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Australian Institute of Health and Welfare
Department of Health and Ageing

Review and evaluation of Australian information about primary health care

A focus on general practice

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Executive summary

Primary health care is the cornerstone of the Australian health-care system, and general practice is its central component. It is vital, therefore, that accurate, reliable and timely information is available to assess the quality, effectiveness and outcomes of services provided in general practice. Such information is essential for:

- determining the need for services
- highlighting inequities in access and outcomes
- assessing the uptake of best-practice guidelines and evidence-based practices
- evaluating the outcomes of interventions
- providing practitioners with evidence for clinical decision making
- informing policy and strategy development.

Although several Australian collections contain information relevant to general practice, the extent and usefulness of these data for meeting priority information needs is variable. In order to improve the data environment, take advantage of advances in information technology and build on the capabilities of existing data collection systems, we need to take stock of what exists now, consider what is needed for the future, and determine the most effective and efficient ways of moving forward.

This report provides a review and evaluation of current data collections and methods. The evaluation considers not only the quality and breadth of the data items collected, but also looks more broadly at the usefulness of the data with regard to meeting the information needs of stakeholders. The report highlights gaps and limitations in the currently available data, and suggests strategies for improving the quality and usefulness of information about general practice in Australia. In addition, it outlines methods currently being used to collect general practice data electronically, and establishes options for further investigation.

Main findings

Usefulness of existing collections

- Data that are able to be used to build a comprehensive picture of the care provided in general practice are limited.
- At the national level, 'quality' is currently only able to be assessed in specific circumstances and for particular health conditions (for example, tracking the annual cycle of care for diabetes).
- To enable thorough investigation of general practice care, data should:
  - be able to be analysed at the individual patient level
  - link each management action (such as a prescription, clinical procedure, pathology or imaging request) to a diagnosis or symptom pattern
  - be able to be linked to allow tracking of presenting problems and management actions over time and to examine patient outcomes.

Options for future collection of general practice data

- Several collections use electronic methods to collect data from or about general practice. These include CONDUIT (Collaborative Network and Data Using IT), GPRN (the General Practice Research Network), the Australian Primary Care Collaboratives, ASPREN (the Australian Sentinel Practices Research Network) and the GP Census.
- The types of electronic methods in use by CONDUIT and GPRN appear to be useful starting points for exploring a national electronic data collection (though some important limitations need to be overcome).
- The CONDUIT system has great potential in that it enables linkage and transfer of clinical records between different health providers and services.
- The experiences and expertise of the groups involved in other collections, such as MEDIC-GP (Medical Enquiry Drug Information Centre—General Practice), BEACH (Bettering the Evaluation and Care of Health) and the Practice Health Atlas, can provide valuable insights to inform decisions about the way forward.
- Collections other than those containing GP–patient encounter data also provide useful information, such as patient satisfaction, functioning and quality of life, and reasons for seeking, or not seeking, care.
- Contextual information, such as workforce data and information about access to care, is necessary to aid interpretation of clinical data.

Enabling the transition to electronic collection

- There is a need for a set of principles around the collection and use of general practice data, covering implementation, data access and use, governance, and resourcing.
- Several important issues need to be tackled before electronic collection of general practice data could be implemented in Australia, including adoption of standards and resolution of legal and ethical issues (such as privacy and consent).
- Internationally, countries that have been more successful in introducing electronic patient records have been those that have had standards, protocols and infrastructure in place at an early stage.
- The low rate of uptake of electronic clinical record keeping in Australian general practices will limit the number of GPs able to participate in electronic data collection.
- GP groups expressed a willingness to participate in data collection, but need to be convinced of the usefulness of the data in terms of informing policy decisions or improving health outcomes or practices.

Recommendations

- A minimum data set specification for GP–patient encounters should be defined, in consultation with all stakeholders, which builds on work already undertaken in this area.
- The options established as potential starting points for an electronic collection should be explored with all stakeholders to formulate an agreed approach for implementing collection of this minimum data set at the national level.
- Where existing collections provide useful data, they should continue to be supported during the transition period and, where appropriate, afterwards.

1 Background and purpose

Decisions about health policy and practice in Australia are informed by data from a wide variety of sources—from financial and administrative records, to large population health surveys, to clinical research studies. Although there are many data collections that contain information relevant to certain aspects of health care—for example, financing and throughput—information relating to issues of performance, effectiveness and quality is less readily available. This makes it difficult to explore performance and quality issues, to develop evidence-based policy and to evaluate the effectiveness of the Australian health-care system.

Primary care is the cornerstone of the Australian health-care system, but comprehensive information about the services provided in primary care is lacking. A discussion in October 2006 between representatives from the Australian Government Department of Health and Ageing (DoHA), the Australian Institute of Health and Welfare (AIHW) and the Australian Commission on Safety and Quality in Health Care (ACSQHC) outlined some of the data issues that need to be tackled in primary health care, with a particular focus on general practice. The need for data to evaluate the extent and quality of primary health care services, compared with best-practice recommendations, was established as a priority.

The AIHW is involved in several pieces of work that either affect, or are affected by, the extent and quality of information available about general practice in Australia. The Health and Hospitals Reform Commission is developing performance indicators across the health system; the ACSQHC is developing indicators of safety and quality across the health system; and the National e-Health Transition Authority is developing an interoperability framework, unique identifiers and other standards to enable the development and use of electronic health records. This is, therefore, an opportune time to review the ways information about primary health care services is collected and used, to establish priority information needs and to investigate options for making the transition to an electronic collection system. This will help to ensure that primary health care information can be harnessed and used to its full capacity in the future—both for clinical purposes and for assessing performance, quality and effectiveness.

The main aim of this report is to inform discussion and decision making regarding the transition to electronic collection of general practice data by providing a review and evaluation of current data collections and methods. The evaluation not only considers the quality and breadth of the data items collected, but looks more broadly at the usefulness of the data with regard to meeting the information needs of stakeholders and assessing the quality and effectiveness of general practice services in relation to best-practice recommendations. The report highlights gaps and limitations in the currently available data, and suggests strategies for improving the quality and usefulness of information about general practice in Australia. In addition, it outlines methods currently being used to collect general practice data electronically, and identifies options for further investigation.

What is primary health care?

Primary care is the care that people around Australia receive from general medical and dental practitioners and Indigenous health workers (and the nurses that work with them) as well as from local pharmacists and other allied health professionals working ‘in the community’ (as opposed to those working in hospitals or other institutions). It is called primary health care because it is usually more basic and first-line than the care given by other parts of the health system, such as hospitals and specialist doctors. It is also primary in the sense that the health professionals involved are usually the first point of contact that Australians have with the health system. The DoHA, in its report *General practice in Australia: 2004*, define primary health care as:

> '… health care provided by the medical professional with whom the patient has initial contact. The category excludes hospital or institutional care and rehabilitation.' (DoHA 2005)

Although hospitals may provide some services that are similar to primary care, in this report the term will not apply to any hospital or other institutional care.

Primary care and the broader health-care framework

The primary health-care system does not operate in isolation. It is part of a larger system involving other services and sectors (Figure 1.1). But primary health care, particularly general practice, is traditionally seen as the 'gateway' to the wider health system. Through assessment and referral, individuals are directed both from one primary care service to another, and from primary services into secondary and tertiary services (such as specialist, hospital and palliative care services) and back again. In this way, general practitioners (GPs) can be coordinators of ongoing and comprehensive health care over an individual's lifetime.

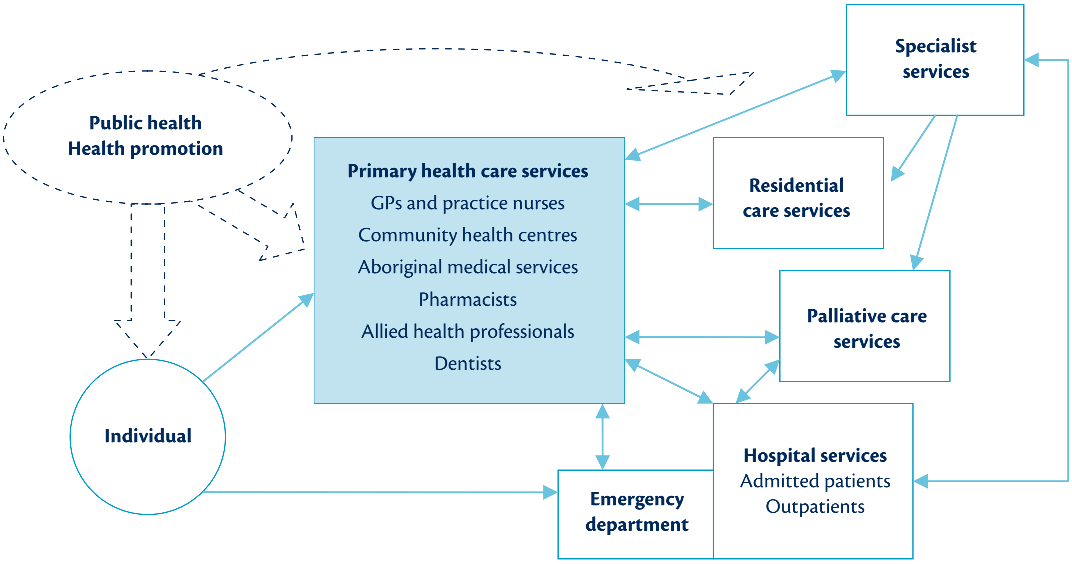
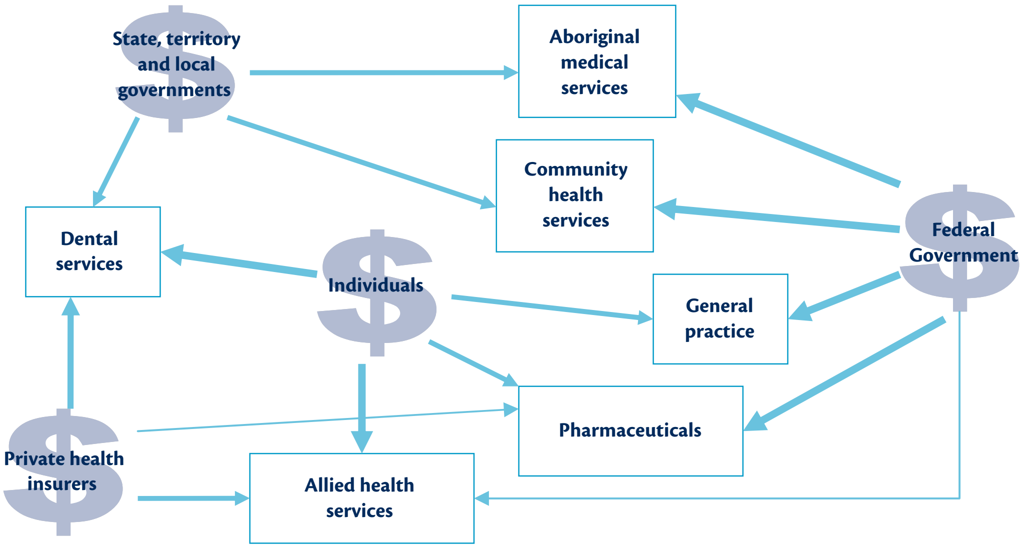


Figure 1.1: The role of primary health care in the Australian health system: a simplified framework

This structure does, however, pose problems for collecting, collating and interpreting data about health care in the Australian context. The administration of different parts of the Australian health system—and even different providers within each type of service—is spread across various levels of government and between the public and private sectors. For example, consider the complexity of funding for primary health care services (Figure 1.2). Each service type is supported by at least two sources of funds, which means that relevant administrative data are often not centrally collected. Governance of data about health services is also spread across a variety of organisations and levels of government. This can make effective monitoring difficult.



