there are medical staff with some IT experience and ability, the tendency has been for them to build their own individualised but parallel electronic data repositories. These microcosms mirror the
functionality of the data bureaucracy by being separate from the routine clinical system, often addressing an area of personal interest. These data repositories rarely influence normal data recording, or feed back to correct errors in the clinical record. (It is not unknown for departments to have all three varieties — routine clinical, data manager-based and personal data repositories!).

Unfortunately, quality assurance is usually not a prominent feature of any of these systems. In the first case, routine clinical data is rarely reviewed or changed; indeed, in some circumstances, it is considered an offence to alter data. In the second case, the degree of knowledge required to accurately assure data resides within medical staff who are largely peripheral to the operations of the bureaucracy. In the third case, the medical staff member frequently assumes that once the data is collected it is accurate because it represents a personal endeavour. The workload to compare multiple data sources with incompatible formats is largely manual and extremely difficult.

In ‘research’ cases, data collection is divorced from the normal stream of clinical activity and the situations where data are usually collected. Previous attempts to quality assure these data collections have found errors of over 20% (Evans et al. 1998; Hobson, Khemani & Singh, 2005; McCulloch, Ward & Tekkis, 2003; Warsi, White & McCulloch, 2002). These rates are unacceptable in data used for epidemiological purposes.

Surprisingly, modern oncology is very fortunate because of the widespread tendency to categorise most of the oncological parameters associated with patients. This tendency stems from the utility and long tradition of statistical analysis in determining what strategies are useful in the management of the cancer patient.

Oncologists therefore are aware of the importance of data and the formats used in research, but generally have been unable to develop and implement coherent strategies for data collection and verification in this format within the normal workflow.

The result is the aforementioned circumstance which conspires to duplicate and divide clinical data. From the data viewpoint, this may render the majority of data of little use for epidemiological research. From the clinical viewpoint, this may compromise the quality of patient care because the clinician might not have access to the latest and best data.

Future data collection paradigms

Data collection is a necessary process within each and every radiation oncology department. Radiation use is accompanied by a lengthy and detailed audit, with all Australian and New Zealand radiation oncology departments being required by legislation to collect and retain the details of the specifications and delivery of radiation for many years up to and after the death of the patient. The National Radiation Laboratory of New Zealand requires that a department should keep a computerised clinical database. Item 8.2.3 states:

A suitable computerised cancer registry should be maintained that contains data on radiotherapy treatments and outcomes of at least the most common types of cancer. Treatment data should include details of the radiotherapy (target dose, fractionation system, etc) together with other treatment modalities used in combination. Outcome data should include tumour response, morbidity, mortality, and recurrence. (New Zealand National Radiation Laboratory 1992).

Similar regulatory requirements offer the prospect of routine data collection that might be provided for epidemiological research.

The recent availability of the modern OIS has promised, but not fulfilled, new opportunities for epidemiological research where the implementation of new systems within radiation oncology departments based on modern paradigms of data manipulation, data storage and retrieval will result in better validated and newer forms of data being available (Chamorro 2001).

The construct that provides the most favourable conditions for data acquisition for epidemiological research is one where all routine data collection within a department is based on the quantised data paradigm. That is, all data is regarded as and collected as if it were research data. This constitutes a reversal of most features within current data flows. To achieve this status, departments should assess software purchases intended for routine clinical use to discover whether it contains a repository with categorised data in a quantised format consistent with the type already acquired by data managers. Such a repository should cover all required fields and be expandable to include all desired fields within the areas of Record & Verify, Schedule, Document Repository, Clinical Assessments and Disease & Treatment outcome measures.

The modern oncology department will require that any newly purchased OIS will also be able to undertake other functionality including scheduling and billing, as well as integrate into the hospital’s overall IT strategy. While the functions that enable the day-to-day running of the department are important, they are not the raison d’être or the prime benefit of OIS. These systems improve efficiency by virtue of their ability to integrate data, improve workflow and increase safety within the oncology context. Rather than applying resources to force radiation staff to use a generic Hospital Information System (HIS) and lose efficiency in the oncology department, effort should be expended in establishing data flow between the OIS and HIS.

The implementation of this new construct requires reorganisation based on the equally new and important concept of data ownership. The primary aims of any repository ultimately used for research should be data coverage (all items completed) and data integrity (all data makes sense). To achieve this in a normal clinical workflow requires the inclusion of the concept of ownership. This is a specifically assigned responsibility for data creation, collection and integrity within an organisation, rather than an emotional attachment to the data collection process, or a legal concept.

Once clinical data is discovered (such as the diagnosis), electronic data should be immediately entered in a quantised format by its owner. This data is then immediately available for use within the normal clinical process, and for automated quality reporting to determine whether it is complete and whether it is internally consistent. For example, it should be possible to use a database report at the end of a clinic to match...
the schedule list of follow-up visits with entries detailing patient follow-up assessments to look for entries that have not been undertaken or are incomplete. The data owner can then attend to the correction of the identified entries.

Of course the determination and assignment of data to particular groups can be difficult, as this explicit paradigm is not active in many departments and may cut across an individual's view of their professional standing and function within a system. The presence of a system of data managers tends to reinforce the view that their data is somehow different to the normal clinical data. The delegation of data collection to data managers was a pragmatic decision that occurred when there were no options for electronic records. This is not the case now and so the decision to delegate needs to be reassessed. The new OIS permits a department to reverse this delegation and redeploy data managers away from data collection and data entry towards ensuring quality and coverage, and undertaking analysis.

Nevertheless, the concept of data responsibility should be associated with frequent quality assurance of the assigned dataset, looking specifically at completion rate and data coherence, and substituting this data collection for normal clinical recording. Obviously, it would be a major undertaking to attempt to quantify all features of the clinical record, however, attempts to isolate areas where quantised data already exist and cover a major portion of an area should have early success. Treatment effects is such an area, where symptomatology is well described (e.g. NCI Common Toxicity Criteria).

While the proposed changes are substantial, some of the currently available OISs already possess this degree of functionality. The size of these software systems is daunting, however, and to expect busy overworked clinical radiation oncologists to undertake the process of discovery, procedural design and implementation within their work space is wishful thinking. Unfortunately, other professional groups are equally unlikely to be successful in undertaking this implementation. Professional implementation services for these systems are difficult to find, as implementation requires a high degree of knowledge about the radiation oncologist's work patterns and data use, the software design and its operational features. The result of purchasing implementation services should be a coherent system designed to deliver data of research quality while achieving similar clinical outcomes, and, it is hoped, with less effort. Implementation costs are built into other software projects (e.g., PACS introduction), however there has been no similar process considered in radiation oncology. Estimating the cost of implementation is difficult, but personal communications suggest that implementation costs are similar to or in excess of the purchase cost of the software.

