3 Electronic collection of GP data

This chapter examines the various electronic methods currently used in Australia for capturing general practice data. Over the past decade, several collections have obtained data by accessing electronic records from individual general practices. The main objective of this chapter is to determine whether an existing electronic data collection system could be built on to develop a national data collection system for Australia.

A literature and Internet search was undertaken, and several GP organisations were contacted, to establish what electronic collections existed and to establish suitable contact persons. A survey instrument was designed (Appendix 5) and circulated by email to the contact persons, along with an explanatory letter outlining the purposes of the exercise. The responses from these questionnaires have been collated into a table format and are reported later in this chapter, with a brief description of the advantages and disadvantages of each.

Before examining how electronic data collection is being undertaken in Australia, it is useful to investigate how primary care data collections are undertaken by other nations, to see whether any system used overseas may also be applicable in Australia.

Electronic collection of GP data overseas

Some countries are further along the journey towards electronic data collection, and it would be useful to learn from their experience. For example, the National Programme for Information Technology, introduced by the UK National Health Service, affords many lessons in the areas of procurement models, resolution of standards and structure, system safety, skilled IT workforce issues, clinical engagement, patient consent models, clinical knowledge services, political leadership, and evaluation (Coiera 2007). Brief overviews of electronic data collections in a number of other nations are presented below.

Much of the literature reporting the 'current' status of GP computer use, IT infrastructure, and the political, legal and practical issues associated with computerisation of primary care is now several years old. In the world of information technology, a few years can be a long time. The information below is gathered from the most recent published sources available.

Austria

Computer usage and GP/patient attitudes

- Approximately 38,000 physicians, of whom approx. 50% are GPs. Most are in solo practice, or in small family practices.
- GPs are formally the gatekeepers to inpatient care and organise referrals. Patients often present directly to outpatient clinics (average outpatient contacts in 2002 was 6.8 per person).
- In 2005, 75% of all physicians used physician office systems, and 25% used them for electronic data exchange. Very few practices are paperless, and these tend to be the younger GPs.

- Over 90% record medications in their computer system, but only younger GPs do the entry themselves—GPs do not always see the prescriptions because they pre-sign thousands of forms, which are then printed as required.
- Very few systems use any form of decision support (such as drug–drug interaction)—some GPs report drug interaction software to be annoying because it cannot be turned off.
- Many GPs run hybrid approaches, where legacy data are maintained on paper although all new data are recorded in the electronic medical record (EMR). It is usual for GPs to dictate notes, which secretaries enter into computers. Most GPs will be obliged to use ICD-10 in the near future (Protti & Maresch 2006).
- About 40% of GPs are able to receive reports from specialists electronically (free text only), although most reports are sent by fax. Some GPs do not want to receive documents electronically at all (Schabetsberger et al. 2006).
- Scanning of paper-based reports is not uncommon—some doctors do not want to receive results electronically as they fear system crashes and distrust the Internet. Only prescription data and accounting details are stored on the computer, and these are not backed up on paper. Discharge summaries and consultant reports are mainly paper based. Most hospitals are not able to transfer data electronically, and only 30% of physicians are connected to a network.
- Few GPs consider the availability of data from clinical research to be important (Protti & Maresch 2006).

Standards, structure and capacity

- 34% of GPs have a computer connected with the national social security database in Vienna, by means of a GINA-box (a mini computer that controls data transfer to the Health Information Network) and two electronic health cards: one for the patient and one for the health service provider.
- There are over 150 suppliers of office systems—fewer than 20 have modern products and even fewer are able to handle the new e-card. The number of vendors is expected to reduce to about 30 when the e-card is fully introduced.
- Broadband communication technical infrastructure is supported in 95% of Austria, but electronic exchange of patient data is limited because of numerous incomplete/isolated systems and independent structures. To overcome the problems of communication between various data exchange formats, the use of fax has become commonplace.
- Improvements to the new e-card system mean that it now provides a secure broadband connection within the health sector and the infrastructure for future projects (PHARMIG 2007).
- Up to 70% of laboratory results are transmitted electronically to GP office systems because all labs are capable of this function. Results are often emailed and then printed for attachment to the paper record (insurance companies insist that a paper copy is held in paper charts). Laboratory results are returned to the GP in any of about 50 different formats. Some use HL7, some use EDIFACT (Electronic Data Interchange For Administration, Commerce, and Transport) or another standard. The formatting depends on the system used by the laboratory.
- Most radiologists send reports electronically using EDIFACT, but some are moving to XML with PDF attachments (Protti & Maresch 2006).

Privacy, security and legal issues

- Existing legislation requires a signature. Since January 2005, prescriptions for expensive medications need to be justified and explained. Generic drugs are preferred—in many systems, the generics are first on the list.
- Only prescription data and accounting details are stored on the computer. The national initiative for a life-long electronic health record (EHR) (ELGA1) does not have physician support and is facing political concerns over privacy. Projects permitting access to a regional or national EHR or clinical data repository are just being piloted, but are not yet operational.
- Clinics attached to hospitals are more automated than GP practices but do not send results electronically—concerns have been raised about who takes responsibility if computer systems fail.
- There is a common framework for data security in health care data exchange, which is defined in recent legislation. Many systems are secure, but are challenged by interoperability and automatic interpretation of messages. Lack of standards and organisational problems also affect security (Protti & Maresch 2006).
- Legal ambiguities need to be resolved before an EHR that allows cooperative care across institutions can be established (Schabetsberger et al. 2006).

Denmark

Computer usage and GP/patient attitudes

- Denmark has approximately 3,500 GPs in 2,000 practices. Approximately 30% of GPs work in solo practice, and typically have 1,400 to 1,500 patients. The average length of a consultation is 10 minutes.
- GPs act as gatekeeper—patients must have a referral from their GP to access a specialist.
- Attitude to computer use has strongly influenced uptake—for nearly a decade patients have considered a GP to be 'second-rate' if s/he did not use a computer. Most GPs enter their own clinical notes, although some dictate them.
- Over 90% of practices are computerised and use EMRs, although few practices are paperless. Almost 90% use computers to send and receive clinical electronic data interchange (EDI) messages such as discharge letters, laboratory requests and results, referrals, prescriptions and reimbursements. GPs are now paid a fee for each email consultation or email about laboratory results.
- GPs are automatically notified when a patient is registered in an emergency department at most hospitals. Discharge summaries arrive within 1 to 3 days (previously 4 weeks).
- Most GPs access the Internet from their offices twice or three times per day, to check on waiting times for X-rays at clinics, or to look up medication information.
- Influence of peers has improved uptake of GP computer use. Collegial pressure is also influential: annual education seminars for GPs include workshops on a range of topics from basic computer use to advanced diagnostic coding (Protti & Graham 2003; Protti & Johansen 2003).

Standards, structure and capacity

- About 85% of GPs are able to send electronic prescriptions and all 332 pharmacies in the country (4 different IT systems) are able to receive them. GPs enter all medications themselves, accessing a drug

1 ELGA is the German speaking abbreviation for the electronic health record.

database maintained centrally by the Danish Drug Agency which updates physician office systems every 14 days. Prescriptions are sent to a pharmacy and an acknowledgement is automatically sent back to the GP.

- EDI is possible because of the successful introduction of national standards for text-based clinical messages and communication standards for communication flow between health care providers and organisations.
- MedCom (a cooperative venture between authorities, organisations and private firms linked to the Danish healthcare sector) sets all standards. Contracts are signed with the counties and the PLO (the labour organisation of GPs) obliging everyone to use them.
- Standardised messages have been implemented in 50 computer systems and are used by about 75% of the health sector. This includes approx 2,500 different organisations—all hospitals, pharmacies, laboratories and about 1,800 general practices. The PLO wrote conversion software to facilitate the transfer of data from one GP system to another.
- There are 11 different suppliers (3 have 57% of the market) and 16 different physician office systems. The number of suppliers is expected to drop to 5 or 6 in the near future.
- The standards adopted for primary care message systems are also being applied to the hospital area in a project covering 26 different types of messages and 36 different IT suppliers.
- GPs are increasingly using International Classification of Primary Care (ICPC) coding to extract episodes of care for specific conditions (Protti & Johansen 2003; Protti et al. 2006).

Privacy, security and legal issues

- Every citizen has a unique national person identification number which is used across multiple jurisdictions including health (Protti & Johansen 2003).

England

Computer usage and GP/patient attitudes

- England has 29,000 GPs working in 8,810 practices. About 25% are in solo practice.
- Over 97% (8,511) have a GP clinical computer system. Nearly all GPs use them for acute and repeat prescribing, with the exception of medications prescribed at a home visit, or those controlled medications which by law still require hand-written prescriptions.
- Many practices scan hospital letters, reports and so on, which are then attached to the patient's record. Approximately one-third of practices run 'paper-light' systems.
- GPs act as gatekeepers to the rest of the health system.
- Patient data has historically been entered by the GP only but a growing trend is for it to be entered by a practice nurse, health care assistant or administrative staff.
- All clinical systems have decision-support capability such as drug–drug interactions, but this needs to be switched on at set-up by the supplier and this does not always happen. There is low uptake of this capability because many GPs believe it will slow their systems and lengthen the consultation (Protti & Wright 2006).
- Differences in data recording across practices have resulted in some identifiable problems such as morbidities not entered, or entered as 'free text' instead of using the coding system, which can prohibit inbuilt alerts from working (Avery et al. 2007).

Standards, structure and capacity

- National Health Service (NHS) standards have been introduced for all clinical information systems, Systematized Nomenclature of Medicine—Clinical Terms (SNOMED-CT) and messaging protocols for NHS communication (UN/EDIFACT). Although SNOMED-CT has been adopted as the new standard, as of 2006 it had not yet been taken up and the majority of GP data were structured and coded using Read2 codes (the previous standard).
- In 2006 there were 10 different physician office systems in England. Three systems account for 93% of the market.
- NHSnet is a virtual private network established to provide a secure communications system to all health organisations that comprise the NHS in England and Wales. By 2001, 97% of general practices had NHSnet lines installed. Since then, e-mail services and a broadband network have been introduced, which allows for electronic transfer of visual data such as video and X-rays. N3 (new National Network) is to replace NHSnet, and is designed to connect all 18,000 locations. The two networks will carry EDI messages and HL-7 messages.
- Pathology results are being transmitted electronically, and standards implemented mean that 94% of GP practices receive pathology results electronically and have their electronic patient records updated automatically. However, results sent back to practices via pathology links the system looks for Read codes in the data—there is only one slot for Read coded data in the pathology links message, which tells that a pathology test has been done, but not the outcome (Protti & Wright 2006).

Privacy, security and legal issues

- Each patient has a unique NHS number, which is mostly only asked for when patients transfer from one practice to another when moving to a new location. Although the unique number exists it is not always used across the health system; for example, hospital admissions use a hospital-generated number that doesn't appear on the patient's general practice record.
- A report from the National Patient Safety Agency revealed that computer systems may not contain all the safety features that are desirable, and important hazard alerts may not be sufficiently well displayed and differentiated from other more advisory information. Other shortcomings include a lack of alerts in relation to contraindications, the presence of spurious alerts, failures of drug allergy warnings, risks from prescribing drugs with similar names, a lack of warnings for certain drugs, and important alert warnings that were poorly designed and too easily overridden. There was also a lack of audit trails (Avery et al. 2007).
- There are concerns that GPs have come to rely on their computers to provide alerts—and, given the shortcomings inherent in GP clinical systems this may result in adverse events where alerts fail (Avery et al. 2007; Morris et al. 2005).
- As part of the General Medical Services contract, all practices in England must be able to produce registers for common disorders (Protti & Wright 2006).

Support and education

- The majority of suppliers provide some support. Few provide whole system support and there is no national or regional 24/7 help desk as is available in some other countries.