Note: The thickness of arrows suggests the relative contribution of funders (majority of funds, moderate or small proportion), but is not to scale. The contributions made by private enterprises (such as for employer-funded health checks) are not noted here, but may be substantial in some cases.

Figure 1.2: Who pays for primary health care services in Australia?

The importance of a good primary health-care system

Primary health care is important because it:

- supports health improvement and provides illness care, and is often the gateway to other health and human services
- incorporates health-promotion and disease-prevention activities, and helps people with chronic conditions to manage their own health
- can coordinate care and help patients to navigate the wider health and human services system
- can help to build community capacity by working with other sectors such as education, justice and housing, and by reaching out to vulnerable populations and people with special needs (CIHI 2006a).

International research has shown that a strong primary health-care system is associated with improved population health, decreased health costs, appropriate care and positive health outcomes (Macinko et al. 2003; Starfield & Shi 2002). These positive health outcomes include: reduced mortality overall, particularly from heart disease, cancer and stroke; lower infant mortality rates; increased life expectancy; and a smaller number of low birthweight babies (Shi et al. 2005; Shi et al. 2003; Shi et al. 2004b). The existence of primary health care services (compared with only specialised services) is also associated with reduced health inequities, and has a moderating effect on race- and income-related health differentials (Shi et al. 2004a; Shi et al. 2005; Starfield et al. 2005).

The need for data about primary health care

Providing and maintaining an effective primary health-care system requires information—'you can't manage what you can't measure' (CIHI 2006b). For example, basic service delivery planning demands information about the types of services required, where these services need to be located, who needs them and for what purposes. And, to fund these services, Australia's universal health insurance scheme, Medicare, requires details of the particular services that are provided, by whom, where and to whom.

But, although information about throughput, costs and need enables primary health care services to be delivered, it cannot tell us whether the services being delivered are equitable, of good quality—that is, safe, appropriate, effective, and based on the best available evidence—and result in good health outcomes for patients. This requires more detailed information about the interactions between primary health-care professionals and their patients, such as the patients' reasons for seeking care, the treatments provided, and the outcomes.

Having reliable, accurate and comprehensive data about health-care services can improve the quality of care and lead to better health outcomes because:

- it helps to highlight areas of need for more or different types of services (for example, services equipped to deal with particular health conditions, age groups, and cultural or language groups)
- it can highlight inequalities and inequities in access to and outcomes of care
- it helps in assessing the uptake of guidelines and evidence-based practices, and to evaluate the effects these practices have on patient outcomes, as well as other consequences (for example, increased or decreased consultation times, cost or practitioner workload)
- it can help to detect barriers to and facilitators of the uptake of best-practice patterns of care
- it can help to recognise changes in practice and consequent changes in outcomes
- it can inform evidence-based policy and strategy decisions
- it provides practitioners with the ability to make appropriate decisions and provide high-quality care.

Obtaining data about general practice

GPs are central to Australia's health system. They are the first port of call for the majority of Australians, and act as points of referral to and coordination of many aspects of secondary and tertiary care. Around 80% of Australians visit a GP at least once each year (Medicare Australia 2007). Services provided by GPs are partly funded by the Australian Government through the Medicare Benefits Scheme.

Several existing data collections provide information about general practice services in Australia, ranging from basic throughput data to detailed information about the conditions managed and treatments provided. A variety of sampling strategies (both paper-based and electronic) are used to obtain this information. Although useful for a variety of purposes, the resulting data are limited in their ability to provide a comprehensive picture of general practice activity—particularly in relation to the quality of care.

An alternative source of information about general practice activity are the data generated by GPs in their practices. These include not only diagnostic information but also the services provided, the disease management strategies used and the overall health profile of the patients. In addition, other administrative data (such as business type, hours worked, and practitioner and patient demographics) are also generated. For a variety of reasons, however, most of this information does not become available to researchers, service planners or policy makers.

This report presents the results of two streams of work: a review and evaluation of existing data collections, and a review of current electronic data collection methods. Together, these two streams of work will inform discussions and decisions about the collection of general practice activity data in the future.

Major stakeholders

Many groups within Australia have an interest in obtaining comprehensive, reliable data about the quality of primary health-care services. These range from government departments, which fund some of these services and create relevant policies and strategies, to professional bodies such as the Royal Australian College of General Practitioners (RACGP), which set standards for practitioners and provide professional development opportunities, to consumers, who want to know that they and their families are receiving the best possible care.

For this evaluation of data collections, the information needs and expert views of a range of stakeholder groups were considered. These groups included:

- the DoHA
- the ACSQHC
- the National E-Health Transition Authority (NeHTA)
- the RACGP
- the Australian General Practice Network (AGPN—formerly the Australian Divisions of General Practice)
- individual divisions of general practice
- academic research units
- the Australian Medical Association
- consumers.

A complete listing of all parties who participated in consultations is provided at Appendix 2.

The e-health agenda

Electronic health information (e-health) systems have the potential to improve the quality of health care in Australia by enabling secure, complete and timely transfer of clinical and administrative information between health-care providers. Providers would be able to access relevant information (for example, medical history, allergies and current medications) at the time of care in order to make the safest and most appropriate decisions about individuals' management and treatment. The addition of new information to the electronic record at the time of care would enable accurate and timely communication between all members of the health-care team.

Although the structure and content of a shared electronic health record (sEHR) for Australia is as yet unclear, the information could also be a valuable resource for research and quality assurance purposes. The ability to capture information connecting diagnosis, treatment, referral and outcomes over time, and between different levels and sectors of the health system, would allow analysts to build comprehensive pictures of the factors affecting service needs and patient outcomes, such as:

- the effectiveness of different treatment patterns
- variation in treatment patterns between regions or patient groups
- variation in rates of disease between regions or patient groups
- areas of need for certain services or medical specialties
- changes in practice
- implementation of new guidelines or policies.

Although this information has the potential to be of great value, it is unclear whether wholesale capture of electronic health records across the population would be a feasible, practical or effective way to obtain it. But, regardless of whether a national and universally available sEHR is created in the future, the data captured within general practice clinical software systems—some of which are already being used for statistical and research purposes—have the potential to be a rich source of national information. A review of methods of electronic data collection is required to inform future decisions about what and how much information will be useful, and to support a transition from paper-based to electronic data collection about general practice.

Aim, scope and structure of this report

For the purposes of this report, a goal for primary health care information in Australia is that, within 5 years, timely, reliable and accurate data will be available for monitoring outcomes, effectiveness, quality, safety, cost/benefit and value of services provided by the primary health care sector.

Achieving this goal requires:

- a review and evaluation of current data collections and methods
- a needs analysis to identify additional requirements
- investigation of the various options for future electronic data collection, taking into account established gaps and deficiencies
- national consultation with relevant stakeholders to determine the best way forward.

This report aims to contribute to progress towards this goal by providing a review and evaluation of current data collections and methods, to inform the transition to electronic collection of general practice data. In the process, some of the additional requirements and needs of stakeholders were established, but a formal needs analysis was not undertaken. Greater consultation with a broad range of interested parties is required to inform decisions about future needs for, and collection of, primary health care information.

Scope

The wide range of health professionals and services encompassed by the term ‘primary health care’, and the short time frame allowed for this review and evaluation of data sources, limited the scope of the work. The remainder of this report—including the review and evaluation of data sources, identification of gaps and review of electronic collection methods—is therefore focused on services provided in general practice. Some data about the interface between general practice and related services, such as pathology and imaging, is incorporated where relevant and practical.

Structure of this report

A systematic approach was taken to critically evaluate the suitability and validity of existing data collections by focusing on the ability of these collections to assist in answering questions about general practice.

Chapters 2 and 3 summarise the outcomes of the review of data collections. Chapter 2 describes current paper-based and administrative collections. Structured descriptions of the data collections—including their purpose, scope, coverage, regularity and the particular data items collected—are given. Some information about specific limitations relating to each collection's methodology, sample frame or particular data items is also provided. Chapter 3 provides more detailed information about the methods used to collect data electronically, as well as summarising how other countries collect general practice data electronically.

Chapter 4 presents a criteria-based evaluation of the existing paper-based and electronic data collections. The criteria development process, including establishment of data needs and outcomes of discussions with relevant stakeholders, is described and the results of the evaluation are presented. A more focused evaluation, based on GP–patient encounter scenarios, is described in Chapter 5.

Finally, Chapter 6 summarises the evaluation results, and highlights issues that should be considered when developing an electronic data collection. The chapter describes an 'ideal scenario' for electronic data collection in general practice: establishing the differences between this ideal scenario and current practice and suggesting what might need to be done to overcome these. Recommendations are made for rectifying some of the gaps, limitations and deficiencies in the existing data, and for progressing towards electronic collection of general practice activity data at the national level.

2 Review of current paper-based, administrative and CATI data collections

Currently in Australia there is a paucity of data collections incorporating detailed records that can assist in determining the use of evidence-based medicine in the general practice environment. This chapter presents an overview of various paper-based, administrative and computer-assisted telephone interview (CATI) data sources involved in the collection of primary health care information. Electronic data sources are covered in Chapter 3.

A systematic review of existing data collections was conducted to identify sources containing data that might be helpful in understanding the use of evidence-based practices and improving the quality of care. This approach entailed assessing the collection's ability to describe the use of best practice and good quality health care. Many of the collections' contact persons or custodians were able to assist by providing updates of their collection's data items, current size and additional information not available in published form or on relevant websites.

Included in this section are national surveys such as the GP-centred Bettering the Evaluation and Care of Health (BEACH) survey and the population-based National Health Survey, along with administrative sources such as the Medical Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS). Various other paper-based collections, state-based and research-centred sources are also described.

For each collection, there is a brief description followed by a tabulated list of the collection's scope and coverage, and relevant data items. Where possible, this metadata has been sourced directly from the data collection to ensure its accurate representation. The methodology and any particular advantages or limitations associated with each collection are presented to illustrate its role in the collection of data about general practice.

Brief overviews of several other data collections are provided at the end of the chapter. Although these collections do not provide the same level of information about general practice services as those described in more detail (for example, because they relate to a small geographic area or a particular health issue), they do provide some valuable information.

To help comparisons to be made between the collections covered in this chapter and the next, Table A3.1 (in Appendix 3) presents a summary of each data collection's information, purpose, advantages and limitations. Table A3.2 provides a summary of the type, size and period of coverage of each collection, and provides relevant contact details.

GP–patient encounter collections

Bettering the Evaluation And Care of Health (BEACH)

BEACH is a continuous paper-based survey of general practice activity in Australia. It is conducted by the Australian General Practice Statistics and Classification Centre (AGPSCC)—a collaborating centre of the AIHW and the University of Sydney. BEACH commenced in April 1998 and has collected information on more than 1,000,000 encounters since then.

Purpose

BEACH data presents the GP's management of patients, providing information on the prescriptions, referrals and investigations conducted by the GP for each patient, considered in the context of the problem being managed. The continuous nature of the survey has resulted in a growing database of information on GP–patient encounters.

Method

BEACH data are collected from a random sample of GPs using a paper-based survey form, and each participating GP is required to provide details for 100 consecutive GP–patient encounters. The selection of participants is taken from a random sample of GPs who have claimed at least 375 general practice Medicare items in the previous 3 months. The BEACH program has tried to involve around 1,000 GPs each year. In 2006–07, more than 900 GPs (representing 31.1% of those who were contacted and were currently practising in Australia) provided details on 101,700 encounters.

Information on specific topics not covered by the consultation-based data is collected through SAND (Supplementary Analysis of Nominated Data) sub-studies. Each sub-study comprises a series of additional questions answered by around 100 GPs (resulting in a sample of 3,000–4,000 'patients' for each sub-study).