Some of the methodologies required to reconcile and integrate these systems into current practice will be the subject of a later article. There are distinct advantages in the linking of these patterns of prospective data collection within a computerised clinical system if the methodologies of collection are synchronised with the desire to reuse the data to answer research questions. Other benefits accrue from this approach. There have already been calls for retrospective practice reviews of patient outcomes to be subject to the same ethics committee approval process as prospective trials (Lertsithichai 2005). Where the quantising and storage of clinical data uses nationally approved and internationally recognised codes in a process of continuous prospective data collection to replace the usual text-based clinical record, there are no requirements for approval by ethics and professional bodies, or to ask a patient's consent to keep a record, or indeed, to even inform them of the record.

This approach is based on the fact that the generation of a clinical record is necessary in all medical situations; however, the format of such a record is not mandated by legislation. When reporting on the information within the database, confidentiality can be maintained by use of the unique database number assigned to each patient, which has no relationship to the Medical Record Number, and by the ability to include relevant patients in a report without actually opening the patient's record. In a well designed system, assiduous, frequent and early quality assurance of the entered data will negate the need to individually review charts.

Data security and storage can be integrated within a hospital's IT initiatives. Although the OIS is a separate system, its data can be freely exchanged with the HIS or any other database through common formats (e.g., NSW Department of Health Radiotherapy Information Strategy where waiting time data is reported directly from the OIS, and where a minimum dataset of diagnostic and therapy data is reported to the NSW Cancer Registry) so that the process engineering benefiting the oncology department is used while the requirement for data accumulation within the HIS is also met. The resultant system does not require the generation of paper forms except as mandated by regulation.

Conclusion

There is a surfeit of data collected within normal clinical radiation oncology using outdated text-based methods that result in repositories of largely unusable data. Implementation of a modern electronic OIS that stores data in quantised formats (e.g., NCI Common Toxicity Criteria) will enable routine clinical data to achieve a status similar to current research data.

The paradigm of data ownership with its attendant quality assurance implications can be used to construct a system which is able to ensure data coverage and integrity. Transfer of this routine data can provide epidemiological agencies with oncological data with a high degree of clinical assurance.

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A comparison of two sources of data on fungaemia in two hospitals

Quoc Nguyen and Beth Reid

Abstract

Fungal bloodstream infection (BSI) is of increasing concern in the hospital environment. This study compared routine hospital discharge data at two inner Sydney hospitals with a pathology database over a 6-year period. A high level of underreporting was found, with only 42% of the pathology database cases assigned an appropriate code in the hospital discharge data despite evidence of the infection being found in 97% of the medical records identified from the pathology database. The location of the evidence in the medical record had an impact on whether or not the infection was assigned a code. There was a greater likelihood that a code would be assigned if the infection was documented on the front sheet of the medical record. Improvements can be made to the reporting of fungal BSI if clinicians record it on the front sheet and if coders review the whole medical record before coding.

Keywords: Candidaemia; fungaemia; hospital discharge data; coding

Introduction

Over the past three decades, the incidence of fungal bloodstream infection (BSI) (also known as fungaemia) has been increasing, particularly among immunocompromised patients, surgical patients, transplant pa-
tients and the critically ill. The increasing use of two medical advances has added to the problem. Vascular
access devices provide an entry point for the oppor-
tuneis organim to enter the bloodstream, and broad-spectrum antibiotics allow the fungus to prolif-
erate following the elimination of bacterial species (Clark & Hajjeh 2002; Garbino et al. 2002). Candida
spp., the main fungal species associated with BSI, is the fourth most common organism recovered from the
blood and it accounts for 8% to 15% of all BSIs in the
United States (Kao et al. 1999).

In Australia, the incidence rate is comparable with
those found in the US and other countries, which range from 0.1 to 0.3 per 1000 separations (Slavin & the Australian Mycology Interest Group 2002). A local
study reported a mortality rate of 34% for patients
diagnosed with Candida spp. in the blood, with 62% of these deaths attributable to the infection (Stratov et
al. 1998). A higher mortality rate (44%) was reported in a recent 3-year Spanish review where 30% of
deaths were attributable to candidaemia (Viudes et al. 2002). In addition, fungal BSIs have been estimated
to increase the length of stay by an average of 22 days
and they cost between US$34 123 and US$44 536 per
episode of care (Rentz, Halpern & Bowden 1998). The
nature of infection and potential to cause a life-
threatening sepsis syndrome (Niewerth & Korting
2002) has led to the consensus that all cases of fungal
BSI during the financial years of 1996–1997 to 2001–
2002 and who had been an inpatient at one of two
major Sydney hospitals. A fungal BSI was defined as
at least one positive blood culture that yielded a yeast
or fungus specimen (Garbino et al. 2002). The 6-year
period was chosen as it included all fungal BSI cases
since the inception of the pathology database up to
the end of the 2001–2002 financial year. Both hospi-
tals, one a public 326-bed tertiary teaching hospital
and the other a private 230-bed facility, are located on
the same campus and use the same pathology service.

The emergence of fungal BSI as an adverse hos-
pital event raises the question as to whether it has been accurately described in the hospital discharge
data. Ideally, hospital discharge data should contain
an accurate summary of the type of patients seen as
well as the care provided. This information can be
used to determine the epidemiology of fungal BSI, the
type of patient at risk and the appropriate treatment
therapy. Previous studies (Alechna, Westbrook & Rob-
erts 1998/1999; Donoghue 1992; Powell, Lim & Heller
2001) have raised doubts about the reliability and
accuracy of hospital discharge data because of the high
rates of error in the way that codes have been as-
signed. The use of coded data for casemix-based fund-
ing means that accurate coding of all the complications and comorbidities has financial as well as research
implications.

Most studies on coding accuracy use a blind re-
coding methodology. However, an alternative ap-
proach is to compare two different sources or coded
outputs to determine the degree of concordance be-
tween them (Reid 1991).

This study examined how well fungal BSI was re-
ported in two data sources; the hospital discharge
data and the pathology database. Pathology databases
contain the reports of all pathology tests performed on
individual patients, and these reports are used by the
attending clinician for treatment decisions. The study
also examined what factors can contribute to the as-
signment of the codes, and whether these codes were
appropriate for the identification of fungal BSI in the
hospital discharge data.