2 Named after Dr James Read who invented and developed the codes in 1982.

- All messaging costs on NHSnet are covered by the Department of Health—GPs and patients are not expected to contribute to the costs (Protti & Wright 2006).
- A significant criticism of NHS Connecting for Health Programme was the lack of consultation with clinicians before procurement of contracts and suppliers, which resulted in resistance from the clinical community (Coiera 2007). A UK study of primary care professionals found that clinicians are motivated when their views are incorporated in the design of processes relating to primary care informatics (Thiru et al. 2003).
- Feedback to UK GPs on the quality of their data has also been found to have a significant effect on data quality (de Lusignan et al. 2002).

Germany

Computer usage and GP/patient attitudes

- There are approximately 145,000 general practitioners in Germany. Most work alone. Only about 20–30% work in practices of more than one clinician. A typical GP will see approximately 1,200 patients per quarter. There is no formal gate-keeping system for GPs, although this is changing. Over 60% of all care is provided by GPs.
- Only about 40% of GPs are hands-on computer users. There are no paperless offices, and only younger physicians use the computer themselves. Younger GPs tend to code their own data, but older ones leave it to clerical or nursing staff. The number of patients also influences who does the coding.
- There is little electronic transmission of medical data—only larger private labs send results electronically. Laboratory results are transmitted using a self-developed protocol, rather than HL7. Occasionally, unencrypted discharge summaries may be sent by e-mail. Consultants' reports are given to the patient to deliver, and some GPs scan these into their computer records. There is virtually no email between GPs and patients (Protti & Engelbrecht 2006).

Standards, structure and capacity

- There are approximately 200 physician office systems of which two or three have 70% of the market. About 30 specialise in GP systems.
- Some attempts are being made to introduce standards for e-health systems, but a more coordinated approach is needed. There is no national health network, so self-developed standards are emerging from smaller networks and regions.
- The potential to increase use of IT is hampered by disagreements with insurance companies; lack of standards; lack of networks; financing and investment problems; questions about liability and data protection; and organisational structures—every institution is an isolated entity with its own unique IT capacity. Incompatibility is a major problem—interoperability works well only in exceptional cases (Protti & Engelbrecht 2006).

Privacy, security and legal issues

- There is no unique patient identifier as yet, although each person has a health-care identity number.
- Since January 2006, e-prescribing is required by law. Unlike other countries, in Germany electronic signatures are acceptable by law.

- Each state has a physician organisation (a KV—Kassenaerztlich Vereinigung). All practices are computerised because GPs are obliged to send their claims electronically. These are submitted quarterly to the KV on a diskette, which contains all the services rendered per patient in a coded format, including patient demographic data; diagnostic data (coded in ICD-10 GM); some secondary diagnoses; selected procedures; and some laboratory results.
- The German Government had planned to introduce the Electronic Health Card (the Gesundheitskarte) by 2006. The card would interlink patients with GPs, hospitals, dentists, pharmacies, and health insurance companies. It would contain medication information, and other health information at a level discretionary to the patient. Each card would have an identification number and a photo of the patient. Data protection experts raised concerns about risk to patient privacy. There is also debate about where the data will be stored: on the card; on a neutral server; a KV server; or a pharmacist server (Protti & Engelbrecht 2006).
- The E-health card roll-out has been repeatedly delayed and, as of 21 April 2008, is still not released, reportedly because of issues surrounding the unique patient identifier (Healthcare IT News EU 2008).

Support and education

- Clinical office systems are not updated with new medication information unless by the GPs themselves. It is also unknown how often drug interactions are detected because the decision-support capabilities in clinical office systems are highly variable.
- There is little help-desk support for GPs (Protti & Engelbrecht 2006).

New Zealand

Computer usage and GP/patient attitudes

- There are approximately 3,000 general practitioners in New Zealand, working in about 1,000 practices consisting of two or three GPs. The average GP carries a patient load of between 1,200 and 2,200 patients, and an average consultation lasts approximately 15 minutes.
- GPs have a gate-keeper role and, in most regions, there is reasonable access to primary care.
- More than 95% of GP practices are computerised and, although the practices are small, more than 85% of GPs are part of a larger network.
- Almost 75% of GPs electronically send and receive clinical messages such as laboratory and radiology results, discharge letters, referrals and when claiming subsidy reimbursements.
- About 50% now use the Internet regularly from their office and use email with patients.
- Few offices are paperless because reports from specialists and other service providers are still sent on paper, although some GPs scan these into the patient's record.
- Most GPs prescribe electronically but prescriptions are still delivered manually to the pharmacy—the issue of electronic signatures is yet to be resolved.
- Independent Practitioner Associations and the GPs themselves see the benefits of collection data for population health.
- The success of integrated care projects has resulted from an attitude of 'make the best thing to do the easiest thing to do', which is producing good cooperation from GPs (Protti & Graham 2003).

Standards, structure and capacity

- There are about nine physician office systems available in the market place.
- A privately run company (HealthLink) handles electronic message traffic in the New Zealand health sector. The company's ability to develop a service using standardised messaging in a secure private network resulted from its involvement in the early stages of HL7 development in New Zealand.
- Message standards have now been implemented in more than 40 computer systems. HealthLink is used by 75% of all health sector organisations in New Zealand—all hospitals, radiology clinics, private laboratories and about 1,800 general practices use the network daily. More than 600 specialists, physiotherapists, other allied health workers and maternity providers also use the network, such that 95% of the total electronic communication in the primary health care sector is exchanged through HealthLink.
- HealthLink has become the de facto national standards body and works with the Ministry of Health and other stakeholders on new standards.
- Future services currently being developed include: electronic pathology ordering; ability to access via open Internet, wireless, satellite, frame relay and ADSL; and full Linux, Macintosh, Windows and other OS platform support.
- The HealthLink network and improvements to clinical software have provided the capacity to collect the latest clinical data about selected patients (such as those with diabetes) from laboratory and GP office systems, then issue automatic alerts, reminders and recommendations to relevant health-care providers as appropriate for each patient (Protti & Graham 2003).

Privacy, security and legal issues

- Patients have a unique national health identifier.
- To ensure confidentially, there is a formalised, secure transfer process of acknowledging receipt or raising an alert if receipt is not acknowledged. HealthLink software enables encryption and compression of files to ensure safety and maximise network efficiency (Protti & Graham 2003).
- A review for the Privacy Commissioner found that academic and medical ethics of those controlling the Dunedin Royal New Zealand College of General Practitioners (RNZCGP) Research Unit database instil trust and confidence in both the medical workforce and the general population, unlike civil servants of the Health Funding Authority (HFA). The reliance on voluntary contributions of data from GPs and patients is a strong incentive to adhere to rigid ethical standards (Dovey et al. 2006).

Support and education

- As in the UK, feedback to New Zealand GPs on the quality of their data has also been found to have a limited, but positive, effect on data quality (Jones & Marshall 2004).

The Netherlands

Computer usage and GP/patient attitudes

- There are approximately 8,000 GPs in the Netherlands. The average practice size is about 2,400 patients, and a GP will usually see 30–40 patients per day.
- GPs act in a gatekeeper role to other areas of the health sector. About 90% of the patients' presenting problems are dealt with by the GP.

- About 97% of GPs use a computer in clinical practice—94% use their information system to record medical notes during a patient consultation.
- GPs are required to enter data themselves rather than using clerical staff.
- Over 90% of prescriptions are generated electronically and printed. All systems can send these electronically to pharmacies, but some GPs choose not to do so (Protti & Smit 2006).

Standards, structure and capacity

- There are eight suppliers offering 11 different systems, two of which hold about 50% of the market. These are expected to reduce to five to seven systems in the near future. Each system must meet requirements specified by the Dutch College of General Practitioners. Communication between different systems has not been possible in the past, but more recently suppliers are offering data exchange capabilities between systems.
- Computer systems are designed specifically for GPs and are installed in modules that perform different functions. Administrative modules are usually installed first, and then other modules added. Typically, the medical record is added last.
- To use decision-support functions in the software, GPs must code patient data. Most systems can only generate reimbursement claims when data are coded; they can only monitor drug interactions if prescribed drugs and doses are coded.
- Most systems provide resources to code data—GPs can choose to follow the SOAP (subjective objective assessment plan) structure in their coding, or the POMR (problem oriented medical record) style.
- Reason for encounter and diagnoses are coded using the ICPC, and medications are coded using a database of all drugs available in the Netherlands, which is maintained by the Royal Dutch Association for the Advancement of Pharmacy. Various resources allow coding of laboratory results, of numerical data, patient history, referrals, and so on.
- There is no national network in the Netherlands at present, but the National IT Institute for Healthcare planned to introduce a national IT infrastructure for a secure electronic information exchange amongst all Dutch health-care providers by 2006, which would allow a National Electronic Healthcare Record. To date, the network has not been realised (European Commission 2008).
- Twenty-two regional networks allow communication between GPs. Protocols have been standardised within the regional networks to the extent that electronic mail can exchange coded data as well as free text—this allows information such as laboratory results to be automatically inserted into the patient's computerised record (Protti & Smit 2006).

Privacy, security and legal issues

- Data security and privacy are important concerns. Data from computerised records can be aggregated in large databases and used for various purposes (such as post marketing drug surveillance).
- The Health Council recommends that consent from the patient be obtained before clinical data are transmitted, and that tracing of individual patients should only be done through their GP. Although data are de-identified, it is considered a sign of good practice to inform the patient (Protti & Smit 2006).

Support and education

- The Dutch College of General Practitioners introduced postgraduate training in computer use 20 years ago—it is still in operation for GPs entering the workforce (Protti & Smit 2006).

Norway

Computer usage and GP/patient attitudes

- There are 4,300 GPs in Norway. Most work in group practices—only about 14% work in solo practices. A patient list system was introduced in 2001 and a full-time GP can have between 1,500 and 2,500 patients.
- EMRs were first used in Norway in the 1980s. Virtually 100% of GPs now use an EMR. Very few GPs retain paper records.
- There are no hand-written prescriptions—GPs enter all prescriptions into their computers and are only paid if they do so. However, only a small number are sent electronically to pharmacies because few are connected to the networks at present.
- Few discharge letters and referrals are sent electronically, but laboratory results are routinely sent electronically. After acknowledgement that the result has been read, the patient's EMR is automatically updated.
- Practices still use disks to send reimbursement requests and prescription information to the National Insurance Administration. Reimbursement data and information on communicable diseases are the only data collected centrally. Prescription information is collected via pharmacies and stored by the national drug agency.
- Electronic information use is increasing, but GPs tend to still ask colleagues rather than seek answers to clinical questions on line (Protti & Treweek 2006a).

Standards, structure and capacity

- There are only three clinical desktop systems in use in Norway. GPs and other practice staff use these systems at every level of patient contact. Local area networks are quite large—it is usual for every GP and each member of the clerical staff to have their own computer. Most practices have an on-site server that stores patient data.
- Decision-support applications are not well developed in Norwegian clinical desktop systems.
- Many municipalities have their own networks, and service providers within the municipalities can be connected to these networks by a single contact point between the National Health Net and the municipality network.
- For nearly two decades, Norway has continued to produce a standardised base for IT in health care, coding and classification systems and definition of terms, standards in EHR systems and information exchange, which is based largely on international standards.
- A non-profit agency, KITH (Norwegian Centre for Informatics in Health and Social Care), has actively supported the implementation and maintenance of Norwegian and international standards for many years. Diagnoses, symptoms and procedures in GP EMRs are coded in ICPC. Some data are entered in free text. KITH is currently developing coding systems for laboratory tests. For electronic messaging, KITH has issued standards for almost 30 different messages (Protti & Treweek 2006a).