Advantages

- Continuous, detailed information on health care encounters.
- Large database suited to time-series analysis.
- Random sample of GPs that is constantly changing.
- Direct link from the actions taken by the GP (for example, prescribing, ordering tests) to the problem being managed.
- Includes all patient encounters, regardless of Medicare coverage.
- Medication data include all prescriptions—prescribed, supplied and advised for over-the-counter purchase—regardless of PBS eligibility.
- Includes non-pharmacological treatments such as clinical counselling and procedures.

Limitations

- No facility for longitudinal analysis of individual patient records.
- GPs who do not register 375 Medicare items in 3 months are excluded from the survey.
- In the 2006–07 collection, and all previous years excluding 2004–05, there was an under-representation of younger GPs (aged <35 years).
- Low response rates to the survey (31.3% on average).

Data collection	**BEACH**
Collection owner	AGPSCC
Information source	GP-reported information about clinical encounters with patients

Data items	**Encounter data** date and type of consultation Medicare/DVA item number specified other payment **Patient data** date of birth sex postcode HCC/DVA concession card non-English speaking background (NESB) Indigenous status patient reasons for encounter (up to three) **Content of encounter** problems managed and their status (new or continuing). treatment and/or medications prescribed, GP supplied or advised for OTC purchase other treatments including counselling, education, and whether provided by practice nurse new referrals to specialists, allied health or hospital investigations (pathology tests, imaging, other) **GP characteristics** age and sex years in practice number of GP sessions worked per week number of GPs in the practice major practice postcode country of graduation training and FRACGP status after-hours availability computer use hours worked in direct patient care and hours on call per week.
Scope and coverage	Random sample of 1,000 GPs who claimed at least 375 general practice Medicare items in the previous 3 months
Frequency	Operating since 1998–99, BEACH is an ongoing annual survey with around 20 GPs providing data each week
Size	1,000 GPs per year, 100,000 GP–patient encounters per year 1,000,000+ encounters in total since 1998 from approximately 10,000 GPs
Availability	Standard reports may be purchased, annual summary reports are available online at no cost
Data access cost	Charges are payable according to the nature of the request
Selected publications	Britt et al. 2008. General practice activity in Australia 2007–08. Cat. no. GEP 22. Canberra: AIHW.
Further information	<www.fmrc.org.au/beach.htm>

Population health survey collections

Australian Longitudinal Study on Women's Health (ALSWH)

The ALSWH is a paper-based, longitudinal population survey that commenced in 1996 and is examining the health of over 40,000 Australian women over a 20-year period. It is conducted by the University of Newcastle and University of Queensland.

Purpose

The survey looks at the lifestyles, health and other factors affecting the physical and emotional health of women in Australia and assesses their use of health services, including GP, specialist and complementary medicine services, as well as medication use. The information collected can be used to assist in establishing the social, psychological, physical and environmental factors that determine good health and those that cause ill-health, in adult females. As well as providing an opportunity for Australian women to have a say about health and health services available, it provides a national research resource on women's health issues.

ALSWH participants are invited to consent to having their survey responses linked with records on the Medicare Australia databases. The Medicare data include information such as the number of GP visits and service costs, but do not contain any clinical or diagnostic information. The opportunity to link these data sets will enable researchers using the data to draw more accurate conclusions than they might if the individual data were used in isolation. This has the potential to make a significant contribution to the understanding of factors influencing health and wellbeing and the use of medications, and to provide assistance in the ongoing evaluation of women's health services.

Method

In April 1996, three age groups of women (18–23 years, 45–50 years and 70–75 years) selected from the Medicare database were sent an invitation to participate in a 20-year study of health and health service use. Over 40,000 women responded and agreed to participate in the project. The three age groups were selected so that women could be followed through the life stages critical to their health and wellbeing. Each age cohort is surveyed once every 3 years using a paper-based postal form. Sampling was random within each age group, except that women from rural and remote areas were sampled at twice the rate of women in urban areas.

Advantages

- Linkage of self-reported data (for consenting individuals) with PBS and MBS data.
- Provides information about use of over-the-counter (OTC) medications.
- Over-sampling in rural and remote areas enables comparisons.
- The longitudinal study design provides the chance to clarify cause-and-effect relationships and assess the effects of changes in policy and practice.
- Response rates of more than 70% were achieved for each cohort's most recent survey.

Limitations

- Response bias—over-representation of tertiary-educated women and under-representation of women from non-English speaking countries.
- Volunteer bias—women who consented to MBS/PBS data linkage in all three age cohorts tended to be better educated and better able to manage financially.
- For linked data, the reduced sample size means that data related to less common conditions, services or medications is not adequate for in-depth analysis.
- Survey of the health needs and practices of women only.
- Recall bias—questionnaire responses are self-reported.

Data collection	**ALSWH**
Collection owner	Data are held in trust by University of Newcastle and University of Queensland
Information source	Longitudinal population-based postal surveys
Data items	**Demographics** country of birth; marital status; education; employment status; income; Indigenous status **Health service use** GP visits in last 12 months diagnoses symptoms and seeking help number and purpose of medications GP (or other) advice on lifestyle change serious illnesses vaccinations specialist and allied health items GP patterns of use female GP health service access GP satisfaction GP cost blood pressure check and cholesterol check **Physical and emotional health** wellbeing, major diagnoses, symptoms **Health behaviours and risk factors** diet, exercise, smoking, alcohol, other drugs **Time use** paid and unpaid work, family roles and leisure **Sociodemographic factors** location, education, employment, family composition **Life stages and key events** e.g. childbirth, divorce, widowhood
Scope and coverage	Women (Australian citizens or permanent residents) selected from the Medicare database and invited to participate Over-sampling in rural/remote areas
Frequency	Ongoing since 1996. Each cohort is surveyed in turn at 3-yearly intervals
Size	Ongoing collection involving around 40,000 women surveyed once every 3 years
Availability	Data may be made available to collaborating researchers where there is a formal request to make use of the material. Permission to use the data must be obtained from the Publications Substudies and Analyses Committee of ALSWH. Data are provided specifically for the analysis described in the request
Data access cost	$100 for each request
Selected publications	Lee C (ed.) 2001. Women's health Australia: what do we know? what do we need to know? Progress on the Australian Longitudinal Study of Women's Health 1995–2000. Brisbane: Australian Academic Press. Various research publications are available and are listed on the ALSWH website
Further information	<www.alswh.org.au>

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

The AusDiab is a population-based cross-sectional survey of national diabetes, obesity, hypertension and kidney disease prevalence, along with associated risk factors, in people aged 25 years and over. It is operated by the International Diabetes Institute in Melbourne. The baseline survey was conducted between May 1999 and December 2000 and a follow-up survey of those who completed the baseline survey was conducted in 2004–05, providing information on incidence rates of diabetes over the 5-year period.

Purpose

AusDiab was established to examine the natural history of diabetes, pre-diabetes (where glucose metabolism is impaired, but not to the level to cause diabetes), heart disease and kidney disease. It was designed to be representative of the general Australian population aged over 25 years. The follow-up survey conducted in 2004–05 presented data on the number of new cases of diabetes, cardiovascular disease and kidney disease over the preceding 5 years, and may assist in the understanding of the factors that increase the risk of these conditions.

Plans are underway for a 10-year follow-up of the AusDiab participants in 2009–10, which provides an ideal opportunity to gauge the changing impact that diabetes, heart disease and kidney disease have on the Australian population. This follow-up will involve the researchers re-visiting all participants—and recruiting another cohort—to again benchmark the nation's health and map the impact these diseases have on the wider community. It will also allow comparisons to be made with the baseline results on the prevalence of diabetes and related conditions, such as obesity and kidney disease.

Method

More than 28,000 households within randomly selected clusters of census collection districts were invited to participate in the survey, of which around 11,480 agreed. Of the 20,000 plus eligible people from these participating households who completed a household interview, more than 11,000 attended the biomedical examination. Of these original participants, 6,500 returned for the follow-up survey 5 years later in 2004–05.

The study consisted of questionnaires and physical tests (oral glucose tolerance test (OGTT), standard anthropometric tests, blood pressure measurements). A team of researchers went to the randomly selected urban and rural testing sites around Australia to individually test each of the 11,000 or more individuals who participated in the baseline study in 1999–00 and those who participated in 2004–05. In addition, self-reported health information was obtained from more than 2,000 of those participants in 1999–00 who could not attend the survey site.

Advantages

- Large national diabetes prevalence study.
- Incorporates biomedical measurements in the study.
- Useful for limited longitudinal analysis on diabetes and related conditions.
- Provides data on the prevalence and possible causes of diabetes.
- Establishes possible risk factors leading to diabetes.
- Excellent response rate (99.6%) to initial household questionnaire component in 1999–2000.

- Good response rates to the follow-up survey in 2004–05 (around 82%, with 62% attending for physical tests compared with 55% in 1999–2000).

Limitations

- Younger age respondents under-represented, middle and older age groups over-represented at the biomedical examination.
- Purpose-designed to collect diabetes-related data.
- Recall bias—questionnaire responses are self-reported.

Data collection	**AusDiab**
Collection owner	AusDiab team at the International Diabetes Institute
Information source	Household interview, followed by a biomedical examination
Data items	demographics (sex, age, Indigenous status, education, employment, country of birth) has the respondent ever been tested for diabetes or high sugar levels? when last tested diabetes status has there been a doctor's or nurse's diagnosis of diabetes? has there been a doctor's or nurse's diagnosis of high sugar levels? respondent's age at diagnosis type of diabetes treatment currently taken how often HbA1C (glycated haemoglobin) tested in last 12 months? other chronic health conditions (angina, heart attack, stroke, hypertension) when blood pressure was last tested has respondent ever had cholesterol/triglycerides checked? when cholesterol last checked medication for high BP or high cholesterol/triglycerides has respondent discussed diet or eating habits with GP or other health professional? has respondent discussed exercise, alcohol or quitting smoking with GP or other health professional does person have a regular GP? how often did he or she visit a GP (i) in the last 12 months (ii) in the last 2 weeks
Scope and coverage	Stratified sample of 28,000+ households resulted in 20,000+ Australians aged 25 years or over eligible to participate and 11,000+ physical examination participants
Frequency	Original survey conducted in 1999–2000, followed up in 2004–2005
Size	**1999–00** 20,000 completed interviews 11,247 attended biomedical examinations **2004–05** 6,500 (of the 11,247 from 1999–00) attended biomedical examinations
Availability	Researchers can apply for access to the accumulated data and biological materials and for participation in ongoing and new data collection activities
Data access cost	There are two fees: 1. Cost recovery for the planning, extraction and provision of the data 2. Contribution to the ongoing storage, maintenance and other infrastructure costs of the AusDiab study

Selected publications	Dunstan et al. 2002. The Australian Diabetes, Obesity and Lifestyle Study (AusDiab) methods and response rates. Diabetes Research and Clinical Practice 57:119–29. In excess of 50 published papers have used AusDiab data
Further information	<www.diabetes.com.au>

National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)

The NATSIHS is conducted every 6 years by the Australian Bureau of Statistics (ABS). The most recent survey was conducted between August 2004 and July 2005.

Purpose

Information was collected in the survey about the health status of Indigenous Australians, their use of health services and health-related aspects of their lifestyle. Information, relevant to the nature of this project, was collected about long-term medical conditions of participants, recent injury events, consultations with health professionals, other actions people had recently taken in regard to their health (such as medication or days away from work), and lifestyle factors affecting their health, such as smoking, alcohol consumption, diet, physical activity and immunisation.

Method

Information in the 2004–05 NATSIHS was mainly obtained through personal interviews with an adult member of a randomly selected household in scope of the survey. There were a total of 10,439 completed questionnaires from 5,234 households, which equates to about one adult and one child per dwelling completing a questionnaire.