Data and Methods

The study sample included all patients listed on the
pathology database who tested positive for a fungal
BSI during the financial years of 1996–1997 to 2001–
2002 and who had been an inpatient at one of two
major Sydney hospitals. A fungal BSI was defined as
at least one positive blood culture that yielded a yeast
or fungus specimen (Garbino et al. 2002). The 6-year
period was chosen as it included all fungal BSI cases
since the inception of the pathology database up to
the end of the 2001–2002 financial year. Both hospi-
tals, one a public 326-bed tertiary teaching hospital
and the other a private 230-bed facility, are located on
the same campus and use the same pathology service.

Approval to conduct the study was granted by the
institutional human research ethics committee that
governs both hospitals.
Fungal BSI cases identified in the pathology database

A list of patients from the two hospitals who had a positive fungal blood culture was obtained from the pathology database and sent to the medical record departments of both hospitals with a request to retrieve the patients’ notes. The pathology database was chosen as the gold standard because it identified all positive blood results. The medical records were reviewed to check whether and where the fungal BSI was reported in the record, and whether a disease code was allocated to the condition. The study period covered data coded in the International Classification of Diseases, 10th Revision, Australian Modification (ICD-10-AM) implemented in 1998 and the now superseded ICD-9-CM classification system (National Coding Centre 1996). Codes in ICD-9-CM were recoded to ICD-10-AM for consistency (Health Information Management Association of Australia 2002). Written evidence included the use of terminology such as ‘yeast in the blood’, ‘fungaemia’, ‘candidaemia’, ‘Candida spp. found in the blood’ and other similar words. The location of the written evidence was noted to identify which section of the medical record, such as the clinical progress notes, would likely lead to the coding of the fungal BSI. Evidence of sepsis syndrome was also documented because some of the codes related to the presentation of the BSI. A data collection form was used to record the codes used, demographic information and some clinical outcome information. The data were entered onto a database and analysed using SPSS (Statistical Package for the Social Sciences) version 10.0.7.

Possible fungal BSI cases identified in the hospital discharge data

To identify the fungaemia cases in the hospital discharge data, six ICD-10-AM diagnosis codes were selected which could indicate a possible fungal BSI (Table 1). The only specific code for fungal BSI is B377, which refers to Candida spp. being found in the blood. The remaining codes either include other organisms in the blood, or sites not confined to the blood. Code P37.52 (neonatal candidiasis) was not included because neither of the hospitals treat patients from this age group.

The hospital discharge data, from the implementation of ICD-10-AM in 1998 onwards, were used to identify any cases with one of the selected ICD-10-AM codes, either as a principal or secondary diagnosis code. These cases were then matched with those obtained from the pathology database. The matched cases were analysed to see which codes were more sensitive in identifying true fungal BSI cases as reported in the pathology database.

Results

Fungal BSI cases identified in the pathology database

During the 1996–1997 to 2001–2002 period, the pathology database identified 63 patients from the two hospitals with a positive blood culture for Candida spp. or Cryptococcus spp. This represented an average of 10 cases per year. Of the 63 cases, 60 records were located and reviewed. The cases per financial year; the number of separations and cases per 1000 separations are set out in Table 2.

Table 2: Fungal BSIs in the two hospitals per financial year

<table>
<thead>
<tr>
<th>Financial Year</th>
<th>No. of hospital separations</th>
<th>No. of cases of fungal BSI</th>
<th>Cases per 1000 separations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996–1997</td>
<td>42 203</td>
<td>6</td>
<td>0.1</td>
</tr>
<tr>
<td>1997–1998</td>
<td>39 757</td>
<td>8</td>
<td>0.2</td>
</tr>
<tr>
<td>1998–1999</td>
<td>40 701</td>
<td>12</td>
<td>0.3</td>
</tr>
<tr>
<td>1999–2000</td>
<td>43 559</td>
<td>8</td>
<td>0.2</td>
</tr>
<tr>
<td>2000–2001</td>
<td>44 799</td>
<td>8</td>
<td>0.2</td>
</tr>
<tr>
<td>2001–2002</td>
<td>45 945</td>
<td>18</td>
<td>0.4</td>
</tr>
<tr>
<td>Total</td>
<td>256 964</td>
<td>60</td>
<td>0.2</td>
</tr>
</tbody>
</table>

The majority of cases were hospital-acquired infections, as they were acquired 48 hours following the admission (Australian Infection Control Association 2001). In 88% of cases, the infection was considered to be important and warranted treatment with an antifungal agent. For the remaining patients, treatment was not provided as the patients were discharged prior to the results being known or treatment would have not improved the patient’s deteriorating condition. In only one case was the positive blood culture considered a possible contaminant, due to the leakage of the specimen bottle.

The mortality rate was 28% (17/60) (Table 3) and examination of the death certificates for 16 of the deaths revealed that the fungaemia or sepsis syndrome was a contributing cause of death in 38% of these 16 cases. Only one record did not include a death certificate. The demographic profile of patients with fungal BSI is shown in Table 3.

Evidence to support the coding of fungal BSI was found in the medical records of 58 of the 60 cases (97%) identified from the pathology database. However, only 25 (42%) had been given a fungal BSI code. Forty-two of the 58 records (72%) contained both written evidence and pathology results, 6 (10%)

<table>
<thead>
<tr>
<th>ICD-10-AM Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A418</td>
<td>Other specified septicaemia</td>
</tr>
<tr>
<td>B377</td>
<td>Candidal septicaemia</td>
</tr>
<tr>
<td>B3788</td>
<td>Candidiasis of other sites</td>
</tr>
<tr>
<td>B379</td>
<td>Candidiasis, unspecified</td>
</tr>
<tr>
<td>B459</td>
<td>Cryptococcosis, unspecified</td>
</tr>
<tr>
<td>B49</td>
<td>Unspecified mycosis, including fungaemia not otherwise specified</td>
</tr>
</tbody>
</table>
had only written evidence and the remaining 10 (17%) only had the pathology results. Table 4 sets out the location of the evidence in the 48 records with written evidence (not just a pathology report).

When fungal BSI was recorded on the front sheet, 80% (16/20) were coded compared to only 29% (8/28) when the infection was not reported on the front sheet. This resulted in an odds ratio of 10 (95% CI: 2.5–39.2) in favour of the fungal BSI being coded if it was reported on the front sheet. If it was reported in the progress notes only, 30% (8/27) were coded compared to 76% (16/21) if it was mentioned in the progress notes and on the front sheet or on the front sheet alone. An odds ratio of 0.1 (95% CI: 0.0–0.5) indicated that it was unlikely that fungal BSI would be coded if it was mentioned solely in the progress notes.

There was no difference in the coding pattern if the patient died during the episode of care (odds ratio: 1.0, 95% CI: 0.3–3.0).

