

The Dunedin RNZCGP Research Unit Computer Research Network: an update to 2003 and beyond

Jason Hall BA DPH, Assistant Research Fellow and Isobel R Martin PhD MPH, Senior Lecturer, Director, Dunedin RNZCGP Research Unit

Jason Hall is the Senior Data Analyst with the Dunedin RNZCGP Research Unit and is interested in the use of the electronic medical record in general practice research.

Isobel Martin is a Senior Lecturer at the Department of General Practice and Director of the Dunedin RNZCGP Research Unit.

Introduction

This paper aims to provide an update of the activities of the Dunedin RNZCGP Computer Research Network, within the context of changing health information in New Zealand.

(NZJP 2003; 30:181–185)

The Dunedin RNZCGP Computer Research Network

The history of the Dunedin RNZCGP Computer Research Network (Dunedin RNZCGP Research Unit) has been well documented.^{1,2,3} The Dunedin RNZCGP Research Unit is an international pioneer in the use of computerised primary care records for medical research and has been developing a database of clinical records since 1989. The Dunedin RNZCGP Research Unit has ongoing ethical approval for collecting these data in collaboration with New Zealand general practitioners. A network of practices

throughout New Zealand regularly contribute data. There are 220 000 consulting patients with full clinical information in the latest available dataset, although some data are available on over 800 000 patients. The database changes from year to year as new practices are added and others decide to withdraw. The Dunedin RNZCGP Research Unit is part of the Department of General Practice in the Dunedin School of Medicine at the University of Otago and is externally funded by the New Zealand Health Information Service (NZHIS). As a research tool, the database permits a range of study designs such as retrospective case control and cohort studies, and accommodates a diverse range of analytical approaches such as pharmaceutical profiling, evidence of disease management, and health economic analysis.

Developments in data transfer

Programmes have been written to Dunedin RNZCGP Research Unit specifications to extract anonymous clinical data from the Practice Management System (PMS) of general practices contributing to the RNZCGP Computer Research Network. Once extracted, data is either couriered via disk media, or in a recent development, sent electronically via secure transmission using Healthlink Ltd's Electronic Data Interchange (EDI) technology. Healthlink EDI is a highly secure data transfer service