Privacy, security and legal issues

- Each patient has a unique personal number that is always contained in an EMR.
- Any use of patient data requires approval by the Norwegian Data Inspectorate, which ensures that data are processed in accordance with national data protection legislation.
- Internet use has increased since the National Health Net was created—the law does not permit unsecured Internet access on a computer that is used to hold patient data.
- Email between GPs and patients is uncommon. Information security continues to be an issue (Protti & Treweek 2006a).

Support and education

- In 2004, the Norwegian Government offered a cash incentive for GPs to connect to the National Health Net (Protti & Treweek 2006a).
- Some studies of data quality have been undertaken, and the quality has been variable (Treweek 2003). Education of GPs and practice staff would improve data quality.

Scotland

Computer usage and GP/patient attitudes

- There are 4,000 GPs in Scotland, mostly working in group practices. Fewer than 20% work in solo practices.
- Over 90% of practices are computerised although only about 3% would be considered paperless.
- NHS Scotland comprises 15 NHS Health Boards, which manage both acute and primary care in the populations within their jurisdictions.
- Patients are registered with a practice and approximately 89% have contact with their practice each year, at an average of 5.6 contacts per year.
- All systems have a medical record and some degree of decision support.
- Most GPs enter their own clinical notes, which must be done at the practice—there is no access to patient data from home computers (Protti & Treweek 2006b).

Standards, structure and capacity

- Diagnoses data are coded with Read codes, but there are plans to move to a version of SNOMED-CT in the near future.
- One software system, GPASS (General Practice Administration System for Scotland), has 85% of the market, with four others sharing the remaining 15%. Most practices have an on-site server for patient data storage, although the latest version of GPASS requires GPs to move their patient data to a central server.
- There is a national network, NHSnet, to which all NHS Scotland organisations, all general practices and all community pharmacies are connected. NHSnet currently supports the transmission of reimbursements, prescriptions to community pharmacies, referral letters to specialists and clinics, laboratory and diagnostic test orders, discharge summaries from hospitals, and test results and reports from specialists.
- Another reason for the capacity of practices to successfully connect with other parts of the health system was the establishment of the Scottish Enhanced Functionality (SEF) for minimum standards

of general practice computer systems in 1999. The SEF is used as a benchmark against which general practice systems are assessed, and assists the NHS to achieve a common level of functionality.

- By 2000, GPASS included care management screens including: clinical criteria defining a minimum level or quality care for the management of diabetes; the secondary prevention of ischaemic heart disease following a myocardial infarction; and the monitoring of dose-critical medications such as warfarin and lithium.
- As a result of these quality initiatives, Scotland now has a coded morbidity database that enables data aggregation at a national level.
- The Electronic Clinical Communications Implementation (ECCI) program is an initiative to facilitate electronic information exchange between primary and secondary care services (Protti & Treweek 2006b).

Privacy, security and legal issues

- The ECCI program is part of the Information Management and Technology strategy, which includes the introduction of a unique patient identifier that enables record linkage.
- Initial implementation trials reported improvements in communication of discharge summaries and test results where systems were fully implemented. System reliability and incompatibility hindered more widespread uptake (Pagliari et al. 2005).
- Recently the ECCI program board meetings for 2008 were suspended pending a review of the Program (NHS Fife 2008).

Support and education

- Uptake has been positive because of continued promotion of general practice (by the government) as being the linchpin of all clinical reporting systems throughout the NHS (Protti & Treweek 2006b).

Sweden

Computer usage and GP/patient attitudes

- There are 4,400 GPs in Sweden, mostly working in group practices of three to eight GPs. Very few work in solo practices; 60% are male and a large proportion work part-time. Group practices are geographically based in primary health care (PHC) centres. There are 1,124 PHC centres in Sweden and a centre of seven full-time and part-time GPs (about 4.2 full-time equivalents) may care for up to 14,000 patients.
- Swedes prefer the term EPR (electronic patient record) to EMR, and the use of these by Swedish GPs is almost universal (97%)—the only non users are older GPs who are due to retire in the next few years. No reliable data are currently available on the overall national use of IT in PHC centres.
- Most practices are 'paper-light' but still maintain paper files for patient letters and specialists' reports. Some practices scan these; others enter sections into the EPR; others dictate a summary for later entry into the EPR.
- Although still not mandatory, about 99% of prescriptions are entered into the computer, but 50% of patients are still given a printed prescription. About 50% are sent electronically to the pharmacies, although this varies between counties.
- Most GPs receive laboratory results electronically, but few requests are sent this way. Electronic transfer of referrals, discharge summaries, specialist reports, and so on, vary greatly between counties.

Internet use for clinical purposes is increasing, especially for printing information for patients. Email between a GP and patients is uncommon.

- There is very little structured data in the EPR. GPs do not usually enter their own clinical notes: these are dictated and entered by clerical staff, in free text. The only coded data are diagnoses and medications. Coding is encouraged, but highly variable. There is no systematic follow-up to ensure accuracy (Protti & Nilsson 2006).

Standards, structure and capacity

- In 1995 there were about 26 different vendors; today there are about 15, of which three have 95% of the market.
- Over the past 10–15 years, a few counties mandated that everyone, including hospitals and GPs, use a single common system. This has reduced the IT costs significantly and has the advantage that GPs now on-line have access to all of their patients' hospital records, including specialists' reports. Similarly, specialists and hospital physicians have access to all GP notes. Some expect that this will increase the amount of data in the record that is structured and coded.
- Most GP systems have some form of decision-support tool but the quality varies and it is at the GP's discretion to activate it.
- There is a lack of national standards—ICD-10, TCP/IP and ATC are the only national standards, along with EDIFAC for messaging. HL7 and SNOMED are being discussed (Protti & Nilsson 2006).
- There has been no national health network in Sweden, but one (Sjunet) is owned by seven counties and is used by most of the 21 counties for transmitting prescriptions.
- In March 2008, InterSystems announced that a national electronic health record, known as the National Patient Overview, using InterSystems HealthShare software is intended to be ready for production within 12 months, commencing in Orebro County Council. HealthShare will enable the creation of a summary view of a patient's medical record on a regional or national basis (Enterprise Open Source News Desk 2008).

Privacy, security and legal issues

- Since July 2005, the law required the national pharmacy company, Apoteket AB, to keep a register of all drugs dispensed in the previous 15 months and to hold repeat prescription information on computer—before this change the Data Protection Act prohibited the storing of cumulative medication information (Protti & Nilsson 2006).

Support and education

- County Councils provide IT support but, because each County has different needs, multiple versions of vendor systems are being supported. There are no national advocates for GPs and no informatics courses readily available for GP education (Protti & Nilsson 2006).

Summary

Although the countries described here are at different stages of computerisation in general practice, none of the electronic data collection systems are without problems requiring resolution. In short, all countries, to varying degrees, are in a transition phase.

There are several universal themes. Those countries most successful in the introduction of EMRs have standards and protocols in place for messaging, IT infrastructure, structure of records, coding, and so on. These were introduced in early design stages, and the nations with limited success to date are those without these elements in place. More successful countries are also those where uptake of IT has been GP driven (for example, Scotland and Sweden).

It is also apparent that the electronic primary care data collection process is multi-faceted and cannot be implemented successfully in isolation. Many clinical desktop systems are adequate for the input and storage of patient information; they are limited only by the completion and comprehensiveness of data entered at each encounter. Although these systems allow the recording of a prescription, test order or referral, the ability to extract detailed information allowing assessment of outcomes is not possible unless these results are electronically incorporated directly into the patient's record. Currently, very few systems have this capability and those that do (for example, in Norway) still need to improve or establish the IT capacity for all other health providers to deliver information in a compatible format.

With the exception of Norway, the countries reviewed have very few paperless offices. Those that are reported to be paperless, scan correspondence, which is then attached to patients' records. Information attached to, but not inserted into, a patient's record cannot be extracted from that record. This is the situation in most countries, and is certainly the case in Australia. The alternative is to manually enter test results and other information into the patient's record when received—and most GPs will not do so when they can access the results from the scanned or paper original.

Very few countries have achieved complete uptake of IT in general practice. Norway has reached this goal and Germany has achieved complete uptake through mandates although there is evidence, as in all other countries, that levels of use vary widely among clinicians. The way in which the computer is used is decided by the individual GP or practice. Although many countries consider their practices to be 'paper light' it seems that hybrid records are used in the majority of practices; that is, where some aspects of patient data are stored on computer and some in a paper file (Walker 1994). Even in Germany and Norway, although practices have the capacity to collate all their claims data electronically they are still delivered to the reimbursement bodies via computer disk.

The levels of computer use vary between nations and are dependent on GP attitudes. There is a high level of electronic prescribing in some countries, but whereas some have the capacity to electronically transfer prescriptions to their pharmacies, others are using the computer as little more than a word processor. Printed prescriptions are still given to patients to present at a pharmacy. Computer use is also greater in countries such as Denmark and the Netherlands where GPs have good support, both from software suppliers, and educationally through collegiate and educational bodies.

The Internet is being increasingly used by GPs as a source of clinical information, but again, this has been embraced more in some countries than in others—for example, GPs in Austria have expressed distrust in it. Emails between GPs and patients are uncommon; many GPs feel that it places too many time constraints on them, and others distrust the security of the systems. The exception to this is Denmark, where GPs are paid for each email consultation or email about laboratory test results. A trend appearing in most countries is that new, younger GPs are most likely to use the majority of computer functions and use coding systems, to do their own data entry, and to use the least paper (or be paperless). The older GPs are the least likely to use the newer methods, and natural workforce turnover may increase overall levels of computer use in the future.

The countries where the best use is made of electronic records and electronic communication are those with well-supported telecommunications infrastructure and good broadband access, which allow networks to function effectively. The most successful of these, regardless of emanating from government or a commercial entity, took a coordinated approach where a standard was agreed upon at an early stage of development and used by most stakeholders. Those with least success are those where a number of self-developed standards have grown in isolation. Interoperability remains a challenge for most, but, again, the most success is being gained in countries where systems are set up with messaging formats that allow health care providers to 'talk' to each other.

The use of computerised decision-support tools also varies widely. In most countries these are not well-developed and their use by clinicians is optional. This is not surprising, because even simple support tools, such as those for flagging drug–drug interactions, can only work effectively if all relevant patient information is entered into the system. These are superfluous in systems where all medications and all morbidities for the patient are not stored in the electronic record. Recall systems may work more effectively, but, again, this is dependent on the relevant information having been entered into the record by the GP.

The data held in computers also varies between countries: some collect complete prescription and accounting data, with other information stored on paper; others keep all patient information electronically, other than that external to the practice. Most information is stored on local servers, but some use a central server. In many countries, the decision about the location of stored data remains unresolved because legal issues around privacy and security are as yet unresolved. A unique patient identifier has been introduced in many countries, but is yet to be used in others. Patient privacy is usually one of the objections to central storage of patient data outside the practice, because patients may be individually identified should security breaches occur. Unresolved technical and privacy issues have resulted in the continual delay of rollout of major projects in Germany, the Netherlands and Scotland. In Australia, issues of data security, privacy and ownership are yet be resolved.

One of the key benefits of computerising patient records is their potential use as a research tool. However, in all of the countries reviewed there are issues with data quality. The variety of coding systems used, the different coders (that is, the GP or clerical staff) and the level of training undertaken by those involved in data entry all have an impact on the quality of the data. Hybrid records also leave significant gaps in patient data, which compromises the quality of information produced from data extracted from these systems. Patient consent to use of the data are also a contentious issue, but research suggests that the majority of patients are happy to see their data used for research by not-for-profit organisations (de Lusignan & van Weel 2006; Fletcher et al. 2004).

There is evidence that the most useful data for research is that which has been entered using a coding system, rather than free text. However, even using a reliable coding system does not guarantee data completeness. Assessing the completeness and accuracy of computerised medical records is problematic (Jordan et al. 2004). The largest general practice research databases in a number of countries still have many issues with incomplete data, and it is difficult to infer meaning when a reliable denominator is unable to be determined (de Lusignan & van Weel 2006). Missing data can alter the aim of a research project from its inception, as became evident in a recent (2004) project undertaken by the Commonwealth Fund to provide a cross-national comparison of primary care practice including the USA, England, Australia, Canada and New Zealand (Bindman et al. 2007).