For cases that were coded, the most frequently used code was B377, candidal septicaemia (Table 5). This code identified Candida spp. found in the blood as being associated with the manifestation of the sepsis syndrome. All records assigned to B377 had documented evidence of sepsis syndrome being present and that Candida spp. were isolated from the blood. One record was coded to A418 (other specified septicaemia), where B377 would have been more appropriate because Candida spp. were found in the blood. However, since no pathology results were found in the medical record for this patient, the coder probably did not know the organism that caused the sepsis syndrome and the decision to use the general sepsis code was understandable.

### Possible fungal BSI cases identified in the hospital discharge data

The hospital discharge data yielded 194 cases with the codes listed in Table 1 from 1998 onwards. Of these only 20 were also found in the pathology database. As expected, code B377 was the most useful code in identifying cases of fungal BSI. There were 11 cases with this code on the hospital discharge data and there were also 11 cases from the pathology database. The remaining codes produced large numbers of cases that were not fungal BSI or cases where the infection was caused by another organism or occurred at another site. A summary of cases found in the hospital discharge data compared with the pathology database is shown in Table 6.

### Discussion

In this 6-year study, the fungal BSI incidence rate was 0.2 per 1000 separations with a mortality rate of 28%.
This is comparable to a review of nine tertiary hospitals in Australia that found the incidence rate to be from 0.1 to 0.3 per 1000 discharges with a mortality rate of 28% (Slavin & the Australian Mycology Interest Group 2002). Age and sex distribution in both Australian studies were also similar to a Canadian study examining candidaemia over a 5-year period (Macphail et al. 2002). The mean length of stay of 36 days for fungal BSI patients is considerably longer than the national mean for all patients of 4 days for the period 1996–1997 to 1999–2000 (Australian Institute of Health and Welfare 2002). While fungal BSI may not be the sole reason for the increase in the length of stay it is a likely contributing factor that would not have been identified if it had not been coded.

The results of the present study suggest there is a high level of underreporting of fungal BSI in hospital discharge data. It found that only 42% of cases identified by the pathology database were eventually assigned a code for this condition. This occurred despite the presence of evidence in the medical records that indicated the development of fungal BSI during the episode of care. Nearly all (97%) of the records reviewed had pathology reports and/or written evidence to support the coding of fungal BSI. In addition, 88% of patients were prescribed an antifungal agent following the diagnosis, suggesting that the infection warranted treatment and was not considered to be a contaminant or clinically insignificant.

Previous studies that reviewed coding practices have found that poor documentation was a contributing factor for coding discrepancies (Donoghue 1992; Alechna, Westbrook & Roberts 1998/1999). This study on the other hand, found that fungal BSI was well documented in the records but this did not lead to all relevant cases being coded appropriately. The location in the record of the evidence for fungal BSI was important for coding. If the infection was reported on the front sheet, there was a high probability that it would be coded. Written evidence in the progress notes and pathology reports had little bearing on whether it was coded. The outcome of care, such as death, also had no impact on the decision to code.

These findings are in line with the Australian Coding Standard 0010, which emphasises that it is the responsibility of the clinician to list the diagnoses to be coded on the front sheet of the patient’s medical record. Coders must verify the information they code by reviewing pertinent documentation in the body of the record. If a discrepancy is found, then the coder must seek advice from the clinician. The standard recommends that abnormal pathology results should not be assigned a code unless verified by the clinician (National Centre for Classification in Health 2004). As the blood is a sterile site, and any positive blood results for any organism are clinically important, coders should confirm these results with the clinician if the clinician has yet to document them.

This study found that fungaemia meets the criteria for inclusion as an additional diagnosis according to Australian Coding Standard 0002. This standard states that additional diagnosis codes can be used if the complication or comorbidity requires further clinical evaluation, therapeutic treatment, diagnostic procedures, monitoring, or increases the length of stay (National Centre for Classification in Health 2004). In the majority of cases, fungaemia meets these requirements and thus should be included as an additional diagnosis. It is mainly a health care associated infection, a complication that is due to the hospital admission. Following the positive blood culture, the standard treatment protocol would require the use of antifungal drugs and the removal of any pre-existing central vascular access devices. Further monitoring and diagnostic tests such as blood screening and radiological studies may be required to determine whether the infection has been cleared from the circulatory system or whether it has infected other body sites. All these events impact on the increase in hospital admissions as well as the use of hospital resources. Additional diagnoses are collected to reflect hospital activity and incidence, not prevalence, of disease.

In general, there are perhaps two valid reasons to exclude fungaemia from being coded as an additional diagnosis. First, if the fungaemia is a community acquired infection and the patient presents with sepsis syndrome and there is no other reason for the hospital admission, the fungaemia should be coded as the principal diagnosis. Second, if there are no signs of sepsis syndrome and the clinician states that the positive blood culture is likely to be a contamination and is not clinically significant, the fungaemia does not meet the criteria for an additional diagnosis because the contamination is an incidental result and not the cause of the diagnostic test.

When fungal BSI was coded, most of the codes, except B377 (candidal septicaemia), were appropriate but not specific enough to identify the organism involved or whether it was a bloodstream infection. The other codes, except B377, included cases where the organism was found at a site other than the blood, and thus were not useful for identifying cases of fungal BSI (Table 6). If a search for fungal BSI cases were conducted using the hospital discharge data, the use of codes such as B3788 and B379 would produce many cases that were not blood borne. Clearly, it is not easy to locate all fungal BSIs using hospital discharge data but this is true for many diseases. ICD-10-AM is a classification system and hence it will be often the case that relatively rare diseases, such as this one, will not have a unique code assigned to them. It is interesting to note that no cases were assigned the general code of B49 (unspecified mycosis, including fungaemia not otherwise specified). This code would have been appropriate if the organism was not known. This would indicate that coders are able to specify the organism involved in the infection but perhaps are unclear as to the site of the infection and hence use a less specific code.

The low rate of coding of fungal BSI (Table 5) indicates that hospital discharge data do not provide an accurate representation of the number of fungal BSI cases at these two hospitals. This underreporting would also obscure associations between fungal BSI and other diseases and outcomes. Given the mortality and the greater length of hospital stay compared to the national average, it is argued that a greater effort is needed to code fungal BSI accurately. The code for candidal septicaemia, B377, is allocated to the most severe complexity level in the Australian Refined Dia-
The BSI was not coded. The complexity levels of at least some of the cases where it is plausible that this may have affected the casemix record were not investigated in this project. However, the wealth of Australia (2002). The implications of not coding fungal BSIs were coded and, with the exception of one 5.0) when used as a secondary diagnosis (Common-

Conclusions

The results of this study highlight the problems in using hospital discharge data to identify episodes of fungal BSI. Fungal BSIs are adverse hospital events yet they are difficult to identify precisely using ICD-10-AM codes. This is because less than half of all possible fungal BSIs were coded and, with the exception of one code, the codes assigned did not indicate that the infection was in the blood.