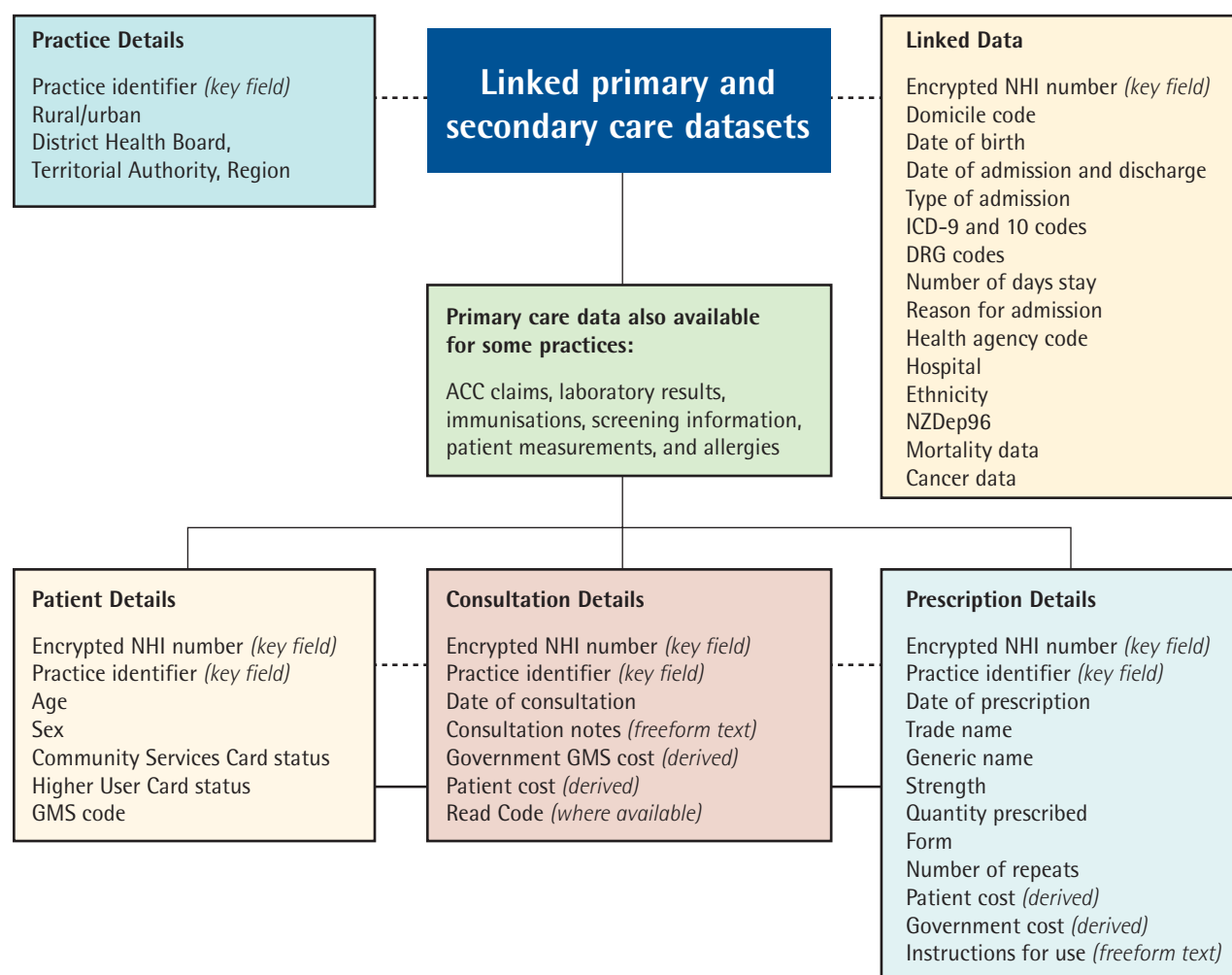
that operates on a 'virtual private network'. There are over 1500 practices in New Zealand using this service and all have client software loaded into their PMS. When data arrive at the Dunedin RNZCGP Research Unit, it is standardised and merged into semester databases stored on a firewall-protected server accessible only to approved Dunedin RNZCGP Research Unit staff. Figure 1 shows some of the data elements contained within the database.

Potential bias in data collections – how can we address this in the future?

The Dunedin RNZCGP Research Unit database is a unique and powerful tool in the study of routine occurrences in New Zealand general practice. Quite simply, it is general practice as it happens. Its strengths include the level of detail recorded, individuation of data while maintaining patient confidentiality, and its wide coverage of participating doctors.

As with any collection of medical records used for research, the Dunedin RNZCGP Research Unit database has limitations. A 1995 self-investigation of biases found the recording of comprehensive computerised records was sufficiently unusual that it marked general practitioners contributing to the database as different from other general practitioners. However, data held by the Dunedin RNZCGP Research Unit were similar to morbidity and case man-

Figure 1. RNZCGP Research Unit database structure



agement obtained from a random sample of general practice services.⁴

Since this bias study was conducted, the database has greatly expanded in both size and quality of recording. Also the use of PMS to record clinical data in general practice is increasing. It is estimated that by 2004, 89% of general practitioners will be using PMS to record patient details, store prescriptions and some clinical data.⁵ New Zealand general practitioners are acknowledged as world leaders in the use of computerised medical records, alongside their UK colleagues.⁶ While repeating a study into potential bias every year would be prohibitive in terms of cost and the continued goodwill

of general practitioners, there have been sufficient changes in the recording of general practice data to warrant a further investigation, which is currently being undertaken.