Australian computer use in primary care

In 1998, fewer than 10% of GPs were using computers in their clinical work (Kidd 2002). By 2003, government initiatives with Royal Australian College of General Practitioners (RACGP) support had increased this usage to 92% (Britt et al. 2003), and by 2007, the levels of computer use by GPs had risen to 97% (Britt et al. 2008). These results indicated that computers were present in practices, but gave no real detail on the functionality that GPs were incorporating into their daily patient care.

Recent studies investigating the use of computers for clinical activity in Australian general practice (Henderson et al. 2006; McInnes et al. 2006) reported that, although computers are available in most practices, there is wide variation in the level of computer use by individual GPs. Some do not use a computer at all, even though one is available; others use them for administrative functions only; a large proportion use them for producing prescriptions; fewer for ordering pathology and imaging tests; and a smaller number for Internet and email (Henderson et al. 2006). McInnes et al. reported that 88% used their software application for checking drug–drug interactions (McInnes et al. 2006) but DSS tools for contraindications may not be reliable given that only 65% record a reason for prescribing. Around two-thirds of GPs in both studies kept clinical notes, but less than 22% were keeping all patient information in an electronic format—the latter scanning correspondence generated outside the practice and attaching these letters and reports to the patient's file (McInnes et al. 2006).

Currently in Australia there is no national electronic communications network, although the NeHTA has been formed to, among other tasks, develop standards and specifications for such a network. The HL7 is the dominant health messaging standard in Australia (Standards Australia e-health 2007) and has been agreed as a messaging standard for pathology referrals and discharge summaries (Protti & Bowden 2006). One problem to be overcome, however, is that pathology laboratories have been sending results electronically to about 60% of general practices for almost 15 years, and initially the private pathology companies agreed on a reporting format—the Pathology Information Transfer (PIT). The PIT messaging system does not contain anatomical data (unlike HL7) and so cannot be directly inserted into the patient's record in current software systems (Protti & Bowden 2006). It may be difficult to bring about a change of format when the one currently in use fulfils the needs of the pathology laboratories, and possibly the GPs, who may consider the change as being only beneficial to those who wish to extract data from patients' records.

The standard for encoding reason for encounter, morbidity and patient self-reported data in primary care is the International Classification of Primary Care—2nd edition (ICPC-2); the International Classification of Functioning, disability and health (ICF) is the standard for data about functioning and disability; and the Australian Standard Geographical Classification (ASGC) is used for demographic data (AIHW 2008). Harmonising the minimum data sets created by NeHTA, the AGPSCC and data elements within the National Health Data Dictionary is currently being discussed. A licence for SNOMED-CT has recently been purchased by the Australian Government for use in electronic health records. Australia (represented by NeHTA) is one of the founding members of the International Health Terminology Standards Development Organisation (IHTSDO) and currently there are projects underway to create a primary care subset of SNOMED-CT for use in Australia and internationally. Australia is heavily involved in the primary care subset work.

At present, there are approximately 35 different clinical software providers servicing general practice. No performance standards were set in software development, for either the prescribing modules themselves or for the medication databases on which they rely.

Current Australian electronic general practice data collections

As previously mentioned, currently there are several groups in Australia who are involved with electronic data collection of GP/practice/patient information. These collections are operated by academic institutions, GP divisions or other not-for-profit organisations, and commercial enterprises.

To assess electronic collection methods currently used in Australia, a review of the literature and Internet was undertaken, and bodies such as the AGPN and Primary Health Care Research and Information Service (PHCRIS) were contacted to identify groups involved in collecting primary care data electronically. A questionnaire (see Appendix 5) was designed and sent via email to a contact person within each of the identified organisations. A list of organisations who received the questionnaire, and those who responded, is available in Table A2.2. The responses received have been summarised below.

GP–patient encounter collections

Australian Primary Care Collaboratives (APCC)

The Collaboratives program was developed in the USA by the Institute for Healthcare Improvement. It has been adopted in other countries—most recently through the National Primary Care Development Team in the UK. Under a 2003 Federal Budget initiative, the National Primary Care Collaboratives (NPCC) was established to implement the Collaboratives program in Australia. Between 2005 and 2007, 487 general practices (representing 6.5% of all practices as at August 2007) were involved in the program through the NPCC.

Phase II of the Collaboratives program, known as the Australian Primary Care Collaboratives (APCC), commenced in 2008. The Improvement Foundation Australia began rolling out the program in New South Wales, Queensland and the Australian Capital Territory in May 2008, followed progressively by the other jurisdictions. Phase II of the program aims to involve approximately 1,000 general practices nationally.

Purpose

The Collaboratives Program involves practices with GPs and staff who are keen to work together to improve their patients' clinical outcomes and reduce their lifestyle risk factors. There is a focus on helping to maintain good health for those with chronic conditions and to promote a culture of quality improvement in primary health care. Practices that get involved in the program need to show commitment to discovering better ways to provide primary health care services to patients through shared learning, peer support, training and education. Ultimately, the program aims to assist practices in developing their capability to provide efficient, sustainable and systematic improvements in quality patient care.

Method

The program requires individual general practices of each collaborative to develop their own objectives and identify the keys tasks, and changes that will assist in facilitating improvement. The focus in Phase I was on the secondary prevention of coronary heart disease (CHD) and diabetes, and patient access to primary care services. The collaborative framework consists of a collection of baseline data at the outset to provide a picture of the practice before their commencement in the program. This is followed by a

series of learning workshops, activity periods and plan, do, study, act (PDSA) cycles along with monthly data collections to detail the progress made towards practice improvement.

Data are extracted using the Canning extraction tool and subsequently loaded onto an online reporting website. Data can be collected from a number of different clinical software systems such as Medical Director, Genie, Communicare, Medtech32, and many others.

Some divisions involved with the initial NPCC program have applied the quality improvement principles to other topic areas (such as asthma and immunisations). Although the focus on CHD, diabetes and patient access will be maintained in Phase II, the APCC plans to widen the data collection to include work in other health-related areas such as asthma, immunisations, mental health, error prevention, and other health indicators.

Advantages

- A set of key clinical and financial indicators is collected from electronic patient records.
- Data can be collected from most clinical software programs that are currently in use.
- The APCC assists GPs via data reports presenting a different perspective on their chronic disease patients.
- Potential to link to other data sources.
- Participant (GP) consent is obtained.
- Has capacity to collect additional data elements about the GP or practice in future.
- Has capacity to collect additional data elements about the encounter and the patient in future.
- The Collaboratives process is resulting in improved health outcomes for patients with chronic diseases, including:
  - improved patient care through better management of diabetes and coronary heart disease
  - increased best-practice care through better use of information systems (clinical and business systems)
  - evolving roles among practice staff to better meet patient demand.
- Checks are made of accuracy, consistency and reliability.

Limitations

- Small sample (6.5%) of general practices—higher risk of sampling error.
- Practices are required to commit significant time and resources to the implementation of the program and participation in it.
- Response rates unknown.
- Currently limited to three specified topics for which data are collected.
- The program does not provide ongoing data for longitudinal analysis (only episodes of longitudinal data collection).
- Still partially paper-based.
- No ethics approval and patient consent not obtained, though data are not identifiable.

Project/collection	Australian Primary Care Collaborative (APCC), formerly National Primary Care Collaborative
Operating organisation	Improvement Foundation Australia (a commercial organisation)
Purpose	Allows practice to track improvements as a result of quality improvement related to the Program's key topics (CHD, diabetes and better access)
Data collected from	General practices; Aboriginal medical services
Data collected about	Selected general practice patients
Data collection period	March 2005—ongoing
Design method	Periodic cross-sectional and periodic longitudinal
Physical data collection method	Partly paper-based, partly extraction from electronic records
Types/brands of clinical software used	MD2; MD3; Genie; Communicare; Medtech32; Practix; Best Practice; Zedmed; MS Classic; Promedicus; Locum; Ferret
Data extraction tool used	Canning NPCC tool; Canning NPI tool
Compatibility of data extraction tool with more than one type of software	Tools can be used with more than one type of software
Potential for alteration of tool for use with other software	Not applicable
Data format	Not specified
Data linked to other sources	No
Data linkable to other sources	Yes
Size	600 practices
Ethics approval	No
GP sampling method	National—opportunistic sampling of practices on a first come, first served basis. Participants can include individual GPs, or multiple GPs from a practice
GP consent to participate	Signed consent obtained for each period of participation
Level of consent	Participants are informed individually of data collection, the storage of data in a database and the uses of the data for particular purposes
Extent to which participants are representative of the GP population.	'Some evidence' and 'good evidence' both reported
Data items collected about the GP or the practice	Practice postcode; number of GPs in practice; accreditation of practice; practice nurse; provider number Capacity to collect additional items about the GP or practice
GPs identifiable	Yes
Patient sampling method	All patients from a practice over a specific period of time
Patient consent to participate	Neither written nor verbal consent obtained and patients are not given the option to opt-in or opt-out
Patients identifiable	No—irreversibly anonymised
Data items collected about the patient	None No capacity to collect additional items about patients in future
Data items collected about the encounter (administrative)	None Capacity to collect additional administrative items about the encounter if required
Data items collected about the encounter (clinical)	Problem/diagnosis; medication prescribed; pathology ordered Capacity to collect additional clinical items about the encounter if required
Linkage of GP and patient data	No
Extent to which individual problems and managements can be followed over time	No

Data coding	Unspecified for diagnoses and medications; HL7 for pathology
Data coded by	Differs in each practice—some have received training
Accuracy checking of coded data	Ranges of elements checked; consistency of elements checked; reliability checked
Data completeness	80–97% of variables at least 95% complete
Availability	Reports released annually and on request. Analyses performed by collecting organisation on request for other parties
Data access cost	Free to all parties
Additional comments from survey participant	None
Information available at	<http://www.apcc.com.au>

Australian Sentinel Practices Research Network (ASPREN)

The ASPREN consists of a national network of GPs collecting data on influenza-like illnesses (ILI) and other selected conditions seen in general practice. The network has been collecting data since 1991 and is managed by the RACGP and University of Adelaide. ASPREN initially consisted of about 140 GPs reporting using a paper-based system on up to 12 conditions per year, but many of these were lost from the network due to retirement.

Purpose

The network is part of the Australian Government's bio-surveillance strategy which includes the capacity to indicate the occurrence or outbreak of emerging communicable diseases in Australia. The increase in animal and human cases of influenza A/H5N1 in parts of South East Asia during 2005 has reinforced the need for an ASPREN type facility in guarding against the threat of an influenza pandemic. The GPs provide a service oriented towards the monitoring of ILI by forwarding de-identified patient data to the network, informing and measuring changes in these and other conditions observed in general practice.

The network monitored four conditions in 2007—ILI, gastroenteritis, chicken pox and shingles. In previous years, information was collected on the use of antibiotics for acute exacerbations of chronic obstructive pulmonary disease (COPD), use of spirometry for COPD, and the use of ambulatory blood pressure monitors.

Method

GPs are recruited into the network via targeted campaigns through the RACGP and regional divisions of general practice. Data were collected using a paper-based system from 1991 to September 2006. Since then, data have been collected electronically via a web-based database. De-identified patient data on ILI (mainly) is submitted on an ongoing basis, using an electronic log-in page on the computer in clinical practices. The GP logs in at the start of the clinic day and, if they encounter one of the diseases for notification, they can easily submit their data to the network in real time. Participants are required to report the number of consultations they have each week even if there are no ILI cases to report.