There is a need to recognise the importance of fungal BSI in terms of risk to patients, the contribution to the increase in length of stay, and cost implications for the episode of care. This should be reflected in the coding standards as well as in the awareness of the clinical coders. To improve the coding rate, clinicians should be encouraged to record fungal BSI in discharge summaries, and coders should use the complete medical record as well the front sheet to obtain information regarding each episode of care especially where patients have longer than average stays. Adopting these recommendations would improve the way fungal BSIs are reported in hospital discharge data.

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Population prevalence rates of birth defects: a data management and epidemiological perspective

Merilyn Riley

Abstract
The Victorian Birth Defects Register (VBDR) is a population-based surveillance system with a primary function of monitoring trends in birth defects. This paper outlines the processes undertaken in Victoria, Australia, to obtain population prevalence rates of birth defects and investigates the effect on the prevalence rates of variations in collection and processing tasks. It includes all birth defects that were notified to the VBDR by 31 December 2004.

The overall prevalence rate of birth defects in Victoria for 2003 was 4.0%, with an overall accuracy rate of 88%. However, this proportion varied according to what birth defects were included, the age by which birth defects were diagnosed, changes to sources of ascertainment, inclusion of terminations of pregnancy, or reporting by cases rate (infants affected) or birth defect rate (individual birth defects). Taking all of these factors into consideration, we are confident that 4.0% is an accurate population prevalence rate of birth defects in Victoria for 2003.

Key words: Birth defects; congenital malformations; prevalence

Introduction
In 2003, birth defects were the major cause of all perinatal deaths in Victoria (Consultative Council on Obstetric and Paediatric Mortality and Morbidity 2004) with 23% of all stillbirths and neonatal deaths attributable to a congenital anomaly. With the decline in childhood mortality from other causes (such as infections), this makes the monitoring of population rates of birth defects a very important public health issue.

The Victorian Birth Defects Register (VBDR) was established in 1982 as a direct response to an epidemiological investigation — the Yarram Inquiry of 1978 (Consultative Council on Congenital Abnormalities in the Yarram District 1978). A possible cluster of birth defects was investigated to determine if there was any association with certain agricultural products. Whilst no association was evident during this investigation, the Inquiry concluded that 'Victoria lacks organised research on the epidemiology of birth defects and lacks an adequate system of surveillance of defects which are not rapidly lethal' (Consultative Council on Congenital Abnormalities in the Yarram District 1978). The Victorian Perinatal Data Collection Unit (VPDCU) was therefore established in 1982 under the auspices of the Consultative Council on Obstetric and Paediatric Mortality and Morbidity (Health Act 1958)\(^1\), and one of its primary functions was to establish and maintain a birth defects register.

The VBDR is a population-based surveillance system of birth defects with the primary functions of:

- monitoring trends in birth defects (prevalence and survival data)
- providing data to organisations responsible for providing health care services to people with birth defects
- providing information for epidemiological research
- assessing the effectiveness of primary prevention and screening programs
- responding to community concerns about perceived clusters of birth defects (Riley Halliday 2004).

Given these purposes, it is a fundamental objective of the VBDR to obtain birth defect prevalence data that is as accurate and complete as possible.

Investigation into factors that may affect local population prevalence rates are very important, especially when comparisons may be made between geographical areas (e.g. states of Australia) or when data from different geographical areas may be pooled to provide one global or national figure. For example, in Australia each state cites its own birth defect population prevalence rates. These figures range from 2.0% (in 2002) of all births in New South Wales to 4.0% (in 2003) of all pregnancies in Victoria (Centre for Epidemiology and Research 2004), to 5.0% (in 2002) of all pregnancies in Western Australia (Bower et al. 2004). Obvious questions arise as to why there is such variation in figures between the states, and which, if any, is the 'true' population prevalence rate of birth defects.

The aims of this paper are:

- to outline the process undertaken by Health Information Managers (HIMs) in Victoria, Australia, to obtain population prevalence rates of birth defects, and
- to investigate the effect on the prevalence rates of variations in collection and processing tasks.

Methodology
The VBDR collects data on all birth defects diagnosed before 15 years of age in all Victorian live births, stillbirths, neonatal deaths and terminations of pregnancy (TOPs) for a birth defect, both before and after 20 weeks gestation, occurring since 1 January 1982. Because age at diagnosis may occur at any time from birth to 15 years, the VBDR is continually being updated and new cases are added each year. The data presented in this paper include all birth defects for

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\(^1\) Part 9B of the Act relates to the Consultative Council on Obstetric and Paediatric Mortality and Morbidity.
children born between 1983-2003 notified to the VBDR by 31 December 2004. A birth defect is defined as ‘… structural defects or chromosomal abnormalities that are present at birth but not necessarily diagnosed at birth’ (Riley & Halliday 2004). Information is also collected on inborn errors of metabolism, haematological disorders, congenital infections, neoplasms and developmental delay, if of probable prenatal origin.

The VBDR is a voluntary reporting system that is maintained by the VPDCU, a mandatory reporting system that collects demographic, obstetric and paediatric information on all births in Victoria on a prescribed form known as the Perinatal Morbidity Statistics Form (‘perinatal form’). Information for the VBDR is obtained from multiple sources (Figure 1). Since 1990, the VPDCU actively has followed up each specific source to ensure that data are obtained from the same sources each year, if possible.

![Figure 1: Sources of notification to the Victorian Birth Defects Register](image)

These notifications come in the form of electronic listings or hard paper copies. Each electronic listing is printed out and all cases reviewed by a Health Information Manager to determine which case should be included (excluded cases include non-notifiable birth defects and interstate or overseas births). Vague, non-specific or questionable diagnoses from any source are followed up with the notifier or treating paediatrician for more details.

Data from all sources (excluding TOPs for a birth defect before 20 weeks gestation) are linked to a perinatal form, if possible. There are three levels of data linkage attempted, dependent upon the information provided:

1. Mother’s full name (if provided), child’s date of birth, sex of infant.
2. Mother’s given name (if provided), child’s date of birth, sex of infant, postcode.
3. Child’s surname, date of birth, sex, postcode.

Linkage is also attempted for major anomalies that cannot be linked to a perinatal form using the above three combinations, using the child’s date of birth, sex and diagnosis. Here the VBDR is searched to determine whether or not these variables match any cases that have been previously notified but do not match on name. Because birth defects are rare events, it is sometimes possible to identify cases based upon diagnosis, date of birth and sex alone.