After the data are processed and validated, each person's record is weighted for the purpose of obtaining national estimates for the Indigenous population, from a randomly selected sample.

Advantages

- Visits to the GP may be cross classified with other items (such as selected long-term conditions) to determine what proportion of people see a GP regularly for their condition and the type of medication used for the condition.
- Provides data about Indigenous people in remote and non-remote areas of Australia.
- Good response rate over 80% (supported by legislation).
- Good time series from 1995 provides a picture of national trends in Indigenous health.

Limitations

- The reason for the consultation was not recorded.
- Recall bias—consultation information is self-reported by respondents.
- Some doctor consultations may be misreported.
- High likelihood of under-reporting for particular items (such as weight).

Data collection	**NATSIHS**
Collection owner	Australian Bureau of Statistics
Information source	Computer-assisted face-to-face interview with a selected member of the household
Data items	where the respondent would usually go if they have a health problem whether they usually go to the same GP/medical service whether they were required to pay any money (co-payment) for their last visit whether the respondent consulted a GP in the 2 weeks before interview number of consultations with a GP in that period whether they consulted a specialist in the 2 weeks before interview number of consultations with a specialist in that period period since last consultation, with GP or specialist (if neither had been consulted in the previous 2 weeks) reasons for not seeking care when needed whether respondent been told by a GP they have a selected condition (e.g. asthma) whether used pharmaceutical medication for a particular condition (e.g. asthma, heart and circulatory conditions, diabetes, arthritis and osteoporosis)
Scope and coverage	**Included in the survey were:** usual residents of private dwellings in both remote and non-remote areas of Australia Indigenous persons in scope were those identified by an adult within each sampled private dwelling as a usual resident of that dwelling only Indigenous households were considered in scope of the survey Indigenous household = household where at least one person of Aboriginal and/or Torres Strait Islander origin was usually resident (including children)
Frequency	6-yearly
Size	Over 10,000 completed questionnaires in 2004–05
Availability	Publications are available on the ABS website without charge A Confidentialised Unit Record File (CURF) can be purchased Ad hoc requests for data analysis are fee-for-service according to time spent
Data access cost	$800 (CURF)
Selected publications	ABS 2006. National Aboriginal and Torres Strait Islander health survey, Australia, 2004–05. ABS cat. no. 4715.0. Canberra: ABS.
Further information	<www.abs.gov.au>

National Health Survey

The national health survey is conducted every 3 years by the ABS. The most recent survey was conducted between August 2004 and July 2005.

Purpose

The 2004–05 national health survey is the fourth in a series of regular population surveys designed to obtain national benchmark information on a range of health-related issues and to enable the monitoring of trends in health over time.

Information was collected about the health status of the population, their use of health services and health-related aspects of their lifestyle. Information relevant to the nature of this project included respondents' long-term medical conditions, recent injury events, consultations with health professionals, other actions people had recently taken in regard to their health (such as days away from work, medication), and lifestyle factors that may affect their health such as smoking, alcohol consumption, diet, exercise and immunisation.

Method

Information was obtained in the 2004–05 survey by ABS interviewers, mainly through personal interviews with an adult member of a randomly selected household in the scope of the survey. There were a total of 25,906 completed questionnaires from 19,501 fully responding households. More than 6,000 children from these dwellings completed questionnaires, adding to the total of completed questionnaires.

After the data are processed and validated, each person's record is weighted for the purpose of obtaining national estimates relating to the whole population in scope of the survey, from a randomly selected sample. The aim of the survey is to provide statistics that represent the population or component groups of the population; the survey does not aim to provide data for analysis at the individual level.

The reference period in the survey for questions about health-related actions was for a 2-week period. The results should therefore be considered as a 'point in time' picture of the health of the population and of population sub-groups. It is possible to produce reasonable estimates of the number of actions taken in a year by multiplying the estimate for 2 weeks by 26. It is not possible, however, to produce estimates of the number of persons who took those actions, using the same method. This needs to be considered when comparing results from this survey to data from other sources relating to different reference periods.

Advantages

- GP visits may be cross classified with other items (such as selected long-term conditions) to determine what proportion of people see a GP regularly for their condition, and the type of medication used for the condition.
- Large random sample of households in Australia.
- High response rate of around 90% (supported by legislation).
- Good time series from 1989–90 provides a picture of national health trends.

Limitations

- Recall bias—consultation information is self-reported by respondents.
- Some doctor consultations may have been mis-reported.
- High likelihood of under-reporting for particular items (such as weight).
- Information about the medical condition or other reasons (such as test, check-up) for taking a health-related action was not generally obtained in the 2004–05 survey; (limited linkage between actions taken and medical condition was recorded for persons reporting some conditions).
- The ABS recommends caution when attempting to extrapolate results of this survey to time periods other than those on which the estimates are based.

Data collection	**National health survey**
Collection owner	Australian Bureau of Statistics
Information source	Computer-assisted face-to-face interview with a selected member of the household
Data items	whether respondent consulted a GP in the 2 weeks before interview number of consultations with a GP in that period whether respondent consulted a specialist in the 2 weeks before interview number of consultations with a specialist in that period period since last consultation, with GP or specialist (if neither had been consulted in the previous 2 weeks) whether been told by a GP they have a selected condition (e.g. asthma) whether used pharmaceutical medication for a particular condition (e.g. asthma, heart and circulatory conditions, diabetes, arthritis and osteoporosis)
Scope and coverage	**Included in the survey were:** members of selected households in urban and rural areas of Australia, excluding very remote areas, who were usual residents of the household or overseas visitors staying or intending to stay in Australia for 12 months or more **Excluded from the survey were:** diplomatic personnel of overseas governments and non-Australian members of their households non-Australian service personnel stationed in Australia and their dependants short-term overseas visitors whose usual place of residence was outside Australia
Frequency	3-yearly
Size	More than 25,000 completed questionnaires in 2004–05 from 19,501 households
Availability	Summary and topic-based publications are available on the ABS website without charge A basic or expanded Confidentialised Unit Record File (CURF) can be purchased Ad hoc requests for data analysis are charged for according to time spent
Data access cost	$800 (CURF)
Selected publications	ABS 2006. 2004–05 National health survey: summary of results, Australia. ABS cat. no. 4364.0. Canberra: ABS.
Further information	<www.abs.gov.au>

Victorian Population Health Survey (VPHS)

The VPHS has been conducted by the Victorian Government Department of Human Services (DHS) as an annual state-based survey since 2001. The most recent survey occurred in the second half of 2006.

Purpose

The survey is conducted to provide an ongoing source of information about the health of Victorians. It offers good quality population health indicators that can assist in policy development and strategic planning across the DHS and the wider community, ensuring public health programs are relevant and responsive to current and emerging health issues.

Method

CATI is undertaken on a state-wide sample of adults aged 18 years and over, randomly selected from households (selected using random digit dialling) in the eight departmental health regions, resulting in approximately 7,500 interviews. The survey was conducted by the Social Research Centre, based in Melbourne, over a period of nearly 3 months. Weighting was applied to the data to reflect the probability of selection of the respondent within the household, and the age/sex/geographic distribution of the population. The participation rate, defined as the proportion of households where contact was made and an interview was ultimately completed, was 62%.

Advantages

- Large random sample.
- Good regional time series over a 5-year period.
- Over-sampling in non-metropolitan regions.
- Good response rate (69%).

Limitations

- Some population groups are excluded as a result of the use of telephones to conduct the survey.
- Recall bias—responses are self-reported.
- Indigenous representation is less than 1%.

Data collection	**VPHS**
Collection owner	Victorian Government Department of Human Services
Information source	Computer-assisted telephone interview with a selected member of the household
Data items	demographics respondent's use of and level of satisfaction with community health centre over the previous 12 months whether respondent has been told by a GP they have a selected condition (e.g. asthma and/or other NHPAs) blood pressure screening cholesterol screening diabetes/high blood sugar level screening bowel cancer screening nutrition and physical activity—self-reported risk behaviours
Scope and coverage	Random selection of adults who resided in private dwellings in Victoria All residential households with landline telephone connections were considered in-scope for the survey
Frequency	Annual
Size	Approximately 7,500 completed interviews in 2006
Availability	The full report from the 2006 survey is available on the department's website, as are survey reports from previous years
Data access cost	Reports are free to download from the VPHS website
Related publications	Victorian Department of Human Services 2006. Victorian Population Health Survey 2006: selected findings. Melbourne: Department of Human Services.
Further information	<www.health.vic.gov.au>

Western Australian Health and Wellbeing Surveillance System (WA HWSS)

The WA HWSS is a continuous state-based population health survey system run by the Western Australian Department of Health. Data collection began in 2002 and more than 27,000 interviews have been conducted since then.

Purpose

In February 2002, the WA HWSS was launched as an important vehicle for supplying the information required to monitor population health status and to enable the early detection and response to changes in health outcomes in Western Australia. The HWSS monitors the health and wellbeing of West Australians using validated, reliable indicators and is able to track lifestyle trends over time. It has the capacity to recognise and report on beneficial health behaviours and risk factor behaviours. To this end, the survey provides good-quality information for informing policy and service provision and is able to evaluate the long-term effects of such programs.

Method

The HWSS is conducted as a CATI monthly survey. A stratified random selection process is used to filter households from the electronic White Pages, to whom an approach letter is sent to inform them of their selection in the survey and provide them with information regarding the survey. The selected respondent from each of these households is the person who has had the most recent birthday. Estimates resulting from the survey are tested for their reliability by re-contacting consenting respondents and running through parts of the survey with them and analysing responses. Rural and remote areas of WA are over-sampled to provide adequate data and the survey results are weighted to compensate for this.

Advantages

- Large sample size.
- Good time series.
- Excellent response rates (approx 80%).
- Continuous sampling enables recognition of seasonal trends.

Limitations

- Indigenous sample is not sufficiently large to make separate estimates about the Indigenous population.
- Includes English speakers only and those who are well enough to respond.
- Recall bias—responses are self-reported.

Data collection	**WA HWSS**
Collection owner	Western Australia Department of Health
Information source	Computer-assisted telephone interview with a selected member of the household
Data items	doctor's diagnosis of NHPA conditions has respondent ever had blood pressure or cholesterol checked? doctor's diagnosis of high blood pressure or high cholesterol whether medications taken for high blood pressure or high cholesterol risk factors use of health services in the past 12 months (primary health, hospital, allied health, mental health, dental) has respondent seen a doctor in last 4 weeks for psychological distress feelings? has respondent had flu or pneumonia vaccination in last 12 months (over 65s only)? demographics

Scope and coverage	People of all ages drawn from a stratified random sample of households selected from the White Pages Rural and remote households over-sampled to enable comparisons People in institutions, the homeless and those households without telephones are excluded
Frequency	Continuous (monthly) since March 2002
Size	550 surveyed each month More than 27,000 interviews since commencement
Availability	Summary reports and bulletins are available on the WA Health Department website De-identified data are available for research purposes
Data access cost	Free
Selected publications	Wood et al. 2008. Health and wellbeing of adults in Western Australia 2007, overview of results. Perth: Department of Health Western Australia.
Further information	<www.health.wa.gov.au>

Administrative collections

Medicare Benefits Scheme (MBS)

MBS data relate to consultations with GPs and other health professionals for which the cost is met in part or wholly by Medicare Australia.

Purpose

The MBS is a national administrative collection that deals with the payment of subsidies for services rendered by GPs and some other health professionals (such as specialists or optometrists). MBS data cover only those services eligible for Medicare benefits, as listed in the Medicare Benefits Schedule.