Data reports are compiled on the number of ILIs per 1,000 consultations presented across the network by week, age category, sex and state. GPs can also collect and submit information on other conditions of interest. Summary reports are produced fortnightly and distributed to participating ASPREN reporters and stakeholders.

Advantages

- Quick, easy data entry operation.
- Information focuses on specific clinical conditions with data collected in real time.
- Summary reports produced fortnightly and forwarded to participating GPs.
- Useful for specific research purposes.
- Data may be traced back through the GP for notification if necessary.
- Good retention rate of GPs since electronic data submission commenced (95%).
- Could be used for data capture of other diseases, although limited at present.
- Potential to expand data elements.
- High level of data completeness.

Limitations

- Requires second entry of data (not extracted from patient's record).
- Small sample size—around 110 GPs participating—and geographically disproportionate. ASPREN is looking to increase this to 150 GPs by mid-2009.
- Low numbers of participating GPs in rural and regional areas.
- Response rates unknown.
- Data can not be linked to other sources.
- Data are downloaded as free text (no coding).
- Repeated visits for the same problem are not connected within the database.
- No ethics oversight or patient consent, although data are not identifiable.
- No checking for accuracy, consistency or reliability.

Project/collection	**ASPREN**
Operating organisation	Operated for the RACGP through the Discipline of General Practice, Adelaide University
Purpose	Surveillance of influenza and other defined conditions in general practice
Data collected from	GPs
Data collected about	GP patients in a practice setting
Data collection period	Continuous since 1991—paper based to 2006; electronic since 2006—ongoing
Design method	One-off recruitment of participants who provide data on an ongoing basis
Physical data collection method	Paper-based survey until 2006—a desktop-based Internet-hosted survey tool since 2006
Types/brands of clinical software used	None specified
Data extraction tool used	No extraction tool used. GPs enter data into a web-based database—Access queries used to extract data
Compatibility of data extraction tool with more than one type of software	No data extraction tool used
Data format	Downloaded as free text
Data linked to other sources	No
Data linkable to other sources	No
Size	110 GPs; 12,000 conditions notified since electronic data collection commenced

Ethics approval	None
GP sampling method	National opportunistic recruitment targeted through RACGP and divisions of general practice; includes all types of GPs; can include individuals, multiple GPs from a practice, or all GPs from a practice
GP consent to participate	Signed consent obtained at first period of participation, which includes subsequent periods of participation
Level of consent	Participants are informed individually and collectively of data collection, the storage of data in a database and the uses of the data for particular purposes
Extent to which participants are representative of the GP population.	'Some evidence' and 'good evidence' both reported
Data items collected about the GP or the practice	GP sex; practice postcode; number of GPs at the practice Capacity to collect additional items about the GP or practice
GPs identifiable	No—but are reversibly anonymised
Patient sampling method	Selected individual patients from the participants practice, with specific morbidity
Patient consent to participate	None
Patients identifiable	No
Data items collected about the patient	Patient sex No capacity to collect additional items about the patient
Data items collected about the encounter (administrative)	None Capacity to collect additional administrative items about the encounter
Data items collected about the encounter (clinical)	Reasons for encounter; problem/diagnosis; pathology ordered Capacity to collect additional clinical items about the encounter
Linkage of GP and patient data	Patient data cannot be linked to either the practice or the GP
Extent to which individual problems and managements can be followed over time	Information is recorded for repeated visits for a patient but does not link the problem within the record over time
Data coding	Data entered as free text—no coding
Accuracy checking of coded data	No checks for accuracy, consistency or reliability
Data completeness	More than 97% of variables at least 95% complete
Availability	Data are available to participants and to other parties. Annual reports and quarterly newsletters with data summaries are available on the website. Other requests for data may be made at any time through ASPREN
Data access cost	Free to all parties
Additional comments from survey participant	Recruiting and maintaining GP participation can be difficult
Information available at	<www.racgp.org.au/aspren>

Collaborative Network and Data Using IT (CONDUIT)

CONDUIT is operated by the University of Melbourne, and commenced collecting information about patients and their visits to health care centres in 2006.

Purpose

The network was established to support and facilitate the sharing of information between health providers in an area of Victoria from Northern Melbourne to North-East Victoria. The network enables data from various sources to be analysed and linked into a single platform to provide a complete picture of the patient.

Method

Data are collected from the electronic health records of participating health providers. Using a data extraction tool known as GeneRic HeAlth Network Information Technology for the Enterprise (GRHANITE), de-identified data are deposited into a secure information warehouse. CONDUIT involves the linking of databases from hospitals, general practices, pharmacies, other health services and research/evaluation projects to enable electronic health information to be shared among clinicians as per the national eHealth program. Fully encrypted data are collected in the same structure as stored in the health record—that is, as free text or coded information.

Advantages

- Data can be collected from various types of clinical software.
- Data are linked with other data sources.
- Collects information about repeat visits linked to the initial visit/problem for longitudinal analysis.
- All communications are fully encrypted.
- Consent is obtained from GP participants.
- Consent is obtained from patient participants.
- Has ethics approval.
- Has the capacity to collect additional data elements about the GP or practice in future.
- Has the capacity to collect additional data elements about the encounter and the patient in future.
- Checks are made on accuracy and consistency before reporting.

Limitations

- Small divisional collection at present, but could be expanded.
- Participation rates unknown as yet.
- Data collected from computerised practices only.
- Average level of data element completeness may affect data quality.

Project/collection	**Collaborative Network and Data Using IT (CONDUIT)**
Operating organisation	University of Melbourne (academic institution)
Purpose	Quality audit and general research of clinician and practice activity, including measurement and monitoring of outcome measures, i.e. multipurpose including data mining
Data collected from	Any health information system, including general practices, community health centres and specialist clinics
Data collected about	Patients in any health setting, as long as there is informed consent to participate, with focus or starting point being general practice
Data collection period	May 2006—ongoing
Design method	Continuous longitudinal and periodic longitudinal
Physical data collection method	Extraction from electronic records
Types/brands of clinical software used	MD2; MD3; Practix; Zedmed; any other based on O1eDB Oracle; DB2; Foxpro; SQL server; Excel; Access
Data extraction tool used	GeneRic HeAlth Network Information Technology for the Enterprise (GRHANITE) (see www.grhanite.com)

Compatibility of data extraction tool with more than one type of software	Tools can be used with more than one type of software
Potential for alteration of tool for use with other software	Not applicable
Data format	Direct replication of existing data a structured in the source system—free text, coded, and so on. Any fields containing sensitive information can be additionally encrypted with access for approved purposes only. All communications fully encrypted. Data are transferred through encrypted electronic transfer, or manual transfer of encrypted data via personal pick-up, post or email. Destination holds the decryption key
Data linked to other sources	Yes
Data linkable to other sources	Yes
Size	12 GPs; 5,000 patients. The study population is expected to grow markedly during 2008–2009 and will link hospital, laboratory and GP records in a de-identified manner
Ethics approval	Yes
GP sampling method	Divisional—opportunistic sampling. Building regional network in Northern Melbourne/Victoria. All types of GPs are included. Participants can include individual GPs, or multiple GPs from a practice
GP consent to participate	Verbal consent obtained for each period of participation
Level of consent	Participants are informed individually of data collection, the storage of data in a database and the uses of the data for particular purposes
Extent to which participants are representative of the GP population.	'Some evidence' reported
Data items collected about the GP or the practice	Age; sex; practice postcode; number of GPs in practice; practice nurse; provider number; bulk-billing status Capacity to collect additional items about the GP or practice
GPs identifiable	Reversibly anonymised
Patient sampling method	All patients from a practice are included over a specified time period
Patient consent to participate	Verbal consent obtained—patients are given the option to opt-out and are included unless they choose not to participate
Patients identifiable	Reversibly anonymised
Data items collected about the patient	Age; sex; postcode; cultural background; HCC status; Veterans' Affairs status; patient status to practice (i.e. new/seen before) Capacity to collect additional items about patients in future
Data items collected about the encounter (administrative)	Date of visit; location. If information is available: start–finish time, direct/indirect consult; Medicare item numbers; payer details Capacity to collect additional administrative items about the encounter if required
Data items collected about the encounter (clinical)	Problem/diagnosis; medication prescribed; pathology ordered; imaging ordered. If information available: referrals, procedures and administrative processes are also recorded Capacity to collect additional clinical items about the encounter if required
Linkage of GP and patient data	Patient data can be linked to a practice but may include information from more than one GP
Extent to which individual problems and managements can be followed over time	Information is recorded for repeated visits that are linked to the initial visit and problems/illnesses can be followed over time
Data coding	Various—unspecified
Data coded by	GPs—level of training unknown
Accuracy checking of coded data	Ranges of elements checked; consistency of elements checked. Cleaning checks are made before reporting
Data completeness	50–79% of variables at least 95% complete

Availability	Reports provided to GP participants—reports not released to other parties unless requested and consented to. Data not available to parties outside the organisation unless practices agree. Raw data available to participants only. Analyses performed on request for other parties dependent on type of consent
Data access cost	Free to all parties
Additional comments from survey participant	The major issues are data quality, especially completeness of structured data, and privacy and security arrangements covering the secondary uses of data beyond the source organisation. The approach and utilities tackle many of the associated issues. There are also problems with system errors affecting data quality. The study team also believe natural language processing of the narrative data in the system should be progressed to enhance quality through triangulation and improving data completeness
Information available at	<http://www.conduit.unimelb.edu.au/about/index.html>

General Practice Research Network (GPRN)

The Health Communication Network (HCN) is a provider of clinical and practice management software (Medical Director) for Australian GPs and specialists. HCN's research division—the GPRN—has been collecting data electronically from randomly selected general practices nationally since 1999.

Purpose

The network was established to provide de-identified longitudinal patient data that could be used to research and evaluate the clinical activity and use of computerised patient records in general practice including, for example, disease surveillance, use of clinical tools and interaction checks. Data on prescribing behaviour is supplied to the National Prescribing Service (NPS) each quarter to assist with their analysis of medications and the quality use of medicines. In addition, data are provided to academic groups for research into general practice and is purchased by pharmaceutical companies (such as for post-marketing surveillance) and IMS Australia, with the revenue being used to support the cost of running the network.

Method

To be eligible to participate in the network, a doctor has to be a Medical Director (MD) clinical software user and from this group a random sample of GP participants is selected. Each week, approximately half of the 396 (as at Feb 2008) GPs enrolled in the network email their de-identified aggregated clinical record data (which are automatically extracted and encrypted using an HCN provided extraction tool) to a secure site. Before being emailed, the data are available for the GP to view, ensuring only de-identified data are being provided. HCN has endeavoured to ensure that privacy and confidentiality matters are respected for all data providers.

Of the 396 participants currently enrolled in the network, one-third (139) have participated for 1 year, another third (132) have been involved for more than one year but less than 5 years, and a further third (125) for more than 5 years.

Advantages

- Data are captured directly from the electronic patient health record.
- Provides information on drugs not listed on the PBS.
- Large collection over a substantial time period.
- Monitors the evolving capacity of the GP computer user.

- Little to no disruption for participating practices by virtue of the extraction process.
- The MD software contains an automatic edit requiring a reason for a prescription on the medical record.
- Has the potential to collect additional data elements about the practice, the encounter and the patient in future.
- Data are encrypted before downloading to the analysing body.
- High level of data element completeness.
- Checks are made on accuracy and consistency before reporting.

Limitations

- Sample is not nationally representative. Participation in the GPRN is only available to the 60–70% of Australian doctors who are MD software users. The national distribution of participants is unknown.
- Variation in the computer using capacity of enrolled GPs—it is unknown whether participants use computer records only or whether hybrid systems exist, which would limit data completeness.
- Participant sample is quite small for the large number of observations—a small amount of very large clusters would create a large design effect.
- Actual response rate is unknown—full methodology and recruitment as yet unpublished. Around 400 GPs currently participating.
- Not all GPs consent—one participant in the practice can provide information from all patients regardless of the GP managing them.
- No ethics approval and patient consent is not obtained, though data are not identifiable.
- Data extraction tool limited to MD software only.
- No potential for data to be linked to other sources.