After linkage, all cases are coded by HIMs using the British Paediatric Association Classification of Diseases ICD-9 Supplement (British Paediatric Association Classification of Diseases 1979). Difficult cases are referred to the VPDCU’s consultant paediatrician for classification. In the case of syndromes, it is the practice of the VPDCU to code all manifestations of the syndrome along with the primary diagnosis, because not all cases of a particular syndrome reveal exactly the same manifestations. However, for conditions with a standard set of defects in all cases, such as Tetralogy of Fallot, only the one condition is coded, not each of the manifestations.

Data is then entered into an ACCESS database, and a hard copy of all of the data entered is printed for subsequent checking. In cases where there is more than one notification with different diagnoses, a ‘case summary’ is created based upon the best composite of the diagnoses. If there is any uncertainty about any of the information that should be included, then the case is referred to the consultant paediatrician.

At the end of each calendar year, when processing has been completed, a combined file of all years from the VBDR is compiled, data validation checks performed and reports produced. This combined file remains the active file from which all research is derived for each particular year, until the file is again updated the following year.

Analysis is annually undertaken on 28 sentinel defects (Riley & Halliday 2004), including such things as trends in overall prevalence (including all birth outcomes), birth prevalence (excluding TOPs before 20 weeks gestation) and live birth prevalence (excluding TOPs before 20 weeks gestation and stillbirths). Rates reported can differ depending on whether or not results are presented according to:

- birth defect cases (case rate) — the number of infants affected by at least one defect or,
- individual defect (defect rate) — the number of occurrences of a particular birth defect.

Time trend analysis for the 28 selected defects is undertaken using chi-square linear trend analysis. Selected infant and maternal characteristics are also investigated for significant associations.

**Results**

In 2003, there were 3544 notifications to the VBDR from all sources (Table 1). The number of notifications exceeds the number of cases due to multiple reporting of cases from different sources. These notifications referred to 2709 cases, approximating to 1.3 notifications per case.

There were 2205 babies born at, or after 20 weeks gestation with a birth defect, and 339 TOPs before 20 weeks gestation with a birth defect. In 2003, there were 63 551 births in Victoria (including late TOPs at 20 weeks or more for any reason). This gives an overall birth defect prevalence rate of 400/10 000 or 4.0%. There were also an additional 165 notifications of conditions that are collected by the VBDR but not reported in our routine publications (e.g., un-
descended testes (UDT) ≥ 37 weeks, vesicoureteric reflux [VUR]). (Centre for Epidemiology and Research 2004). If these conditions are included then the overall birth defect prevalence rate for 2003 is 420/10 000 or 4.2%.

Table 2 shows the birth defect prevalence rate from 1983 to 2003, incorporating all notifications (excluding UDT, VUR and other excluded minor anomalies) received by 31 December 2004. This table shows an increase in the overall birth defect prevalence rate from a minimum of 2.6% in 1985 to a maximum of 4.6% in 1999.

Table 2: Birth defects by year, 1983–2003

<table>
<thead>
<tr>
<th>Year</th>
<th>Total births 20 weeks and later</th>
<th>Defects 20 weeks and later</th>
<th>Defects before 20 weeks (terminations)</th>
<th>N/10 000 pregnancies (including terminations)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1983</td>
<td>60 628</td>
<td>1675</td>
<td>2</td>
<td>276.3</td>
<td>2.8</td>
</tr>
<tr>
<td>1984</td>
<td>60 737</td>
<td>1714</td>
<td>19</td>
<td>283.7</td>
<td>2.8</td>
</tr>
<tr>
<td>1985</td>
<td>61 189</td>
<td>1599</td>
<td>18</td>
<td>264.3</td>
<td>2.6</td>
</tr>
<tr>
<td>1986</td>
<td>61 253</td>
<td>1624</td>
<td>80</td>
<td>278.2</td>
<td>2.8</td>
</tr>
<tr>
<td>1987</td>
<td>61 566</td>
<td>1638</td>
<td>55</td>
<td>275.0</td>
<td>2.8</td>
</tr>
<tr>
<td>1988</td>
<td>63 666</td>
<td>1886</td>
<td>103</td>
<td>312.4</td>
<td>3.1</td>
</tr>
<tr>
<td>1989</td>
<td>64 255</td>
<td>1987</td>
<td>123</td>
<td>327.8</td>
<td>3.3</td>
</tr>
<tr>
<td>1990</td>
<td>66 878</td>
<td>2205</td>
<td>132</td>
<td>348.8</td>
<td>3.5</td>
</tr>
<tr>
<td>1991</td>
<td>65 248</td>
<td>2294</td>
<td>140</td>
<td>372.2</td>
<td>3.7</td>
</tr>
<tr>
<td>1992</td>
<td>66 305</td>
<td>2344</td>
<td>152</td>
<td>375.6</td>
<td>3.8</td>
</tr>
<tr>
<td>1993</td>
<td>64 737</td>
<td>2278</td>
<td>203</td>
<td>382.0</td>
<td>3.8</td>
</tr>
<tr>
<td>1994</td>
<td>64 932</td>
<td>2327</td>
<td>250</td>
<td>395.4</td>
<td>4.0</td>
</tr>
<tr>
<td>1995</td>
<td>63 717</td>
<td>2496</td>
<td>255</td>
<td>430.0</td>
<td>4.3</td>
</tr>
<tr>
<td>1996</td>
<td>62 951</td>
<td>2231</td>
<td>272</td>
<td>395.9</td>
<td>4.0</td>
</tr>
<tr>
<td>1997</td>
<td>62 308</td>
<td>2338</td>
<td>298</td>
<td>421.0</td>
<td>4.2</td>
</tr>
<tr>
<td>1998</td>
<td>62 091</td>
<td>2369</td>
<td>276</td>
<td>424.1</td>
<td>4.2</td>
</tr>
<tr>
<td>1999</td>
<td>62 689</td>
<td>2598</td>
<td>296</td>
<td>459.5</td>
<td>4.6</td>
</tr>
<tr>
<td>2000</td>
<td>62 564</td>
<td>2545</td>
<td>288</td>
<td>450.7</td>
<td>4.5</td>
</tr>
<tr>
<td>2001</td>
<td>62 148</td>
<td>2283</td>
<td>300</td>
<td>413.6</td>
<td>4.1</td>
</tr>
<tr>
<td>2002</td>
<td>63 072</td>
<td>2294</td>
<td>300</td>
<td>409.3</td>
<td>4.1</td>
</tr>
<tr>
<td>2003</td>
<td>63 551</td>
<td>2205</td>
<td>339</td>
<td>398.2</td>
<td>4.0</td>
</tr>
<tr>
<td>Total</td>
<td>1 326 485</td>
<td>44 930</td>
<td>3 901</td>
<td>368.1</td>
<td>3.7</td>
</tr>
</tbody>
</table>

Presented in Table 3 are variations in overall prevalence rates and birth prevalence rates for selected conditions when TOPs before 20 weeks are included and excluded respectively.