Continued lack of clinical coding of general practice data

Coded portions of the electronic medical record are used extensively for health care research. However, the unstructured text portions of the record have been relatively inaccessible, except by resource-intensive manual chart review. The use of large text files in recording consultation details makes analysis time-consuming and difficult. Research Unit staff write programmes to retrieve records

for further examination. Records identified by these programmes are visually scanned for accuracy to take into account the many abbreviations and acronyms used by general practitioners (not to mention spelling mistakes). Some practices use coding systems such as Read, the International Classification of Primary Care classification system and ICD. Coding is not used universally and the level of coding is inconsistent between practices. It is reasonable to assume that general practitioners need to perceive some benefit to themselves or their patients in order to code patients' data. If no such benefit is demonstrated, coding will continue to be unreliable. A reduced Read

Code set for general practice has been proposed as a means to capture diagnostic information.⁷ The authors of this paper believe that standardising and simplifying the recording of reasons for patient consultation would benefit the patient, general practice research and allocating health care resources.

Clinical coding should be seen as complementary to the narrative medical record, not a replacement of it. Some argue the patient record should contain richer narrative descriptions of patient perspective.⁸ This may not be possible for the electronic medical record due to the time constraints of entering large amounts of free text. This is not to discount the utility of the free text narrative which, with the appropriate resources and analysis, can yield a wealth of information.

Another method of classifying patient subsets on the database is by their prescribed medications. Assigning a patient to a specific medical condition on the basis of their prescribed medication is not always valid, as many medications are prescribed for more than one condition. However some medications can provide a proxy for subjective diagnoses. For example, patients prescribed insulin or an oral hypoglycaemic agent can be reliably identified as diabetic.⁹

The Dunedin RNZCGP Research Unit database is intrinsically bound to the way data are recorded in general practice, the type of data they record, and the PMS used to store and extract these data. It is reasonable to assume that general practitioners only record information that they see as adding value to their practice and improving patient care. However, we have observed that the completeness and accuracy of general practice data is improving.¹⁰ Much of this is a function of improving software, increasingly sophisticated extraction programmes, Independent Practitioner Associations and gov-

ernmental requirements such as electronic claiming.

Patient registration – defining populations

The lack of a defined population in general practice is problematic. The design of medical software packages requires active management of patient registers. This means that patients who have moved away, died or ceased to be patients of the practice should be removed from the system by the practice staff. This is not always the case. Without accurate registered practice populations it is not feasible to make inferences about patients who did not consult, although it is acknowledged that this is of importance. Under the new Primary Health Organisation (PHO) structures this situation may change, with the creation of enrolled populations of patients, improved information systems, and well-maintained patient registers.

Addressing ethical issues

The use of patient records by those other than their primary care provider is a sensitive subject, and one about which Research Unit staff are very mindful. Electronic medical record research must be bound by ethical principles. It is only by adhering to these principles that public confidence can be gained and thereby reduce demands for restrictive practices concerning access to databases.

It has been proposed that privacy can be protected by early anonymisation and aggregation of personal health data without prejudicing the viability of a research project in conjunction with monitoring by an appropriate local ethics committee.¹¹ The Dunedin RNZCGP Research Unit acts in accordance with these principles. One of the key standards of ethical collection of general practice data is whether the individual patient is iden-

tifiable. No information relating to the name, address or occupation of patients is extracted from contributing practices. An alpha-numeric code assigned by the PMS software at each practice is used to link patient demographic information to the clinical records of each patient. The NHI (National Health Index) number is encrypted before storage on the network. Only aggregated data leaves the Dunedin RNZCGP Research Unit. Af-

ter-hours access is by swipe card only and all staff sign confidentiality agreements.

Patients are informed that the practice is contributing anonymous data through a poster in the practice and are able to with-

draw their records from any data extraction. Whether this constitutes informed patient consent is a topic for debate. However, it has been argued that general practice population data belongs to the practice¹² and in the case of the Dunedin RNZCGP Research Unit consent is obtained from the practice to access the anonymised patient data for research. Practices are informed about the research projects undertaken using their data. No information about individual general practitioners is collected, nor practice locations released. All research projects intended for publication undergo ethical review by the Otago Ethics Committee.