Project/collection	**General Practice Research Network (GPRN)**
Operating organisation	Health Communication Network Limited (commercial organisation)
Purpose	Research of General Practice clinical activity, including, but not limited to, disease surveillance, prescribing behaviour, use of clinical tools and interaction checking
Data collected from	GPs
Data collected about	GP patients in all settings
Data collection period	Jan 1999—ongoing
Design method	Continuous longitudinal and periodic longitudinal; periodic cross-sectional and periodic longitudinal
Physical data collection method	Extraction from electronic records
Types/brands of clinical software used	MD2; MD3
Data extraction tool used	MD data extraction tool
Compatibility of data extraction tool with more than one type of software	Tool cannot be used with other software
Potential for alteration of tool for use with other software	Not possible
Data format	Encrypted, de-identified and compressed at source
Data linked to other sources	No

Data linkable to other sources	No
Size	884 GPs; 18,997,534 GP–patient encounters; 2,200,148 unique patients; 18,003,598 prescriptions
Ethics approval	No
GP sampling method	National—random sample of approx 14,500 GPs who user MD software (approx 64% of all GPs). All types of GPs are included. Participants can include individual GPs, multiple GPs from a practice or all GPs from a practice
GP consent to participate	Signed consent obtained at first period of participation, which includes subsequent episodes of participation
Level of consent	Participants are informed individually of data collection, the storage of data in a database and the uses of the data for particular purposes
Extent to which participants are representative of the GP population.	'Good evidence' is reported
Data items collected about the GP or the practice	Age; sex; practice postcode; number of GPs in practice; number of years in practice; provider number Capacity to collect additional items about the GP or practice
GPs identifiable	Reversibly anonymised to users of data
Patient sampling method	All patients from a practice are included over a specified time period
Patient consent to participate	None—according to GPRN, 'practices notify patients that the practice participates in GPRN and that no identifiable patient data are sent from the practice. Hence patient consent is not required'. A poster identifying the practice as a participant of the GPRN panel is displayed prominently at each participating practice along with patient information leaflets. The patients can choose to opt-out of the database—in which case, the GP will have to flag them in Medical Director
Patients identifiable	Irreversibly anonymised
Data items collected about the patient	Age (date of birth is randomised to the 15th of the month to protect patient privacy); sex; HCC status; Veterans Affairs status Capacity to collect additional items about patients in future
Data items collected about the encounter (administrative)	Date of visit; postcode; start–finish time Capacity to collect additional administrative items about the encounter if required
Data items collected about the encounter (clinical)	Reason for visit; problem/diagnosis; medication prescribed; pathology ordered; imaging ordered; referrals; procedures (a detailed list can be provided on request) Capacity to collect additional clinical items about the encounter if required
Linkage of GP and patient data	Patient data can be linked to a practice but may include information from more than one GP
Extent to which individual problems and managements can be followed over time	Information is recorded for repeated visits that are linked to the initial visit and problems/illnesses can be followed over time
Data coding	Reasons for visit and diagnoses coded using Docle. Mapping to ICPC-2 available
Data coded by	GPs (who have been trained)
Accuracy checking of coded data	Ranges of elements checked; consistency of elements checked. Cleaning checks are made before reporting
Data completeness	80–97% of variables at least 95% complete
Availability	Data/reports are released weekly/monthly and on request, to participants and other parties
Data access cost	Data are free to participants only. Other parties pay fee determined on request
Additional comments from survey participant	None
Information available at	<http://www.hcn.net.au/doctors/gprn.asp> or contact gprn@hcn.com.au

Practice Health Atlas (PHA)

The PHA, developed by the Adelaide Western General Practice Network (AWGPN), is based on the synthesis of relevant, high-quality practice health data with national census data and other data sources, to provide an epidemiological picture of practice data.

Purpose

The PHA is a decision-support tool, designed for GPs, practice managers and other practice staff. The focus is on managing patients with chronic disease by improving the quality of clinical data, through which the practice can implement changes to improve their clinical and business performance. It is the practice's individual responsibility to enact the changes needed to improve the quality of care for their patient population.

The health data collected for the atlas is integrated with other data sources (such as Census and bio-informatics data), population health informatics and spatial mapping (Geographical Information Systems—GIS). The integrated data are used to provide information to practices that can assist in improving their quality of care in tandem with improving business outcomes. In addition, the AWGPN is establishing a General Practice Research Group to bring together data from individual practices (including PHA data) and create aggregated data, with the intention of developing a regional health atlas. This will enable participating practices to benchmark themselves against the overall results of the research group.

Method

The construction of the PHA is performed at the division using Microsoft Office tools (Access, Word and Excel) and MapInfo Professional GIS software. Data are collected at the practice or divisional level using a purpose-built extraction tool developed by PEN Computer Systems. The PEN tool is a clinical audit system that searches the electronic patient data records, providing a clinical analysis picture using a graphical format.

The PHA is generated from up-to-date and complete health summaries, including all comorbidities. Around 15 months worth of data are required. All data are collected from the practice's backup system to reduce the risk of corrupting clinical data. The output is a de-identified data set that is analysed and synthesised with other data sets, and a report is produced for the practice. The division can then collaborate with the practice to reflect on their data and encourage them to make changes for the better, using the evidence from the PHA.

Advantages

- Data are collected electronically and mapped to the National Health Data Dictionary (NHDD) where possible.
- Data elements are coded where possible.
- Integration with other data sources provides a more complete picture of the state of play for the practice.
- Ability to compare the practice with other practices in the region.
- Additional information is collected on the practice's billing pattern for the relevant chronic disease Medicare item numbers (to inform business options).
- Minimal disruption after the initial PHA establishment.
- Quality of care improvements occur in tandem with improved business systems.

- Has the capacity to collect additional elements about the GP, the practice, the patient and the encounter.
- Checks are made for accuracy, consistency and reliability before reporting.
- Excellent potential for collection of workforce data if implemented on a national scale.

Limitations

- Currently only available for MD software users, though there are plans to extend the service to other medical software users as data export functionality evolves.
- A regional cross-sectional data collection, so limited for national use at present.
- Poor level of data item completeness.
- No ethics approval and patient consent not obtained, though data are not identifiable.
- Data are patient-based rather than encounter-based, so treatment patterns cannot be followed over time.

Project/collection	Practice Health Atlas (PHA)
Operating organisation	Adelaide Western GP Network (a GP division/group)
Purpose	Quality audit; clinical epidemiology and mapping; business and clinical analysis, financial modelling
Data collected from	General practices
Data collected about	GP patients and MBS items claimed in all settings (as long as entered into the billing and clinical system entered at the practice)
Data collection period	Start date not specified—ongoing
Design method	One-off recruitment of practices within the division on an opt-in basis. Annual wholesale collection of total practice population (i.e. not a sample)
Physical data collection method	Paper-based survey for personnel component Manual extraction for the billing component Electronic extraction from medical records for the clinical component
Types/brands of clinical software used	Clinical—currently Medical Director (MD) 2 and 3; shortly Genie and Best Practice to be included Billing—any billing software
Data extraction tool used	MD 2 and 3 programs—extraction tool designed specifically for the PHA. Genie and BP programs have a native data export functionality that will export the clinical data required
Compatibility of data extraction tool with more than one type of software	Tool designed for use with MD 2 and 3 is for single vendor use only
Potential for alteration of tool for use with other software	Low—not likely to be required. Genie and BP have included an export function. Other clinical software vendors have indicated that they will be building export capability (our preferred option) so a tool would not be needed
Data format	Down loaded as free text in an XML file
Data linked to other sources	The PHA links Census data to the collected data at the postcode level. In terms of the billing and clinical data, they are collected for exactly the same time periods but there is no linking between patient clinical records and MBS items claimed for the patients—this cannot be done with the level of patient de-identification we use
Data linkable to other sources	Only at postcode level
Size	As PHA is done for individual practices the databases are separate. Currently working on ways to aggregate these, which would provide 50–60 GPs and approximately 100,000 patients. Numbers change on a per-division basis depending on the population, number of practices, practice size, number of practices in a division which have had a PHA done, and so on

Ethics approval	None
GP sampling method	Opportunistic sampling of practices that are computerised with the required clinical software. The PHA is done at a practice level and includes all GPs in the practice. All types of GPs are included (i.e. vocationally recognised (VR); non-VR; OMPs; full-time; part-time, and so on)
GP consent to participate	Signed consent obtained at each period of participation
Level of consent	Participants are informed individually of data collection, the storage of data in a database and the uses of the data for particular purposes
Extent to which participants are representative of the GP population.	'Some evidence' and 'good evidence' both reported
Data items collected about the GP or the practice	GP sex; practice postcode; number of GPs at the practice; practice accreditation status; whether practice nurse is employed; practice address; areas of special interest; opening hours; languages spoken by GPs; composition of practice staff (practice manager, other clerical, and so on); other services (e.g. wheelchair access) Capacity to collect additional items about the GP or practice
GPs identifiable	Yes—PHA is performed as a consultative service between the division and the practice. It is not a public document so there is not requirement to de-identify GPs and practice staff
Patient sampling method	Patients include all those in the database considered 'active' (i.e. have not left the practice or whose records have not been deactivated for some other reason)
Patient consent to participate	None
Patients identifiable	No—irreversibly anonymised
Data items collected about the patient	Patient age; sex; postcode of residence; Veterans Affairs card holder status; pensioner status; Indigenous status Capacity to collect additional items about the patient if required
Data items collected about the encounters (administrative)	Date of last visit Capacity to collect additional administrative items about the patient if required
Data items collected about the encounters (clinical)	Problem/diagnosis; medication prescribed; medication provided; pathology results; height; weight; blood pressure; foot/eye examination and date performed Capacity to collect additional clinical items about the patient if required
Linkage of GP and patient data	Patient data cannot be linked to either the practice or the GP
Extent to which individual problems and managements can be followed over time	Information is recorded for repeated visits for a patient, but does not link the problem within the record over time
Data coding	Problem/diagnosis coded with Docle/ICPC2/Proprietary; Medication data coded with MIMS/ Proprietary; Pathology data coded with HL7
Data coded by	GP and practice staff during normal operations
Accuracy checking of coded data	Ranges of elements are checked; consistency of data elements is checked. Cleaning checks are made of data before releasing or reporting
Data completeness	Less than 50% of variables at least 95% complete
Availability	Data are not available to anyone outside the collecting organisation. Analysis of request done by the collecting organisation for participants only. Raw data available to participants only. Currently considering analysis on request performed by collecting organisation for other parties, but not yet available
Data access cost	Yet to be determined. Dependent on the data required and whether the data will be released by AWGPN and the relevant practices
Additional comments from survey participant	Prefer collection of age to date of birth—date of birth makes re-identification easier
Information available at	<http://www.awgpn.org.au/site/index.cfm?display=5462>

Other electronic data collections

Southern Highlands Division of General Practice (SHDGP)

Southern Highlands Division of General Practice is situated in the Wingecarribee Shire, and includes approximately 51 GPs in 16 practices, servicing the towns of Mittagong, Bowral, Moss Vale and Bundanoon. The division runs a number of chronic disease programs in aged care, cancer support, diabetes education and management, immunisation, mental health and quality use of medicines.

Purpose

The higher number of persons aged 50 or over in the area compared with the New South Wales average, together with the general ageing of the community requires concentration on chronic illness. The division accordingly gives priority to programs for diabetes, aged care and mental health problems. The SHDGP operates a pilot program for secondary prevention in ischaemic heart disease. As part of their chronic disease program, the division collects data from practices on the management of several chronic diseases, such as Type 2 diabetes and cardiovascular disease, to assess ongoing management and to monitor risk factors for these diseases.