Figure 2 shows graphically the differences in the overall prevalence rate and birth defect prevalence rate for anencephaly when TOPs before 20 weeks are included.
Neural tube defects (NTDs), which are major structural abnormalities, continue to be a focal point of interest in birth defect monitoring. In 2003, there were 79 cases of NTDs (case rate) reported to the VBDR, giving an overall prevalence rate of 12.4/10 000 pregnancies. Of these 79 cases, five had two NTDs (i.e., anencephaly with spina bifida, or spina bifida with encephalocele). If each condition rather than each case is counted separately, then there were a total of 84 NTDs in Victoria in 2003, giving a birth defect rate of 13.1/10 000.

Of the 28 selected defects which are routinely reported (Centre for Epidemiology and Research 2004), the following significant trends were observed between 1997–2003:

- increase in overall prevalence (including terminations) — Trisomy 21
- decrease in overall prevalence (including terminations) — spina bifida, oesophageal atresia and/or stenosis, anorectal atresia and/or stenosis and limb reduction defects.

### Table 3: Overall prevalence and birth prevalence for 28 selected defects, 2003.

*Rates are cases per 10 000 births*

<table>
<thead>
<tr>
<th>Defect</th>
<th>Overall prevalence (including all outcomes)</th>
<th>Birth prevalence (excluding TOPs before 20 weeks)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nervous system</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anencephaly</td>
<td>6.3</td>
<td>1.1</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>5.3</td>
<td>3.1</td>
</tr>
<tr>
<td>Encephalocele</td>
<td>1.6</td>
<td>0.8</td>
</tr>
<tr>
<td>Microcephalus</td>
<td>1.6</td>
<td>1.4</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>10.3</td>
<td>8.2</td>
</tr>
<tr>
<td><strong>Cardiovascular system</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transposition of great arteries</td>
<td>4.5</td>
<td>4.5</td>
</tr>
<tr>
<td>Tetralogy of Fallot</td>
<td>4.2</td>
<td>4.1</td>
</tr>
<tr>
<td>Ventricular septal defect</td>
<td>29.3</td>
<td>28.3</td>
</tr>
<tr>
<td>Hypoplastic left heart syndrome</td>
<td>3.4</td>
<td>2.7</td>
</tr>
<tr>
<td>Coarctation of aorta</td>
<td>4.1</td>
<td>3.9</td>
</tr>
<tr>
<td><strong>Digestive system</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleft palate</td>
<td>10.5</td>
<td>10.2</td>
</tr>
<tr>
<td>Cleft lip</td>
<td>3.9</td>
<td>3.9</td>
</tr>
<tr>
<td>Cleft lip and palate</td>
<td>6.6</td>
<td>6.0</td>
</tr>
<tr>
<td>Oesophageal atresia and/or stenosis</td>
<td>3.1</td>
<td>3.1</td>
</tr>
<tr>
<td>Atresia of the small intestine</td>
<td>3.1</td>
<td>3.1</td>
</tr>
<tr>
<td><strong>Genitourinary system</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anorectal atresia and/or stenosis</td>
<td>4.2</td>
<td>3.9</td>
</tr>
<tr>
<td>Hypospadias</td>
<td>28.0</td>
<td>28.0</td>
</tr>
<tr>
<td>Renal agenesis and dysgenesis</td>
<td>7.4</td>
<td>6.5</td>
</tr>
<tr>
<td>Cystic kidney disease</td>
<td>5.2</td>
<td>5.0</td>
</tr>
<tr>
<td>Obstructive defects of renal pelvis</td>
<td>35.4</td>
<td>35.1</td>
</tr>
<tr>
<td><strong>Musculoskeletal system</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital dislocation of hip</td>
<td>24.9</td>
<td>24.9</td>
</tr>
<tr>
<td>Limb reduction defects</td>
<td>3.9</td>
<td>3.6</td>
</tr>
<tr>
<td>Diaphragmatic hernia</td>
<td>3.3</td>
<td>2.8</td>
</tr>
<tr>
<td>Exomphalos</td>
<td>3.3</td>
<td>1.4</td>
</tr>
<tr>
<td>Gastrochisis</td>
<td>2.0</td>
<td>1.9</td>
</tr>
<tr>
<td><strong>Chromosomal anomalies</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trisomy 21</td>
<td>26.6</td>
<td>8.5</td>
</tr>
<tr>
<td>Trisomy 13</td>
<td>2.7</td>
<td>0.9</td>
</tr>
<tr>
<td>Trisomy 18</td>
<td>8.9</td>
<td>2.8</td>
</tr>
</tbody>
</table>
However, if the period over which trends are monitored is changed from 1997–2003 to 1983–2003, then the following significant trends are observed:

- increase in overall prevalence (including terminations) — hydrocephalus, hypospadias, cystic kidney, obstructive defects of the renal pelvis, Trisomy 21, Trisomy 13, Trisomy 18
- decrease in overall prevalence (including terminations) — coarctation of aorta.

Discussion

Determining prevalence rates of disease is fundamental to all epidemiological endeavours. However, interpreting these rates can often be complex, as with the case of determining population prevalence rates of birth defects in Victoria.

Impact of variations in inclusion criteria (i.e., birth defects included or excluded)

In 2003, Victoria reported a birth defect prevalence rate of 4.0%. This figure excludes cases with UDTs of 37 weeks or VUR. If these cases are included then the prevalence rate increases to 4.2%. From this example, it is apparent that the inclusion of these two conditions substantially increases the birth defect prevalence rate. When we note that other states such as Western Australia report a higher birth defect prevalence rate, we must immediately consider whether or not they are including other conditions which Victoria has excluded. Conversely, when considering the lower New South Wales birth defect prevalence rate, we must consider whether or not Victoria has included conditions which they have excluded.

Impact of variations in reporting period

Not only do we need to consider whether or not the conditions included by each state birth defects register are the same, but also whether or not the reporting covers the same ‘type’ of population and reporting period. Victoria includes birth defects diagnosed before 15 years of age in all live births, stillbirths, neonatal deaths and TOPs. Western Australia, on the other hand, includes birth defects diagnosed before 5 years of age, and New South Wales includes cases diagnosed within the first year of life. These differences could give rise to variations in birth defect prevalence rates between the states.