When evaluating the collection insofar as it might reflect best practice, it is assumed that the Medicare data items relating to the various health assessments indicate that the components of each item have been performed according to the procedure as outlined in the Schedule. This can also be the case when considering items such as the Enhanced Primary Care (EPC) Chronic Disease Management (CDM) items, including the GP Management Plan (GPMP), the Team Care Arrangements (TCA). The 'cycle of care' and mental health care plan items may also be similarly judged.

Method

MBS data include a Medicare item number, the amount of Medicare benefit applied, date of service and processing, provider number, recipient of the service and an indication of whether or not the item was provided in a hospital. Any GP consultation that is paid for in full, or partly, through the MBS is recorded by Medicare. No information is collected on non-fee-for-service components in general practice and there is no diagnostic information or details about the doctor–patient encounter.

Advantages

- De-identified MBS and PBS data can be linked, subject to appropriate approvals being granted and the commitment by government agencies to adhere to the privacy guidelines.
- Internal linkage of individual records can enable examination of patterns of care over time.
- Information on records of referrals and investigations such as pathology and imaging can provide insight into the clinical problem presented at the consultation.
- A national source obtained directly from GPs accessing Medicare.

Limitations

- No information about the content of the consultation or the underlying medical condition.
- Limited to eligible MBS items.
- Information not included in the MBS data collection:
  - services rendered under an entitlement conferred by legislation other than the *Health Insurance Act 1973*; for example, services covered by third party or workers' compensation, DVA card holders or defence personnel
  - services rendered for insurance or employment purposes
  - health screening services
  - services rendered under grant provisions such as the Health Program Grant arrangements.

Data collection	**MBS**
Collection owner	DoHA
Information source	Fee-for-service patient consultations with GPs, for which Medicare benefits were paid
Data items	**Provider information** name and address speciality by qualification registered major speciality derived speciality based on type of claims **Patient information** sex and date of birth Medicare item number benefit paid period of service and processing and dates of request/referral—monthly/quarterly/yearly indication of whether or not the service was provided in hospital
Scope and coverage	Any consultation with a GP that is paid for in full or part through the MBS **Consultations not included:** services rendered free-of-charge in recognised hospitals services rendered under an entitlement conferred by legislation other than the *Health Insurance Act 1973*, e.g. services covered by third party or workers' compensation, or services rendered to repatriation beneficiaries or defence personnel services rendered for insurance or employment purposes health screening services services rendered under grant provisions such as the Health Program Grant arrangements
Frequency	Continuous
Size	More than 107 million Medicare claimable GP (including practice nurse items) services were recorded in 2006–07
Availability	Item transaction data are available each quarter on the DoHA website, around 1–2 months after the end of the quarter. Data from 1984 on is available on the website De-identified person level data are available (subject to certain conditions) to government agencies
Data access cost	Free
Selected publications	Quarterly summaries of Medicare activity are available on the DoHA website at <www.health.gov.au/internet/main/publishing.nsf/Content/Medicare+Statistics-1>
Further information	<www.medicareaustralia.gov.au/>

Pharmaceutical Benefits Scheme (PBS)

Pharmaceutical Benefits Scheme (PBS) data relate to the value (benefit) or volume of PBS prescriptions that have been processed by Medicare Australia. They refer only to paid services processed from claims presented by approved pharmacies.

Purpose

The PBS is an administrative collection that deals with the supply of pharmaceutical medicines subsidised by the Australian Government.

Method

PBS data are collected through pharmacy electronic records when the prescription is filled. The data relate to the value (benefit) or volume of PBS prescriptions that have been processed by Medicare Australia. The data refer only to paid services processed from claims presented by approved pharmacies and include information on prescriptions for which the Australian Government has made a contribution. Around 80% of prescriptions dispensed are subsidised by the PBS.

The patient categories of general or concessional refer to a patient's eligibility status at the time of supply of the benefit. General patients hold a Medicare card; concessional patients hold a Medicare card and one of either a Pension Concession Card, Commonwealth Seniors Health Card, or a Health Care Card. There are two safety net thresholds: one for general patients and the other for concessional patients. When patients and/or their families reach the safety net threshold, PBS medicines are cheaper for the remainder of the calendar year for those in the general category and free for those in the concessional category.

Advantages

- Linkage of de-identified PBS and MBS data is possible, subject to appropriate approvals being granted, as noted earlier in this chapter under the MBS data collection.
- Internal linkage enables examination of patterns of medication supply over time.

Limitations

- The collection is only about claims data for PBS subsidised drugs.
- Prescription items that cost less than the threshold, or for which there is no government subsidy, are excluded.
- As the threshold changes, medicines move from being subsidised to costing less than the threshold and not included in the data.
- Data related to prescription items for non-concessional patients that are under the threshold contribution for subsidy, or for which there is no subsidy, are excluded from the collection.

Data collection	**PBS**
Collection owner	DoHA
Information source	Administrative collection
Data items	medicine: type of drug, item code, generic name, brand of item, strength and quantity cost original or repeat prescription date of prescription

Data items (cont'd)	date of supply payment category (e.g. concession, safety net, doctor's bag) number of repeats authority items state (supply—based on approval ID) total number of scripts total number of patients
Scope and coverage	Includes information on prescriptions for which the Australian Government has made a contribution Excludes data related to prescription items for non-concessional patients that are under the threshold contribution for subsidy, or for which there is no subsidy
Frequency	Continuous
Size	In excess of 2 billion prescriptions recorded between 1992 and 2007 are available from the Medicare website
Availability	Monthly data are available on the Medicare Australia website and are usually available less than one month after processing Requests for additional statistical information can be sent to the Legal Privacy and Information Services Branch. Information requests are considered taking into account the provisions of the *National Health Act 1953* which strictly limits the disclosure of PBS information and Medicare Australia's policy relating to the release of information for the benefit of the health of Australians
Data access cost	Free
Selected publications	Various summary reports are available online at <www.health.gov.au/internet/main/publishing.nsf/Content/health-pbs-general-stats.htm-copy3>
Further information	<www.medicareaustralia.gov.au>

Practice Incentives Program (PIP) and Service Incentive Payments (SIPs)

The PIP replaced the Better Practice Program on 1 July 1998 following a series of recommendations made by the General Practice Strategy Review Group, which was formed to report to the Commonwealth Government on GP services. SIPs are made quarterly to remunerate individual GPs for the service provided.

Purpose

PIP provides a number of incentives that aim to encourage general practices to improve the quality of care provided to patients. It recognises general practices that provide comprehensive, quality care, and which are either accredited or working towards accreditation against the Royal Australian College of General Practitioners' (RACGP) *Standards for General Practices*. The PIP is part of a blended payment approach for general practice. Payments made through the program are in addition to other income earned by the general practitioners and the practice, such as patient payments and Medicare rebates.

Method

The function of PIP is to compensate for the limitations of fee-for-service arrangements. Under these arrangements, practices that provide numerous quick consultations receive higher rewards than those that take the time to look after the ongoing health care needs of their patients. The incentive payments focus on aspects of general practice that contribute to quality care, including the use of Information Management/Technology (IM/IT), provision of after-hours care, student teaching and better prescribing practices. In addition, rural and remote practices receive a rural loading. PIP payments are mainly dependent on practice size—in terms of patients seen—rather than on the number of consultations performed.

Advantages

- Data on GPs and practices that have provided PIP/SIP services.
- A national source obtained directly from GPs.

Limitations

- No record of the consultation.
- Assume all GPs have participated to the same level of service to receive the PIP.

Data collection	**PIP**
Collection owner	Administered by Medicare Australia on behalf of the DoHA
Information source	Administrative collection
Data items	**Incentive payments are provided for a number of items:** information management and technology (use of electronic prescribing and records, register/recall system and capacity to send and receive data electronically, including appropriate backup and security measures in place) access to after-hours (24 hours) care for patients rural practices support to encourage rural general practitioners (GPs) to provide procedural services to support practices to employ practice nurses to encourage practices to teach medical students participation in educational activities to improve prescribing behaviour; (participation in the National Prescribing Service quality use of medicines program) to encourage cervical screening (SIP) to assist with best-practice management of asthma and diabetes (cycle of care—SIP)
Scope and coverage	All practices that are accredited, or are working towards accreditation
Frequency	Data are presented on a quarterly basis in line with payments to participating practices
Size	More than 4800 practices are participating in the PIP as at November 2007
Availability	Spreadsheets and customised reports may be generated from the Medicare website and are available for quarterly or annual data within 1–2 months after the end of the quarter
Data access cost	Free
Selected publications	Not applicable
Further information	<www.medicareaustralia.gov.au/provider/incentives/pip/index.jsp>

Repatriation Pharmaceutical Benefits Scheme (RPBS)

The Repatriation Pharmaceutical Benefits Scheme (RPBS) is administered by the Department of Veterans' Affairs (DVA).

Purpose

The RPBS is an administrative collection that deals with the supply of pharmaceutical medicines and dressings for the treatment of entitled veterans and war widows. All the drugs included in the PBS Schedule, plus a range of pharmaceutical items to cover veterans' needs, are contained within the RPBS. There are approximately 350,000 people eligible to receive pharmaceutical benefits through the RPBS. The average age of those eligible is around 74 years, with 15% under the age of 60 years and 66% aged 75 years or over.

Method

RPBS data are collected through pharmacy electronic records when the prescription is filled. The data relate to the value (benefit) or volume of RPBS prescriptions that have been processed by Medicare Australia. They refer only to paid services processed from claims presented by approved pharmacies and include information on prescriptions for which the Australian Government has made a contribution.

RPBS items may only be prescribed to patients with a current entitlement card such as:

- Repatriation Health Card (gold) and Repatriation Pharmaceutical Benefits Card (orange) holders can obtain pharmaceuticals under the RPBS for all of their medical conditions.
- Repatriation Health Card (white) holders can obtain pharmaceuticals for specific disabilities accepted by the DVA.

Advantages

- Linkage of de-identified PBS (including RPBS) and MBS data, subject to appropriate approvals being granted, as noted earlier in this chapter under the MBS data collection.

Limitations

- Only collects data for claims on RPBS subsidised drugs by those persons eligible.
- Data mostly about persons over 60 years of age.

Data collection	**RPBS**
Collection owner	DoHA
Information source	Administrative collection
Data items	medicine: type of drug, item code, generic name, brand of item, strength and quantity cost original or repeat prescription date of prescription date of supply payment category (e.g. concession, safety net, doctor's bag) number of repeats authority items state (supply—based on approval ID) total number of scripts total number of patients
Scope and coverage	Eligible veterans, war widows/widowers, and their dependants
Frequency	Continuous
Size	In excess of 179 million prescriptions recorded between 1992 and 2007 are available from the Medicare website
Availability	Monthly data are available on the Medicare Australia website and is usually available less than one month later Data available from the Medicare Australia website dates back to 1992, and is classified according to the anatomical system it is applicable for or by patient category
Data access cost	Free
Selected publications	Not applicable
Further information	<www.medicareaustralia.gov.au>

Service Activity Reporting (SAR)

SAR is conducted jointly by the National Aboriginal Community Controlled Health Organisation (NACCHO) and the Office for Aboriginal and Torres Strait Islander Health (OATSIH).

Purpose

SAR collects data on service activity, staffing profiles and the number of clients of Australian Government-funded Aboriginal and Torres Strait Islander primary health care services. It is the most comprehensive collection of data about these services currently available. SAR provides valuable information to inform government policy and health service planning.

Method

Annual survey questionnaires are distributed to all Australian Government-funded Aboriginal and Torres Strait Islander primary health care services. The data collected in the SAR relate to health-oriented activities, staffing, episodes of care and contacts with clients. No diagnostic information or details about doctor–patient encounters are collected.