Method

Data are collected at the patient encounter. Practice data relating to chronic disease management are extracted manually from electronic patient records. Some data are collected on paper. Electronic data are encrypted before downloading to the division.

Advantages

- Data extraction tool selected for implementation can be used with other software—will give the opportunity to include more than MD software users in the future.
- Has the capacity to collect additional elements about the GP, the practice, and the patient in future.
- Patient consent is obtained.

Limitations

- Only available for MD software users.
- A regional cross-sectional data collection, so limited for national use at present.
- No known response rates.
- No ethics approval.
- Repeated visits for the same problem are not connected in the record.
- No checks made of accuracy, consistency or reliability.

Project/collection	Electronic data collections
Operating organisation	Southern Highlands Division of General Practice (a GP division/group)
Purpose	Chronic disease management practice data
Data collected from	General practices
Data collected about	GP patients
Data collection period	1995—ongoing
Design method	Continuous longitudinal

Physical data collection method	Manual extraction from electronic clinical records. Data are collected electronically and on paper
Types/brands of clinical software used	Medical Director (MD)
Data extraction tool used	Nil now—Canning in future
Compatibility of data extraction tool with more than one type of software	Tool can be used with more than one type of software
Potential for alteration of tool for use with other software	Not applicable
Data format	Data are transferred electronically and on paper. Electronic data are downloaded in encrypted format
Data linked to other sources	No
Data linkable to other sources	Yes—not specified
Size	Currently 59 GPs and 'large number' of patients
Ethics approval	None
GP sampling method	Regional—opportunistic sampling of practices within the division. Types of GPs included not specified (i.e. VR; non-VR; OMPs; full-time; part-time, and so on). Participants can include individual GPs or multiple GPs from a practice
GP consent to participate	Signed consent obtained at first period of participation, which includes subsequent episodes of participation
Level of consent	Participants are informed individually of data collection, the storage of data in a database and the uses of the data for particular purposes
Extent to which participants are representative of the GP population.	'Some evidence' and 'good evidence' both reported
Data items collected about the GP or the practice	GP sex; practice postcode; number of GPs at the practice; practice accreditation status; whether practice nurse is employed; business model (i.e. solo GP, partnership, corporate owned Capacity to collect additional items about the GP or practice
GPs identifiable	Yes
Patient sampling method	Not described
Patient consent to participate	Signed consent obtained only at first participation but that includes subsequent episodes
Patients identifiable	Reported as both 'Identifiable' and 'reversibly anonymised'
Data items collected about the patient	Patient age; sex Capacity to collect additional items about the patient if required
Data items collected about the encounter (administrative)	Location (i.e. where consult occurred) No capacity to collect additional administrative items about the encounter if required
Data items collected about the encounter (clinical)	No information provided
Linkage of GP and patient data	Patient data can be linked to a single GP only
Extent to which individual problems and managements can be followed over time	Information is recorded for repeated visits for a patient, but does not link the problem within the record over time
Data coding	No information provided
Data coded by	Clerical staff
Accuracy checking of coded data	No checks for accuracy, consistency or reliability
Data completeness	No information provided
Availability	Data are released on request. No information provided re recipients of data or reports
Data access cost	Free to participants only. If data are available to other parties cost was not disclosed

Additional comments from survey participant	None
Information available at	<http://www.shdivgp.com.au/>

Australian Primary Care Collaboratives (APCC)—General Practice and Primary Health Care NT (GP&PHC NT)

The APCC is a 3-year, $14.6 million program funded from the Australian Government's *Focus on Prevention—Primary Care Providers Working* initiative. The Collaboratives assist general practices and Aboriginal medical services (AMSs) to improve patient clinical outcomes, reduce lifestyle risk factors, help maintain good health for those with chronic and complex conditions, and promote a culture of quality improvement in primary health care.

Purpose

Information obtained through data collection helps inform the provision of primary health care services to patients with diabetes and coronary heart disease, to improve access to care, and to improve quality in chronic disease management.

Method

Changes in the clinics are tested in small cycles so they are manageable and are measured to demonstrate improvement along the way. Data are collected at the practice and are manually extracted from electronic clinical records. A desk-top based, Internet-hosted survey tool is used to extract data from electronic patient records.

Advantages

- Data can be collected from several different types of software.
- The data extraction tool can extract data from several different types of software.
- Has the potential for data to be linked to other source.
- Has ethics approval.
- Accuracy, consistency checks are made on data elements.
- High level of data element completeness.

Limitations

- No capacity to collect more data elements about the GP, practice, patient or encounter in the future.
- No known response rates.
- No patient consent, though data are not identifiable.
- A regional cross-sectional data collection, so limited for national use at present.

Project/collection	**Australian Primary Care Collaboratives (APCC)**
Operating organisation	General Practice & Primary Health Care NT (GPPHCNT) (a GP division/group)
Purpose	Access to general practice. Quality improvement in chronic disease management
Data collected from	General practices
Data collected about	GP patients in practice settings

Data collection period	July 2004—ongoing
Design method	Periodic cross-sectional
Physical data collection method	Manual extraction from clinical records; extraction form electronic records; desktop-based, Internet hosted survey tool
Types/brands of clinical software used	Medical Director (MD); Communicare; Ferret; PCIS
Data extraction tool used	Canning tool
Compatibility of data extraction tool with more than one type of software	Tool can be used with more than one type of software
Potential for alteration of tool for use with other software	Not applicable
Data format	Not provided
Data linked to other sources	No
Data linkable to other sources	Yes—not specified
Size	Currently 19 practices in the Northern Territory; patient numbers not provided
Ethics approval	Yes
GP sampling method	Regional—opportunistic sampling of practices within the division, but including rural, remote and urban practices. All types of GPs included (i.e. VR; non-VR; OMPs; full-time; part-time, and so on). Participants can include individual GPs, multiple GPs from a practice or all GPs from a practice
GP consent to participate	Signed consent obtained at first period of participation, which includes subsequent episodes of participation
Level of consent	'Participants are informed individually of data collection, the storage of data in a database and the uses of the data' and 'participants not informed explicitly of data collection, storage or uses of data' were both reported in this section
Extent to which participants are representative of the GP population.	'Some evidence' and 'good evidence' both reported
Data items collected about the GP or the practice	Practice postcode No capacity to collect additional items about the GP or practice
GPs identifiable	No
Patient sampling method	Patients are selected individuals from each practice with Type 2 diabetes or other chronic conditions
Patient consent to participate	None obtained
Patients identifiable	No
Data items collected about the patient	None No capacity to collect additional items about the patient if required
Data items collected about the encounter (administrative)	Medicare item numbers No capacity to collect additional administrative items about the encounter if required
Data items collected about the encounter (clinical)	Problem/diagnosis; medication prescribed No capacity to collect additional clinical items about the encounter if required
Linkage of GP and patient data	Patient data cannot be linked to GP or practice
Extent to which individual problems and managements can be followed over time	None
Data coding	No information provided
Data coded by	GPs—these have been trained in coding
Accuracy checking of coded data	Checks are made on ranges and consistency of data elements

Data completeness	More than 97% of variables at least 95% complete
Availability	Reports from the data are provided to the participants and to other parties. Raw data are not available to participants but are available to other parties for research purposes
Data access cost	Free to all parties
Additional comments from survey participant	Would like to see improvements in data extraction tools
Information available at	<http://www.gpphcnt.org.au//www/index.cfm?ItemID=126>

GP Census

The GP Census is a web-based tool that automates the annual survey requirements of divisions with GPs and practices within their division. The AGPN has worked with GP Tasmania to update the product for use across the network, ensuring appropriate access for users at the division, state and national levels. The system will be available to the divisions from mid-2008.

Purpose

The Census tool enables the AGPN to take a snapshot of GP workforce participation over a given week. The system was initially developed by General Practice Tasmania, and successfully used across Tasmanian divisions for 3 years.

Method

Workforce data about GPs, practice nurses and practices are collected to enable workforce planning via the internet-hosted survey tool. All GP members of each division are included. Data are collected from each practice over one week in each year, with Census week being nominated by the AGPN.

Advantages

- A potential national collection, which appears to be limited to some divisions at present. However, national rollout is expected over the next 2 years.
- Good potential for collecting information about GP workforce.
- Excellent potential for collecting nationally representative GP workforce data once rolled out.
- Tool can be used with multiple types of software.
- Potential for linkage to other data sources.
- Has capacity to collect additional data elements about the GP and practice.
- High level of data element completeness.

Limitations

- No patient or encounter data collected, and no capacity for future collection of these data.
- Response rates unknown.
- No ethics approval.

Project/collection	**GP Census**
Operating organisation	Australian General Practice Network
Purpose	General practice workforce profile and feeder data for report, annual survey of divisions and workforce planning

Data collected from	General practices and general practitioners
Data collected about	GP and practice nurse participation in general practices. GP 'time consulting with patients' in all settings. Configurable questions at local division and state level, with anticipated uses including collection of national quality and performance system national performance indicators
Data collection period	Start date unspecified—ongoing
Design method	Periodic longitudinal
Physical data collection method	Internet-hosted survey (backed up on paper)
Types/brands of clinical software used	No information provided
Data extraction tool used	GP Census tool
Compatibility of data extraction tool with more than one type of software	Tool can be used with more than one type of software
Potential for alteration of tool for use with other software	Not applicable
Data format	Online query builder with CSV download of reports
Data linked to other sources	No
Data linkable to other sources	Potentially
Size	Currently 292 GPs; 0 patients. At pilot phase—trialled in ACT and Tas, next trial SA. Expected full rollout over 2008–09
Ethics approval	No
GP sampling method	Opportunistic sampling of practices within each division. Not all types of GPs included, but all GP members of each division. Participants can include individual GPs, multiple GPs from a practice or all GPs from a practice
GP consent to participate	Consent implied by participation—indicated in online check box in survey software—obtained at first period of participation, which includes subsequent episodes of participation
Level of consent	Participants are informed individually of data collection, the storage of data in a database and the uses of the data. Online consent form includes privacy statement which can be varied at local level
Extent to which participants are representative of the GP population.	Reported as 'Total eligible population is included'
Data items collected about the GP or the practice	Age; sex; practice postcode; number of GPs in practice; number of years in practice; accreditation of practice; practice nurse; business model Capacity to collect additional items about the GP or practice
GPs identifiable	Identifiable at local level only—all state and national level reports are aggregated and no individuals are identifiable
Patient sampling method	No patients participate
Patient consent to participate	Not applicable
Patients identifiable	Not applicable
Data items collected about the patient	None No capacity to collect additional items about the patient if required
Data items collected about the encounter (administrative)	Total number of sessions or care provided for the census week is collected Limited capacity to collect additional administrative items about the encounter if required
Data items collected about the encounter (clinical)	Problem/diagnosis; medication prescribed No capacity to collect additional clinical items about the encounter if required
Linkage of GP and patient data	Not applicable

Extent to which individual problems and managements can be followed over time	Not applicable
Data coding	Not specified
Data coded by	Data coded by software
Accuracy checking of coded data	Some checks made on consistency
Data completeness	More than 97% of variables at least 95% complete
Availability	Reports released annually. Analyses performed by collecting organisation on request to other parties
Data access cost	Free to practices. External requests for data not yet dealt with in policy
Additional comments from survey participant	Sample of survey questions provided
Information available at	<http://www.adgp.com.au/site/index.cfm?display=26837>

Annual Survey of Divisions of General Practice (ASD)

The Primary Health Care Research and Information Services (PHCRIS), based at Flinders University, conducts the ASD on behalf of DoHA. The reporting includes national performance indicators for the AGPN. The results provide an overview of divisions and summarise the broad range of activities they are involved in.