A review prepared for the Privacy Commissioner found that the academic and medical professional ethics of those who control the Dunedin RNZCGP Research Unit database 'are much more likely to engender the trust of both the health sector and the general populace than are the civil servants of the HFA and, as long as the database relies upon the voluntary contribution of data by doctors, there is a strong incentive for it to adhere to open and rigidly applied ethical standards.'¹³

**Clinical coding
should be seen as
complementary to
the narrative
medical record, not
a replacement of it**

Developments with primary and secondary care record linkage

The Dunedin RNZCGP Research Unit has access to the National Minimum Dataset for Secondary care (NMDS), which contains inpatient and day-care data. The Dunedin RNZCGP Research Unit has piloted work in primary/secondary care data linkage using the NHI.¹⁴ The authors concluded that the methodology for information linkage provided the potential for comprehensive examination of publicly funded health care in both general practice and hospital settings, thereby promoting better coordinated and more rational planning of services. Since these pilot studies, larger integrated primary/secondary care databases were compiled for studies commissioned by Treasury and the Health Funding Authority. Integrated data were used to create predictive models for primary care utilisation and funding. All general practice patient data held by the Dunedin RNZCGP Research Unit can now be linked to secondary care data from 1996 through to 2002 provided they have an encrypted NHI.

Additional variables which can be linked to primary care data

Primary care data can now be integrated with a number of other data sources. In addition to secondary care morbidity data, mortality, ethnicity and cancer data can be sourced from the NMDS. The New Zealand Deprivation Index (NZDep) can also be linked to general practice data through geocoding NHI address data held in the NMDS. NZDep is a small area deprivation

scale developed by the Health Services Research Centre at the Wellington School of Medicine.¹⁵ A study using data from the Wellington Independent Practice Association (WIPA) achieved an 83.3% success rate of geocoding NHIs.¹⁶ A similar matching rate has been found with Dunedin RNZCGP Research Unit data (unpublished data). This rate of matching can be further improved using a manual matching process in addition to automated matching by the NZHIS, although manual matching would create an additional cost.

Accurate data on patient ethnicity are important for health researchers. General practice is seen as ideally positioned to provide this health information by collecting ethnicity as part of patient registration if barriers to data collection are addressed.¹⁷ It is possible, using the encrypted NHI, to

link ethnicity codes to general practice patients who have accessed secondary health care in New Zealand. The WIPA study matched 99.2% of all records with an NHI number to an ethnicity code, although 54.7% of these were either 'Not stated' or 'Other'. However, when these unassigned codes were excluded they found a similar ethnic distribution to that found in the 1996 census. The researchers concluded that this is likely to be an improvement on current general practice ethnicity recording but suggest that in the long term, direct recording of ethnicity in

general practice is likely to be a more accurate and complete method of collecting this information. A study of registered patients collected in the year 2000 by the Dunedin RNZCGP Research Unit indicates that ethnicity recording in general practice is poor, with only 34.9% of patients allocated an ethnicity code on patient practice registers.¹⁰

Geographical mapping of health care data

Health data maps and Geographic Information Systems (GIS) are important resources for health planning and health services delivery. The potential with Dunedin RNZCGP Research

Unit data is the ability to combine health data with location and service level data. Ensuring the confidentiality of health records requires that the Dunedin RNZCGP Research Unit aggregate data to the level at

which potential disclosure of individuals is prevented. While patient anonymity is preserved by this method, it does limit the usefulness of some analyses. Methods of protecting the confidentiality of health records through masking individual-level data have been put forward, however these have certain statistical limitations.¹⁸

Prescribing data – a unique resource

There is a paucity of published information in New Zealand which reflects the prescribing decisions of

One of the key standards of ethical collection of general practice data is whether the individual patient is identifiable

general practitioners. At present the only national source of prescription data in New Zealand is the pharmaceutical information database (Pharmhouse) which is jointly owned by the Ministry of Health and Pharmac. Pharmhouse contains claim and payment information from pharmacists for subsidised dispensings processed by the HealthPAC General Transaction Processing System. Data from this warehouse can provide valuable information on dispensed medications, but lack individualised patient information and information on a significant number of medications that fall beneath patient co-payment thresholds. The

Dunedin RNZCGP Research Unit database contains individualised (but non-identifiable) prescription data which can be linked to age, gender and health card status.