Advantages

- Two types of data are collected that reflect health care provision: episodes of health care and client contacts.
- Provides information about preventive health care activities

Limitations

- No information about the content of the consultation or the underlying medical condition.
- Data covers contacts and episodes with the health service in general, including nurses, social workers and other health care staff, not necessarily contact with a GP.
- Episodes of care, contacts, and client figures are often estimates and there has been no ‘audit’ to check the accuracy of these figures.
- Includes Aboriginal and Torres Strait Islander health organisations only, which receive at least some Australian Government funds to facilitate access to primary health care.

Data collection	**SAR**
Collection owner	A joint data collection project of NACCHO and OATSIH
Information source	Annual reporting questionnaire
Data items	proportion of health services providing screening services and maintaining adequate medical records. data collected on health-related community and support services proportion of health services providing clinical health care and tackling substance use issues provision of social and emotional wellbeing programs by the health services computer use by the health service number of episodes of care and client contacts provided by different types of staff (including doctors, nurses and Aboriginal and Torres Strait Islander health workers) practice size (in terms of FTEs by type of staff and Indigenous status) whether service is accredited whether service provides after-hours care

Scope and coverage	The SAR only collects information from Aboriginal and Torres Strait Islander primary health care services that receive Australian Government funding
Frequency	Annual
Size	Involves around 140 health services each year
Availability	The key findings of the SAR data collection are available on the DoHA website
Data access cost	Key results reports are free to download
Selected publications	DoHA & NACCHO 2008. Service activity reporting: 2004–05 key results. Canberra: DoHA. <www.health.gov.au/internet/main/publishing.nsf/Content/health-oatsih-pubs-sar.htm>
Further information	<www.health.gov.au>

Other surveys and research collections

Health Information Technology (HIT)

HIT is considered an important strategy in reducing medical errors and improving quality of care. In 2005, McInnes et al. conducted a national survey of GPs in Australia to describe how they use computers for clinical purposes.

Purpose

A survey of GPs was conducted over a three month period in 2005 to provide a picture of their use of computers in their practices and to what extent they use the functions available in medical software. The majority (90%) of respondents reported that they used a clinical software package. Results were also obtained for the use of the software for electronic prescribing (98%) and to check for drug–drug interactions (88%). However, a smaller proportion of GPs used the software for chronic condition patient lists (58%) and fewer still used the electronic decision-support function (20%) on a regular basis.

Method

A stratified sample provided by the DoHA, of 3000 GPs consisting of 70% urban/regional and 30% rural/remote was sent a paper-based survey form. There was an over-sampling of rural and remote GPs to allow statistical comparisons between urban and rural areas. To be eligible to be selected, the GPs had to have had at least 375 Medicare claims in the quarter ending June 2005.

Advantages

- Highlights particular areas of information technology not used regularly by GPs; for example, to generate patient recall lists, use of the decision-support function.
- Good representation of rural/remote GPs.

Limitations

- Low response rate (39.5%).
- Recall bias—responses are self-reported by GPs.

Data collection	**HIT survey**
Collection owner	Authors of the study
Information source	National paper survey by McInnes et al.

Data items	use of computers use of computerised clinical functions such as: – prescribing, and reason for prescribing – medication checking, drug-drug interactions – generating health summaries – running recall systems – writing progress notes – ordering laboratory tests
Scope and coverage	A postal survey of a cross-sectional national stratified sample of 3000 GPs from the Medicare database
Frequency	One-off survey conducted over 3 months in 2005
Size	Nearly 1200 GPs
Availability	Publication on the results of the study published in the Medical Journal of Australia (MJA)
Data access cost	Free
Selected publications	McInnes DK, Saltman DC & Kidd MR 2006. General practitioners' use of computers for prescribing and electronic health records: results from a national survey. Medical Journal of Australia 185:88–91.
Further information	McInnes et al. 2006.

National Prescribing Service (NPS)

The National Prescribing Service (NPS) is the quality use of medicines service agency for Australia's National Medicines Policy, funded by the DoHA. It is a member-based organisation and includes GPs, specialists, consumers, nurses, pharmacists, government and pharmaceutical industry representatives, academics and educators.

Purpose

The purpose of the NPS is to achieve improvements in health and wellbeing through the better use of medicines and to help develop and implement the body of knowledge on the quality use of medicines (QUM). It also has a role to provide unbiased educational activities for health professionals and consumers to encourage the sensible use of medicines. To fulfil these goals, the NPS uses self-audits, case studies and surveys of participating GPs and consumers. The GP survey asks GPs about their knowledge of evidence-based prescribing practices and use of different types of information sources. Information has also been gathered around GPs' views on generic and complementary medicines.

Method

National, paper-based mail surveys of GPs and pharmacists are undertaken every 2 years to track changes in attitude to topics of interest among these target groups. GP surveys commenced in March 1999 and now collect data from, on average, around 800–900 GPs.

National telephone surveys of consumers using CATI technology for data collection are undertaken every 1–2 years to track any changes among this target group. Results are post-weighted for age and gender using relevant ABS census data. Surveys commenced in August 1999, collecting data from around 1200 consumers.

Advantages

GP paper-based surveys

- Provide data surrounding the QUM and the GPs knowledge about QUM.

Limitations

GP paper-based surveys

- Low response rate (around 40%).
- Under-representation of male GPs compared with national data.
- Under-representation of GPs in the less than 35 age category.
- Over-representation of GPs over the age of 45.

Pharmacist paper-based surveys

- Low response rate (34%, of pharmacists employed in a pharmacy or health-related field, in 2006).
- Under-representation of community pharmacists.
- Over-representation of young pharmacists (29 years and under).
- Is particularly focussed on NPS activities and the pharmacist's knowledge of them.

Data collection	**NPS**
Collection owner	National Prescribing Service
Information source	Focus groups and surveys of GPs, pharmacists and consumers
Data items	**GP survey** GP knowledge of evidence on some prescribing options—quality use of prescription medicines information sources used by GPs GP perceptions regarding the best options for keeping up to date with advances and changes in the use of medicines computerised prescribing and GPs' views on generic medicines GP awareness and participation in NPS divisional activities the value of NPS to GPs GP perceptions about the trustworthiness and completeness of NPS prescribing and feedback information **Pharmacist survey** perceptions regarding the NPS use of information technology communication with patients **Consumer survey** self-rated health status management of health and wellbeing consumers' use and management of prescription and non-prescription medicines consumer attitudes to medicine use and alternatives to medicines use consumer awareness and use of information sources provided by and promoted by NPS consumer attitudes towards sources of information about medicines
Scope and coverage	The national GP survey is mailed out to around 2000 GPs across Australia. Of these, approximately 40% were returned for the 2006 survey GP sample drawn randomly from the AMPCo Direct Medical Masterfile database. AMPCo Direct is a subsidiary of the Australian Medical Publishing Company, which is a subsidiary of the Australian Medical Association (AMA) The sample is stratified by state and RRMA and not dependant on NPS participation

Scope and coverage (cont'd)	The consumer surveys obtained national randomised samples of the Australian population aged 15 years and over, stratified by age, gender and region. Phone numbers were obtained from the electronic White Pages
Frequency	GP surveys 2-yearly; consumer surveys irregular (1–2 yearly)
Size	GP survey involves responses from around 2000 GPs Consumer survey involves around 800 persons Pharmacist survey involved responses from around 650 pharmacists employed in a pharmacy or health-related field
Availability	Not determined
Data access cost	Free
Selected publications	Summary results of the surveys are available online at <www.nps.org.au/research_and_evaluation/publications/reports>
Further information	<www.nps.org.au/>

Threats to Australian Patient Safety (TAPS)

The TAPS study was conducted prospectively over a 12 month period from October 2003 to estimate the incidence of errors reported by GPs in NSW.

Purpose

The study was performed to estimate the rate of reporting of errors (anonymously) by GPs in NSW.

Method

The DoHA provided a random stratified sample of 320 GPs from a population of 4,666 GPs in NSW. A secure website and reporting process was used to deliver and hold the questionnaire and to ensure anonymity. Errors could be reported anonymously by GPs over a 12 month period from October 2003.

Errors considered in the context of this study included events that might have affected, or had the capacity to affect, the quality of care of patients. Reported errors could be administrative or clerical in nature, with or without discernible effects, but were occurrences that the GP would want to avoid in the future.

Advantages

- Provides data about the incidences of reported error in general practice.
- State-based data from practices in urban (49%), regional (26%) and rural/remote (25%) areas.
- Participants were considered representative of the source population of NSW GPs in respect to Medicare items claimed and the age and sex of the participants.

Limitations

- Low response rate of 26%.
- Small sample size (320 GPs).
- Single state-based sample.
- GPs are likely to under-report adverse drug events and so possibly other patient safety threats may also be under-reported.
- It is possible the GP may not be aware of an error occurring.

Data collection	**TAPS study**
Collection owner	Authors of the study
Information source	Secure online questionnaire to GPs
Data items	RRMA area of practice patient demographics (age, sex, NESB status, Indigenous status) error report – event – result – contributing factors – place of occurrence – outcomes/harm done – what could have prevented the error
Scope and coverage	A sample of 320 names from a total of 4,666 full-time GPs in NSW were provided by the GP branch of DoHA
Frequency	One-off study conducted over 12 months in 2003–2004
Size	Involved 84 GPs More than 166,000 patients 418 errors reported
Availability	Publication on the results of the study published in the Medical Journal of Australia (MJA)
Data access cost	Free
Selected publications	Makeham et al. 2006. The Threats to Australian Patient Safety (TAPS) study: incidence of reported errors in general practice. Medical Journal of Australia 185(2): 95–98.
Further information	Makeham et al. 2006.

Other collections

There are a number of other surveys and studies that have collected primary care data, some of which were conducted for a particular research purpose by academic organisations. Although these surveys and studies—some of which are still current—do not provide sufficient information relevant to this report to incorporate them under the earlier detailed analyses, they are worthy of a brief synopsis presenting their purpose and method of collection, followed by contact details for further investigation. The following surveys and studies, although not necessarily an exhaustive list for this topic, are presented as they cover various aspects relevant to best-practice primary health care data collection, but their data collections generally lack adequate information to warrant more comprehensive analysis for the purpose of this report.

State and territory surveys

In addition to the VPHS, the other jurisdictions perform their own population-based CATI surveys. Topics covered in these surveys relevant to the subject of primary health care include:

- GP diagnosis of certain conditions (for example, have you ever been told by a doctor that you have arthritis?)
- the frequency of use a health service over a particular time period (2 weeks, 4 weeks, 12 months)
- avoidance of seeing a doctor because of medicine cost that may need to be incurred
- instances where a medicine was not collected, or its usage stopped or cut down because of the cost

- instances where difficulty was experienced in obtaining health care, and the types of difficulty.

Contacts:

New South Wales—Margo Eyeson-Annan, meyes@doh.health.nsw.gov.au, <www.health.nsw.gov.au>
Queensland—Catherine Harper, Catherine_Harper@health.qld.gov.au, <www.health.qld.gov.au>
Victoria—Loretta Vaughan, loretta.vaughan@dhs.vic.gov.au, <www.health.vic.gov.au>
South Australia—Anne Taylor, Anne.Taylor@health.sa.gov.au, <www.health.sa.gov.au>
Western Australia—Alison Daly, Alison.M.Daly@health.wa.gov.au, <www.health.wa.gov.au>
Tasmania—Rosie Hippel, rosie.hippel@dhhs.tas.gov.au, <www.dhhs.tas.gov.au >
Australian Capital Territory—Cathy Baker, Cathy.Baker@act.gov.au, <www.health.act.gov.au>
Northern Territory—Steve Guthridge, Steve.Guthridge@nt.gov.au, <www.nt.gov.au/health>

Aged Care GP Panels Initiative

The aim of the Panels Initiative is to improve access to primary medical care for residents of aged care homes, and to enable GPs to work with aged care homes to assist with quality improvement strategies in the care of all residents. It was conducted in 2004 and 2006. In 2006, surveys were sent to 2,061 aged care facilities from a total national number of 3,054. 1,413 responses were received.