Impact of variations in ascertainment

Variations between the states can occur because of inclusion or exclusion criteria; they can also occur within a single state over long time periods where there may be variations in either the collection methodology or conditions reported. Table 2 shows that the prevalence of birth defects in Victoria varied from a low of 2.6% in 1985 to a high of 4.6% in 1999. Either more pregnancies are now being affected by birth defects or there has been some other reason for the increase in Victorian birth defects.

A validation of the VBDR in 1986 (Kilkenny, Riley & Lumley 1995) showed that the register was receiving notifications for 43.5% of babies with birth defects treated as inpatients at two paediatric teaching hospitals. A repeat of this exercise in 1993 and 2001 showed that the notification rate had increased to 73.5% and 87.8% respectively (Riley, Phyland & Halliday 2004; Hennekens & Buring 1987). This shows that reporting, or ascertainment, has been the major reason for the increase in the birth defect prevalence rate in Victoria. In 1988–1989, the VPDCU began to receive inpatient listings from two paediatric teaching hospitals for all children who were admitted to these hospitals with a birth defect. This accounts for an increase from 2.8% to 3.1% over this time period. In the mid 1990s, the VPDCU also began to receive listings from certain outpatient clinics that also treated children with birth defects that did not require hospitalisation. This could account for an increase from 3.5% in 1990 to 4.0% in 1994. The continued rise to 4.6% in 1999 can probably be related to the practice of receiving notifications of children up to the age of 5 years who have been admitted, or attended, a paediatric teaching hospital in any single year. Sources of notification have now substantially remained the same for 10 years, so variations in birth prevalence rates will need to look to other sources for an explanation.

Impact of inclusion of terminations of pregnancy (TOPs) before 20 weeks gestation

The inclusion of TOPs before 20 weeks gestation for a birth defect can greatly affect the reported prevalence rate, as shown in Table 3 and Figure 2. For some conditions, such as hypospadias or congenital dislocated hip, where very few of the cases are terminated, exclusion of TOPs has very little impact on the prevalence rates, with the overall prevalence rate for the latter being 24.9/10 000 and the birth prevalence rate of 24.9/10 000. However, for conditions where a large proportion of the cases are terminated, exclusion of these cases dramatically affects the overall prevalence rate. This can be seen in Figure 2 where the number of cases of anencephaly are presented both with and without terminations. The birth prevalence of anencephaly in 2003 was only 1.1/10 000 births compared with an overall prevalence of 6.3/10 000 pregnancies.

The most appropriate prevalence rate to cite is dependent upon the issue of interest. For instance, if a group were responsible for planning health services for children with Down Syndrome, then their area of interest is the live birth prevalence rate. However, genetic counsellors, wishing to advise clients on the risk of recurrence of Down Syndrome would be more interested in the overall prevalence rate (i.e., how many pregnancies are affected by Trisomy 21). The issue is not so much determining what is the true prevalence, but rather clearly indicating the type of prevalence which is being quoted.

Impact of case rate versus birth defect rate

Another factor which affects the reporting of a birth defect prevalence rate is whether or not reporting is
concerned with how many infants are affected by a particular condition (case rate), or rather with the individual birth defects (birth defect rate). As indicated in the results, there were 79 cases affected by NTDs in Victoria in 2003, but there were 84 individual birth defects. Since the effectiveness of the periconceptional use of folic acid in the primary prevention of NTDs is monitored through prevalence figures of NTDs, reporting by defect rate rather than case rate could alter conclusions drawn about the effectiveness of the program.

Impact of variations in trend analyses

We have also shown in the results that trend analysis is another complex area that can be affected by the time period over which the trend is reported. For the 7-year period between 1997–2003, only one of the 28 selected defects showed a significant increase in overall prevalence — Trisomy 21. However, if the trend analysis covered 21 years, from 1983–2003, then a significant increase in prevalence was also observed for six other birth defects. This indicates that careful and meaningful consideration needs to be given when attempting such analyses. We have already discussed changes in sources of notification that have contributed to the increase in the state-wide birth defect prevalence rate. These same concerns come into consideration here. To obtain the most meaningful trends in prevalence we need to choose the time period over which the birth defects have been consistently collected, that is, 1993–2003.

Given all of the factors discussed above — issues of inclusion criteria of conditions and reporting periods, ascertainment of cases, overall prevalence versus birth prevalence, case defect rates versus birth defect rates, and variations in trend analyses over time — the question remains: Is there such a thing as a true population prevalence rate for birth defects? As Hennekens states, ‘epidemiology is the study of the distribution and determinants of disease frequency’. The merit of the prevalence rate reported is directly proportional to the quality and accuracy of the data obtained.

In Victoria, the population birth defect prevalence rate in 2003 was 4.0%, with an accuracy rate from our latest validation study of 88% (Riley, Phyland & Halliday 2004). We cannot extrapolate this figure to other areas of Australia without extensive comparison between the collection methodologies; however, we can be confident of this figure as the population birth defect rate in Victoria.

References


Health Act 1958 (Vic).


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Book Review

Charting made incredibly easy! (3rd edition)

Contact details of publisher:
Suite 200, 323 Norristown Road, Ambler, PA 19002-2756 USA <http://www.lww.com/>

Written as a training manual for nursing staff, 13 specialists including nurses, educators and lawyers have contributed to the content of this new publication. The purpose of the book is to provide guidance on clinical ‘charting’ — a term which we would translate to refer to nursing documentation within the medical record. Explanations of a wide variety of documentation techniques are provided with discussion on their application. Each chapter of the book contains a range of illustrations of completed forms accompanied by tips and examples.

One of the values of this book for Health Information Managers lies in the detailed information it contains about clinical documentation techniques, including: critical pathways; Problem Oriented Medical Recording (POMR); narrative progress notes; Problem-Intervention-Evaluation (PIE); Focus; Charting by Exception (CBE); graphic records; Flow sheets, Assessment, Concise notes, Timely entries (FACT); and Data-Action-Evaluation (DAR).

In addition to information on charting systems, the book provides clear generic guidelines with many examples relating to documenting objectively, concisely and legibly, and includes advice on correction of errors. These guidelines are relevant to medical and allied health clinicians in addition to the nurses who are the intended readers of the book. Detailed instructions give advice on documenting special situations such as incidents and many clinical procedures, including lumbar punctures, mechanical ventilation, and peritoneal dialysis.

This would be a useful resource for health information services, and could be used to update Health Information Management understanding of current nursing practice to assist effective communication with clinicians and the design of clinically appropriate medical record forms. Examples and guidelines from the book could be adapted to local situations to assist with the development of training materials, policies and guidelines, and documentation auditing criteria for evaluating medical record content.

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