There are a number of exciting possibilities for further research using the Dunedin RNZCGP Research Unit database

throughout the lifecycle have recently been undertaken^{19,20} and an examination of general practice casual consulting has been completed. In the future, we will be conducting more research with linked primary and secondary care data, using geographi-

In the future?

There are a number of exciting possibilities for further research using the Dunedin RNZCGP Research Unit database. A series of papers on prescribing

cal information systems, and establishing longitudinal cohorts of patients with up to six years of concurrent data. The goodwill and support of the contributing practices is crucial to the continued viability of the Dunedin RNZCGP Research Unit. Keeping pace with rapid developments in information technology, and structural changes in New Zealand general practice, will be the challenge for the Dunedin RNZCGP Research Unit as we look to the future.

Acknowledgements

The authors thank the participating general practitioners, practice staff and research officers who managed the data collection. The Dunedin RNZCGP Research Unit is funded by the New Zealand Health Information Service.

References

1. Dovey SM, Tilyard MW. The computer research network of the Royal New Zealand College of General Practitioners: an approach to general practice research in New Zealand. *Br J Gen Pract* 1996; 46(413):749–52.
 2. Tilyard MW, Dovey SM. The role of sentinel networks in general practice research in New Zealand and internationally. *NZFP* 1999; 26(2):48–51.
 3. Dovey SM, Tilyard MW. RNZCGP computer research network: An update. *NZFP* 1999; 26(6):37–9.
 4. Tilyard MW, Dovey SM, Spears GF. Biases in estimates from the RNZCGP computer research group. *NZ Med J* 1995; 108(997):118–21.
 5. Ministry of Health. From strategy to reality – The WAVE project. Wellington: Ministry of Health; 2001.
 6. Mathews M. The 'wired' practice – what's new in primary care IT? *NZFP* 2002; 29(4):267–71.
 7. Cunningham W, Tilyard MW. Making Read Codes easy and useful in New Zealand general practice. *NZFP* 2000; 26(2):48–51.
 8. Donnelly WJ. Righting the medical record. Transforming chronicle into story. *JAMA* 1988; 260(6):823–5.
 9. Tierney WM, McDonald CJ. Practice databases and their uses in clinical research. *Stat Med* 1991; 10(4):541–57.
 10. Hall J, Tomlin A, Martin I, Tilyard M. A general practice minimum data set for New Zealand. *NZ Med J* 2002; 115(1163): URL: <http://www.nzma.org.nz/journal/115-1163/>
 11. Horner JS. Research, ethics and privacy: the limits of knowledge. *Public Health* 1998; 112(4):217–20.
 12. Townsend T. The transfer of information in general practice ethical issues – A Discussion Paper. *NZFP* 1993; 20(4):159–60.
 13. Stevens R. Medical record databases. Just what you need? 1998.
 14. Tilyard MW, Phillips DE, Dovey SM, Skelly L, Whitney RK. The health services utilisation of a general practice population. *NZ Med J* 1991; 104(923):463–5.
 15. Salmond C, Crampton P, Sutton F. NZDep91: A New Zealand index of deprivation. *Aust N Z J Public Health* 1998; 22(7):835–7.
 16. Love T, Crampton P. Deprivation profiles in Wellington IPA practices. *NZFP* 2001; 28(5):327–32.
 17. McLeod D, Mansell J, Harris R, Bailey T, Dowell A, Robson B et al. The collection of patient ethnicity data: a challenge for general practice. *NZFP* 2000; 27(3):51–7.
 18. Armstrong MP, Rushton G, Zimmerman DL. Geographically masking health data to preserve confidentiality. *Stat Med* 1999; 18(5):497–525.
 19. Hall J, Martin I. Paediatric prescribing in New Zealand. *NZFP* 2002; 29 (1):14–18.
 20. Martin I, Hall J, Gardner T. Prescribing for patients aged 65 years and over in New Zealand general practice. *NZ Med J* 2002; 115(1164):URL: <http://www.nzma.org.nz/journal/115-1164/>
-