The surveys measured many different aspects of GP involvement in residential aged care, including:

- GP access
- GP involvement in quality improvement
- communication between aged care homes and divisions of general practice.

The surveys and fact sheets associated with the initiative are available on the Department's website.

Contact: DoHA.

Email: agedcaregppanels@health.gov.au

Web: <www.health.gov.au>

Asthma management and outcomes in Australia: a nation-wide telephone interview survey

The aim of this study was to assess the burden of asthma and describe current asthma management in Australia. A CATI survey was conducted in 2003–04 among randomly selected participants, fully funded by GlaxoSmithKline (GSK).

- 46,855 telephone numbers dialled
- 14, 271 responses to the screening questionnaire
- Among 1,734 respondents with current asthma, 1,205 completed the detailed questionnaire.
- The survey questionnaire included two sections: the first was to identify the presence of asthma; the second was to gather information about the effects and treatment of asthma was gathered from respondents with asthma. Questions were asked about:
- use of medications
- peak flow meters
- seeing a specialist

- having written instructions from their doctor on how to manage worsening asthma
- type and frequency of disease exacerbations.

Contact: Professor Guy Marks, Woolcock Institute of Medical Research, g.marks@unsw.edu.au

Publication: Marks GB, Abramson MJ, Jenkins CR, Kenny P, Mellis CM, Ruffin RE et al. 2007. Asthma management and outcomes in Australia: a nation-wide telephone interview survey. Respirology 12(2): 212–19.

Australia's Community Pharmacy Survey: National Pharmacy Database Project, 2002–2003

The project aimed to construct a reliable, national baseline set of data on current community pharmacy services in Australia. A random sample of Australia's registered pharmacies stratified into jurisdictions and location categories was chosen. The survey was posted to 1,391 pharmacies, of which 1,131 (81%) responded. There was an online facility to enable completion of the survey by participants if they preferred. Data items were categorised into five sets of services:

- prescription-related
- primary care (including over the counter medicines)
- prevention (including screening, health information, sterile needles)
- specialty (including institutional and aged care facilities, methadone maintenance)
- other (including complementary medicines) .

Contact: Mr. Con Berbatis, School of Pharmacy, Curtin University

Email: berbatis@git.com.au

Web: <beta.guild.org.au/research>

Evaluation of Asthma 3+ Visit Plan: National GP Survey

Conducted once in 2004 by the Centre for Primary Health Care and Equity (CPHCE)—a research group associated with the School of Public Health and Community Medicine at the University of New South Wales—to establish the degree of uptake of the Plan within general practice assessing:

- GP factors that influence uptake and use of the Asthma 3+ Visit Plan
- GP barriers to implementation of the Asthma 3+ Visit Plan
- GP experience of implementation of the Asthma 3+ Visit Plan with patients, and establish factors that impeded or supported implementation.
- A number of different elements were combined to provide a picture of the uptake of the plan including:
- a divisional survey
- a GP survey
- analysis of Medicare data
- consumer interviews and focus group discussion
- an evaluation of Aboriginal and Torres Strait Islander uptake of the plan
- GP focus groups.

Contact: DoHA—Email: monica.johns@health.gov.au or

CPHCE—Email: n.zwar@unsw.edu.au

Web: <notes.med.unsw.edu.au/cphceweb.nsf >

General Practice Victoria (GPV)

GPV is a not-for-profit, non-government organisation receiving funding, as the state-based organisation for Victorian general practice divisions, from the DoHA. GPV has collated data from Medicare Australia, the Primary Health Care Research and Information Service (PHCRIS) and other organisations and presents it in a state-based format for Victorian divisions of general practice. It includes data covering PIP-registered practices and the uptake of diabetes, asthma, mental health and cervical screening PIPs and SIPs, along with the uptake of practice nurse PIP plus MBS items for Enhanced Primary Care Chronic Disease Management (GPMPs and TCAs).

Contact: email: gpv@gpv.org.au

web: <www.gpdv.com.au/>

Medical Labour Force Survey

The annual paper-based Medical Labour Force Survey commenced in 1993 and is managed by the individual state and territories through the Medical Registration Board in each jurisdiction. It collects information from GPs at the time that they renew their registration with the Board, covering demographics, employment characteristics, their work locations and work activity. Response rates in excess of 71% have been recorded for the 3 years from 2003 to 2005.

Internet data tables and publications are available on the AIHW website. Data are provided on medical practitioners working in both the private and public sectors. There is also some information on registered medical practitioners who are not undertaking clinical work, or who are not employed.

Contact: AIHW

email: labourforce@aihw.gov.au

web: <www.aihw.gov.au>

New South Wales Colorectal Cancer Care Survey

The primary aim of the New South Wales (NSW) Colorectal Cancer Care Survey was to measure the care given to colorectal cancer patients in NSW and to determine whether care was managed according to best-practice guidelines and the effect of this on tumour recurrence. The project was conducted at the Cancer Council NSW and the Discipline of Surgery at the University of Newcastle. Doctors taking part in the survey could benchmark the management of their own patients in comparison with other doctors in NSW.

The sample was selected from all newly diagnosed colorectal cancer cases reported to the NSW Central Cancer Registry over a 12-month period from February 2000. A questionnaire regarding details of the diagnosis and surgical treatment was sent to surgeons treating these patients. Questionnaires seeking details on chemotherapy or radiotherapy were sent to oncologists to whom patients may be referred.

Information regarding follow-up practices, patient outcomes and further treatment were obtained 24 months after each patient's initial diagnosis.

Contact: Katie Armstrong

email: katief@nswcc.org.au

web: <www.cancercouncil.com.au>

OATSIH Services Collection, Analysis and Reporting (OSCAR)—Healthy for Life (HFL) program

The purpose of OSCAR is to capture and report on data on Aboriginal Health services participating in the HFL program. The aim of the HFL program is to improve the health of Aboriginal and Torres Strait Islander mothers, babies and children; improve the quality of life for people with a chronic condition; and over time, reduce the incidence of adult chronic disease. Participating services are required to submit data reporting against qualitative and quantitative indicators via the web-based OSCAR system.

The collection commenced in July 2007 and data are reported either annually or 6–monthly. Information collected covers community health service activities, child and maternal health data (including child health checks MBS item), chronic disease management (including adult health checks and other associated MBS items) and HbA1c characteristics for people with diabetes. Data completeness and availability of age- and sex-specific information varies substantially across participating services.

Data from the collection are not available for public use.

Contact: AIHW

email: tulip.penney@aihw.gov.au

web: <www.health.gov.au/healthyforlife>

Royal Flying Doctors Service (RFDS)

The Royal Flying Doctor Service of Australia is a not-for-profit charitable operation that provides medical emergency and primary health care services to people who live, work and travel in regional and remote Australia. The RFDS conducts regular primary health care clinics at locations such as Indigenous communities, remote stations, mines and oilfields, national parks and island resorts. These clinics include GP and specialist services and are not covered by Medicare. The RFDS receives funding from the Commonwealth Government to provide services to rural and remote communities. The RFDS compiles data for their annual report about the number of clinics conducted, patients attended to, telephone/videophone consultations performed and patients transported to hospital.

email: enquiries@rfdsno.com

web: <http://www.flyingdoctor.net>

Divisions of General Practice

Information systems—particularly computerised systems—can assist in the management of many chronic illnesses (such as diabetes). These systems include:

- Disease registers, which allow for the identification of patients with particular diseases, or at risk of them, the recording of treatment plans, test results, and so on, and the tracking of clinical outcomes.
- Recall and reminder systems, which provide the facility for systematic recall and review of the patients on a regular basis, according to clinical management guidelines.

The process for electronic register, recall/reminder systems for diabetes involves:

- recording clinical data for patients
- searching for patients with diabetes
- setting up diabetes review recalls
- searching for recalls due
- sending reminder letters
- maintaining recall.

These disease registers are a component of the better management of chronic disease which is one of the National Performance Indicators developed in 2005 by the DoHA. Diabetes, mental health and asthma are the focus of the chronic diseases for which the data are collected as part of the strategy. The indicators are being used to provide feedback to the divisions to assist them in improving support to general practices in their management of patients and to form a strong base for broader primary care and general practice information.

There are a number of general practice divisions that have established, and are currently managing, disease registers for their divisional practices. These systems are used to remind doctors when particular patients on the register are due for appropriate health checks and clinical tests. Some general practice divisional activities are listed below.

- In the **Macarthur Division of General Practice**, by registering patients with Diabetes on the division's diabetes program, GPs are sent a diabetes recall report every month. The report is sent from the division to every GP who has five or more patients registered on the database. The report lists all of the GP's diabetes patients who have not been reviewed in the previous 6 months. Often patients had been reviewed but the data had not been sent to the division and so the report acts as a reminder for GPs to forward the data on—especially if the GP is participating in the Division Diabetes Audit. The program uses the Cardiab database and offers GPs and patients:
  - a patient register
  - patient recall reports and letters
  - audit reports
  - RACGP QA&CPD clinical audit activity
  - diabetes education.
- A software tool developed by **Canning Division of General Practice** aggregates and manages diabetes data at a practice level. The 'Diabetes Data Aggregation Tool' improves practice systems by identifying those patients who have diabetes and assisting with the following:
  - establishment and maintenance of recall reminder systems for patients with diabetes
  - assist practices with forward planning for consultation reviews

  - assist practices with downloads of diabetes pathology results using HL7 messaging format for direct upload to medical software (including; Medical Director; Medtech32; Best Practice; Medical Spectrum Classic and more to follow)
  - support practices in implementing best-practice strategies such as Diabetes PIP/SIP and Medicare CDM Items (GPMP and TCA).
- The **Southern Highlands Division of General Practice** electronic data collection has been operating in the regional area since 1995. Approximately 59 GPs are involved in the collection, which requires manual extraction from clinical records or electronic records. Data are collected covering practice details and chronic disease management, but nothing is collected on the doctor–patient consultation. Data are available free to participants and can be provided to other interested groups on request.
- **GPpartners**, a division of general practice in Brisbane North, manages a shared electronic health record system that can be used by GPs, hospitals and allied health providers. Known as the Health Record Exchange (HRX), the system uses a central repository to hold the health summary information, which is aligned with NeHTA standards for electronic health records. GPs connected to the HRX receive an automatic notification in to their clinical systems when their patients' records are accessed by other members of their care team. The notifications will automatically arrive with other investigation results. At April 2008, there were 166 GPs connected and more than 1,000 patients had given consent to the sharing of their health records.

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

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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.

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[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>

4 Criteria-based evaluation of existing data collections

The previous two chapters have described the existing data collections that provide information about Australian general practice, outlining their general characteristics and the data collected. This chapter describes a set of criteria for evaluating the usefulness of these data collections for providing relevant information about general practice, and summarises the results of the evaluation of existing data sources against these criteria. It also highlights some of the gaps and limitations in the existing data, in relation to its usefulness for providing information about the quality of care in general practice compared with best-practice recommendations.

The criteria were developed in consultation with various stakeholders, taking into account their information needs and the requirement for sufficient information to evaluate the effectiveness of care. As a way of better understanding the application of the criteria, a set of GP–patient encounters (scenarios) were developed to test the type of information that could be made available and extracted for serving the immediate and long-term needs of stakeholders. This scenario-based evaluation is described in Chapter 5.

Stakeholder information needs

To determine whether or not existing data collections are useful, one needs to understand the types of questions stakeholders want the data to answer and the ways in which they want to use the data.