Purpose

As part of their contractual obligations, all divisions of general practice are required to complete the survey, which includes questions about their membership, activities (including population health) and infrastructure for the previous financial year.

Method

A purpose-built web interface was developed for online data entry to improve the timeliness and quality of the information collected. An online consent form provides part of the privacy statement for GP participants. The survey includes all 117 divisions, providing data on support activities, workforce profile of the practices, disease prevention and intervention measures, and chronic disease management.

Advantages

- Excellent potential for collecting nationally representative data, if participation restriction issues are tackled.
- Potential for collecting workforce information.
- Tool can be used with multiple types of software.
- Potential for linkage to other data sources.
- Has capacity to collect additional data elements about the GP and practice or encounter.
- High level of data element completeness.
- Data coded by trained staff.
- Some checking of consistency and reliability.
- Some capacity to assess interventions through 'flagged' targets in divisions' target groups.

Limitations

- Participation of GPs can be restricted by the corporate structure—some employers may not allow participation.
- No patient data are collected and there is no capacity to do so.
- Minimal encounter data are collected currently.
- No ethics approval.
- Still partly paper based.

Project/collection	Annual survey of divisions of general practice
Operating organisation	Primary Health Care Research and Information Service for the AGPN (an academic institution)
Purpose	Division support activities for general practice, workforce profile, disease prevention and intervention, and chronic disease management
Data collected from	Divisions of general practices
Data collected about	All GP divisions
Data collection period	Start date unspecified—ongoing
Design method	Periodic longitudinal
Physical data collection method	Partly paper-based, partly desktop-based Internet-hosted survey in future
Types/brands of clinical software used	Various—none specified
Data extraction tool used	Various—none specified
Compatibility of data extraction tool with more than one type of software	Tools can be used with more than one type of software
Potential for alteration of tool for use with other software	Not applicable
Data format	Free text plus check box
Data linked to other sources	No
Data linkable to other sources	Yes
Size	117 divisions; 22,564 GPs; 0 patients
Ethics approval	No
GP sampling method	National—opportunistic sampling of practices within each division. All types of GPs included, but not all GPs working for private corporate clinics may participate. Participants can include individual GPs, multiple GPs from a practice or all GPs from a practice
GP consent to participate	Participation is a contractual requirement with DoHA. Neither written nor verbal consent is specifically obtained
Level of consent	Participants are informed individually of data collection, the storage of data in a database and the uses of the data. Online consent form includes privacy statement, which can be varied at local level
Extent to which participants are representative of the GP population.	Total eligible population is included
Data items collected about the GP or the practice	Sex; number of GPs in practice; practice nurse; business model; allied health professional employed Capacity to collect additional items about the GP or practice
GPs identifiable	Identifiable only through divisions with their consent
Patient sampling method	No patients participate
Patient consent to participate	Not applicable

Patients identifiable	Not applicable
Data items collected about the patient	None, but the types of health prevention interventions made, and chronic disease management intervention levels are extensively described without identification. In general, sufficient information only to flag individuals who may belong to divisions' targeted groups (migrants, Indigenous, refugees, domestic violence, homeless, mental health, and so on) to assess interventions No capacity to collect additional items about individual patients if required
Data items collected about the encounter (administrative)	Data on after-hours services are collected Capacity to collect additional administrative items about the encounter if required
Data items collected about the encounter (clinical)	Some referral trends Capacity to collect additional clinical items about the encounter if required
Linkage of GP and patient data	Not applicable
Extent to which individual problems and managements can be followed over time	Not applicable
Data coding	No information provided
Data coded by	Division staff with training in coding
Accuracy checking of coded data	Some checks made on consistency and reliability
Data completeness	80–97% of variables at least 95% complete
Availability	Reports released annually via PHCRIS annual report and their website. Reports and data are available to other parties—data searchable on website. Raw data available to participants only. Analyses performed by collecting organisation on request to other parties
Data access cost	Free to all parties
Additional comments from survey participant	Sample of survey questions can be provided
Information available at	<http://www.phcris.org.au/products/asd/results/05_06.php>

Past and future collections

In addition to the survey responses received, there are two collections for which survey responses were not received, but which are presented here for completeness. These are MEDIC-GP—a collection that is no longer active—and the Northern Territory Aboriginal Health Key Performance Indicators—a collection that is not yet active at the time of writing. The capability of these two collections to assist in evaluating the use of best practice and the performance of good quality health care in a general practice setting was assessed. For each, there is a brief description with a tabulated list of the collection's scope and coverage and relevant data items. Collection methodology, and any particular advantages or limitations associated with each data source, are presented to replicate a similar format to the above collections.

Medical Enquiry Drug Information Centre—General Practice (MEDIC-GP)

The Medical Enquiry Drug Information Centre—General Practice (MEDIC-GP) is a pharmaceutical-related epidemiological database containing anonymous data from computerised Australian general practices. The database is maintained by the Department of General Practice at the University of Adelaide and contains de-identified clinical records covering 10 years from July 1994 to June 2004.

Purpose

In 1996, two academics from the Department of General Practice, University of Adelaide conducted a pilot study testing the viability of creating a database using general practice medical records. Following completion of the study, the collaboration with participating GPs was maintained and additional practices were recruited. The database was designed to incorporate key data elements available from clinical management software used in the general practice setting. The specific data items selected for the database were those considered to have maximum use and application for research purposes, particularly in the study of the use of pharmaceuticals by the population.

Method

Data was extracted from the collaborating practices using standard data extraction and export programs written in collaboration with the medical software providers. Following initial practice approvals, the database project team worked with practice administrative staff to derive the appropriate data extracts. Data were de-identified at the site of the practice and no personal details were collected. Data, once extracted, were processed at a 'safe-house' and provided with new index numbers not related to any practice derived numbers or a patient's date of birth. The records are loaded to the Medic-GP research database, which is located on a local network and unable to be accessed via the web. It is only accessible by authorised individuals.

Advantages

- Patient sample was considered to be representative of Australian general practice patients in terms of age and gender (Beilby et al. 2002).
- Useful in the investigation of research questions from a longitudinal perspective.
- Data dictionary of key terms facilitates comprehensive searching of the database.
- Large data collection over a 10-year period.
- Contains qualitative elements of the GP–patient encounter.

Limitations

- Sample only consists of nine practices, of which more than half were located in South Australia.
- Limited reporting of diagnostic criteria predisposes uncertainty surrounding reliability of the recorded diagnosis (Wilson 2003).
- Data collection ceased in June 2004.

Project/collection	**Medical Enquiry Drug Information Centre—General Practice (MEDIC-GP)**
Operating organisation	The Data Analysis Unit (DAU) in the Discipline of General Practice at the University of Adelaide maintains the Medic-GP database
Purpose	To establish a database incorporating key data elements from general practice medical software to enable research into pharmacoepidemiology
Data collected from	Nine computerised general practices in four states
Data collected about	Clinical encounter data from patients of participating doctors/practices
Data collection period	July 1994 to June 2004. Currently no plans to collect additional data.
Physical data collection method	Extraction from electronic records
Types/brands of clinical software used	Various clinical software programs

Data extraction tool	Extracted using standard data extraction and export programs, and processed before being integrated into the Medic GP database
Compatibility of data extraction tool with more than one type of software	The data are extracted using standard data extraction and export programs that were developed in conjunction with, and to suit, various software providers and their programs
Size	150 GPs 99,000 patients and 2 million clinical records
Data items collected	Encounter patient demographics—age, sex subjective and objective information assessment of problem treatment plan allergies and adverse reactions symptoms, comorbidities specialist referrals blood pressure, weight Laboratory pathology tests Radiology diagnostic imaging Prescribing medications
Availability	Following appropriate approvals, third parties may be provided with secondary text files or databases arising from the validation process associated with a particular project Initial applications are considered by the project group and examined for feasibility. Access to the data is determined by the project group
Data access cost	Costs associated with undertaking a particular investigation are on a cost-recovery basis, determined by the scope of the question, the extent of programming and validation required, and the time taken. In addition there is provision for amortised fixed costs of computer hardware and software, university administrative fees and a 'practices levy and data usage' payment, which represents some remuneration for general practices participating in the Medic-GP project
Information available at	<www.adelaide.edu.au/health/gp/units/medic-gp>

Northern Territory Aboriginal Health Key Performance Indicators (NT AHKPI)

The NT AHKPI system is a collaboration between the NT Aboriginal Health Forum (AHF) partners to develop a Northern Territory-wide primary health care performance reporting system for capturing and reporting Northern Territory Aboriginal primary health care KPI data. The collection is due to commence in July 2008.

Purpose

The KPI have been developed to provide information to support health centres in their planning activities and evidence-based reporting needs. The collection and analysis of KPI data on behalf of all health providers in the NT will assist in informing understanding of trends in individual and population health outcomes and recognising factors influencing these trends. The data will assist in informing appropriate action, planning and policy development to improve the health of Indigenous residents of the Northern Territory.

Method

Information will be obtained from more than 20 of the community health centres managed by the Department of Health and Community Services (DHCS) in the Northern Territory. The method of collection of KPI information is based around the process used for collecting client information. For medical electronic information systems, the AH KPI group is working towards making this as automated as possible, although for health centres using a paper system to collect KPI data, the AH KPI Interim Data Collection Tool is designed to assist them. The Interim Data Collection Tool is to be implemented in community health centres in remote areas until replaced by the Primary Care Information System (PCIS), currently being rolled out to all DHCS remote health centres.

Advantages

- Will assist in informing understanding of trends in health outcomes in Aboriginal communities, and recognising the factors influencing these trends.
- Can provide information on the quality of health care in remote Indigenous communities.
- Intended to provide a minimum data set on Northern Territory Indigenous population health care.

Limitations

- Data collection is limited to the state-operated community health centres.
- Aggregated data includes consultations with persons other than GPs, mainly Aboriginal health workers, which affects comparability with other primary health care data collections.

Project/collection	**NT AHKPI**
Operating organisation	The Aboriginal Health Forum (AHF) comprising of representatives from the DoHA, Aboriginal Medical Services Alliance (AMSANT) and Northern Territory DHCS
Purpose	Provide key indicator data to facilitate evidence-based reporting
Data collected from	NT Community Health Centres
Data collected about	Clients of NT community health centres
Data collection period	Data collection is due to commence in July 2008
Physical data collection method	Automated or web-based data collection, as possible
Types/brands of clinical software used	Not determined
Data extraction tool	Using an interim data collection tool until the Primary Care Information System (PCIS) is rolled out
Compatibility of data extraction tool with more than one type of software	Not determined
Size	Expected to be relatively small as it will be aggregated data
Data items collected	patient demographics (sex, age group, Indigenous status) locality (establishment) and reporting period Indicators reported: number of service contacts x gender x age group x Indigenous status x locality number and proportion of women attending first antenatal visit before 13 and before 20 weeks gestation number and proportion of low birth weight babies (less than 2,500g) proportion of children fully immunised at 1, 2 and 6 years of age x locality x Indigenous status number and proportion of children less than 5 years of age who are underweight x client population

Data items collected (cont'd)	number and proportion of children between 6 months and 5 years of age who are anaemic proportion of resident clients age 15 years and over with a preventable chronic disease who have had an EPC item 720 claimed in the previous year proportion of resident clients with diabetes who have had at least one HbA1c within the last 12 months proportion of diabetic patients with albuminuria who are on an ACE inhibitor number of resident clients 15–55 years who undertook a well person's screen during the past 2 years x age group x gender x locality (Pap smears, STI, chronic disease) proportion of residents over 55 years who have had a full adult health check in the past 12 months x gender x locality proportion of resident women having PAP tests for cervical cancer in the previous 24-month period for the target group 18–69 years x locality
Availability	Access to be through NT Aboriginal Health Forum Data access protocols are being developed
Data access cost	NA
Information available at	<www.nt.gov.au/health/ahkpi>