A set of questions was developed for discussions with stakeholders to elicit their information needs. To ensure consideration of a range of issues relevant to the quality of care, questions were grouped under five broad categories:

- accessibility and availability
- prevention and detection
- quality, safety and appropriateness
- use of guidelines
- use of new technologies.

The ‘discussion starter’ presented to stakeholders is included in Appendix 1.

Stakeholders were consulted during March and April 2008. Small group discussions were held in Adelaide, Sydney and Canberra. Individuals and organisations that were unable to attend group discussions were consulted via email and teleconference. Discussions were also held separately with various sections and individuals within the DoHA. A list of individuals consulted and their affiliations appears at Table A2.1, Appendix 2.

The discussions aimed to elicit the types of information stakeholders need, the types of questions to which they seek answers, and whether they are currently able to obtain answers to these questions.

Information needs expressed by stakeholders

The full 'wish-list' of data and information needs as expressed by stakeholders is sorted into six major themes. These are presented below in no particular order.

Outcomes: the need for data relating to outcomes (both short- and long-term)

- data on clinical outcomes relevant to GPs and patients
- data to report against national and jurisdictional indicators
- information about the distribution of health problems—for example, relating to rurality, socioeconomic status, numbers of GPs in geographic areas
- estimates of the number of patients with undiagnosed disease
- information about medication outcomes for chronic disease in the 'real world' (as opposed to clinical trial data, which are often of limited generalisability)
- accurate disease prevalence estimates—in many cases, survey estimates based on self-reported information were considered 'not good enough'
- data to enable evaluation of interventions
- data for examining the quality use of medicines and assessing compliance with medication guidelines
- longitudinal data following patterns of care and tracking the 'patient journey'
- the ability to undertake analysis at the division of general practice level.

Patient perspectives: the need for data about the patient experience (for example, about quality of life, functioning and satisfaction with care)

- information about patient satisfaction with care and their care team
- information about patient quality of life
- information about patients' impressions of their health outcome/progress
- information about functional status
- data about comorbidities.

Services: the need for data about services (including consultations, prescriptions and tests) to be linked with a diagnosis and/or reason for the service

- a diagnosis or reason for the service/prescription/test (these are different concepts; both may be necessary)
- information about post-hospital care
- data on GP prescribing patterns for a particular condition.

Processes: the need for data about the care process (for example, prescribing practices and referral patterns) that will provide information about the quality of care

- data relating to health care differentials—currently this is mainly related to socioeconomic status, but other factors are important (for example, access to GPs)
- data to explore quality-of-care issues and identify evidence-practice gaps
- information about referral patterns

- reasons for attendance at emergency departments—not in terms of diagnoses or symptoms, but why the emergency service and not the GP?
- information about people who don't attend GPs
- data relating to external influences on health (such as socioeconomic status, patient perceptions/beliefs)
- details about adverse events.

Events (electronic service event): the need for data about a service event that is transferable between different service providers and able to be linked with other health-related information

- data on computerisation rates and uses (for example, the proportion of referrals that are done electronically)
- information about the quality of computerised functions, compared with whatever standards are set
- the ability to link data to other health-related data sources (for example, hospital and mortality data).

Health-care provider: the need for data about service providers, such as distribution of the workforce and use of various technologies (both clinical and administrative)

- information about other primary health care practitioners (for example, allied health professionals) and the interface between different health services
- accurate workforce distribution data—existing data were considered inadequate.

It also became clear that there is a desire by some key stakeholders for contextual information around the patients' needs for primary health care services. For example, accurate data are required to understand the incidence and prevalence of various conditions in small geographic areas and, in some cases, to develop estimates of the number of undiagnosed cases.

Other issues relating to the collection and use of data

In addition to the specific data and information needs listed above, a range of other issues were raised by stakeholders. Some of these relate to the process of collecting data; others concern the definition of various concepts in the primary health care field and therefore the interpretation of results.

Three major themes emerged:

Data collection: encouraging and facilitating participation in data collection

- Not meeting a guideline or an indicator-based 'target' does not mean care is poor—the results depend on the particular case.
- GPs need an incentive to participate in data collection—they need to see the benefits and want to use the results. To whom are they submitting data, and for what purpose?
- Data collection should not interfere with the practitioner's clinical workflow.
- Consider the appropriate use of the health workforce—who is the most appropriate data collector? It may not be the GP.
- GPs deal with individuals, not communities—the 'sickness model' of health services compared with the 'wellness model' of health policy.
- Context is important when interpreting information.

- Analysts need to be trained to use and interpret the data appropriately.
- Basic throughput counts are not particularly useful to practitioners.
- Recording an event is not the same as recording a problem and the follow-up related to that problem.
- There is a need to ‘sell’ to GPs the benefits of using electronic records for tasks other than prescribing.

Standards: adopting standards (relating to coding, terminology, data and concept definitions and evidence-based guidelines)

- Data need to be transferable across an integrated care system.
- ‘Quality’ is difficult to define and to measure (evidence-based guidelines).
- What is a ‘preventive action’? This may differ from case to case (evidence-based guidelines).
- Much of the existing data are of poor quality—this leads to flawed results, inappropriate conclusions and inadequate information for making policy and strategy decisions.
- The variation in practice software and ways information is collected and coded is a barrier to data comparability.
- Data definitions and terminology are often not standardised, so data are at best non-comparable and at worst complete nonsense.
- Measurement of patient compliance is important, as this has an impact on outcomes (evidence-based guidelines).
- National registration could incorporate information about the practice and be a source of detailed workforce data (accreditation).

Linkage: enabling data linkage

- Data need to be linkable (for example, to mortality or hospital data) to examine population-based outcomes.
- Outcomes analysis requires longitudinal data.
- Linking cause and effect is often difficult when many people are involved.
- Software does not always provide a link between administrative data and clinical data within the practice.

Criteria development

The responses obtained from stakeholders were collated and recurring themes identified. From these themes, a set of 10 ‘priority questions’ was constructed. The questions aimed to solicit the most common, and most important, information needs across the stakeholder groups. These 10 questions, plus an overall assessment of data quality, formed the core criteria against which each of the data collections was tested.

Although some of these criteria do not appear to directly tackle the issues of quality of care and uptake of best-practice guidelines, discussions with stakeholders confirmed the view that many different aspects of the general practice—as part of the health system and the community it serves—influence decisions about the care that is delivered and hence the outcomes that are achieved (Figure 4.1).

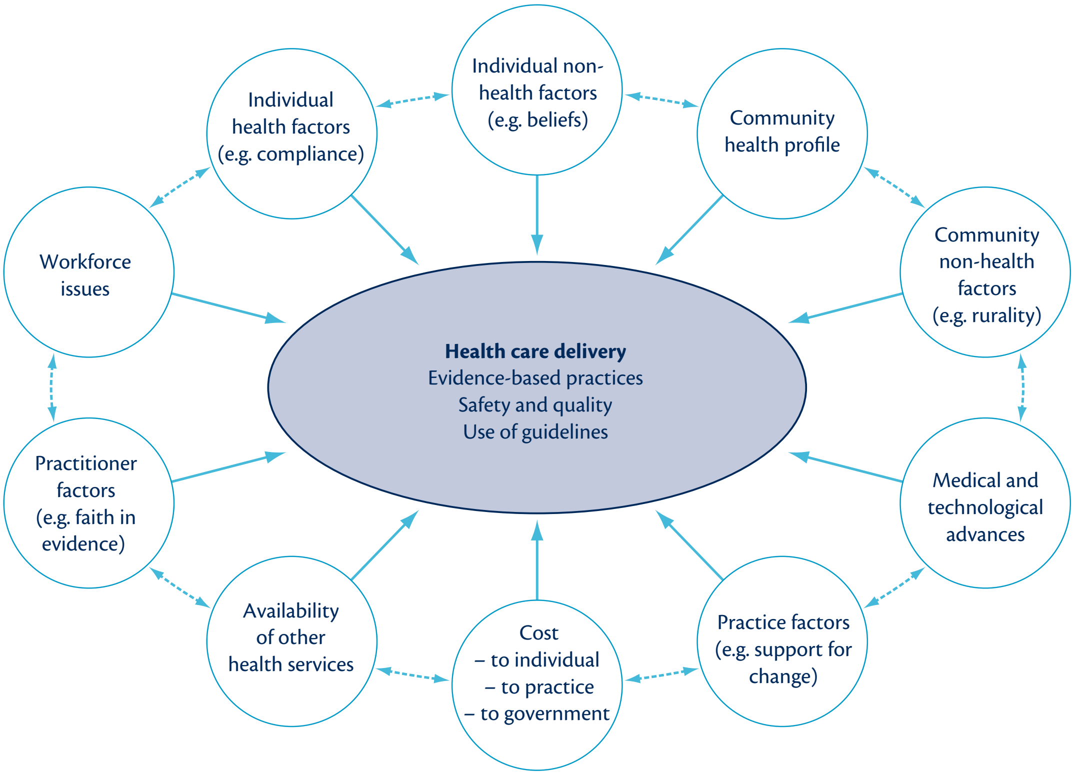


Figure 4.1: Factors influencing uptake of and adherence to 'best-practice' in general practice

Therefore, in order to adequately assess the quality of care, other factors that provide the context for the interpretation of the data collected need to be examined. For example, determining whether a drug is being prescribed appropriately requires information about the condition(s) for which it is prescribed, the comorbidities exhibited by people with these conditions and any potential contraindications in the use of the drug.

A synthesis of the main evaluation criteria

The criteria below were developed from the information needs described in the previous pages. They attempt to capture the various types of data that would be necessary to assess the quality of care provided in general practice, including the evaluation of patient outcomes.

1. Demographic information

Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)

2. Workforce information

Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)

3. Problem managed

Can each encounter/prescription/service be connected with a diagnosis or problem managed?

4. Comorbidities

Is information about the patient's comorbid conditions available?

5. Clinical outcomes

Can the treatment of a specific problem in an individual, and the results of this, be followed over time?

6. Adherence to guidelines

Does the database provide information to examine the use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)

7. Best-practice care

Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can the completion of an annual cycle of care be identified and (ii) are the results of individual components of the cycle available?

8. Patterns of care

Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used and results of tests/specialist consultation)

9. Patient perceptions

Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?

10. Potential for linkage

Does the database contain information to enable (i) internal linkage (for example, to other episodes of care); (ii) external linkage (to other data collections, for example, hospital records or the National Death Index)?

11. Data quality

Is the sample nationally representative? Are the data reliable? Are the data complete (that is, low frequency of missing data)?

Results of the evaluation

Due to the varied nature of the collections considered, making a comparable assessment across the board is difficult. Some of the collections—both the paper-based collections discussed in Chapter 2 and the electronic ones discussed in Chapters 3—are condition-specific (for example, ASPREN, AusDiab), whereas others are generic. Although population health surveys provide valuable information about patient perceptions, functioning, comorbidities, satisfaction with care and quality of life, they do not capture detailed data about the content of encounters between individuals and health-care providers. Administrative data have the advantage of near-complete coverage, but also provide little detail about encounter content. Conversely, collections of GP–patient encounter data are a rich source of information about the care process, but provide little contextual information.

Each of the different types of collection—indeed each collection—has advantages and limitations; no currently existing data collection fulfils all of the needs expressed by stakeholders. The collections provide different, but complementary, views of a very complex whole: the components, processes and outcomes of the Australian primary health-care system. However, the evaluation does illustrate which data collections are most appropriate for providing different kinds of information, and which have the most potential for providing comprehensive information in a future electronic data collection system.

Assessment of the current collections

Tables 4.1 and 4.2 summarise the results of the criteria-based evaluation of existing data collections. Detailed results are provided in Appendix 4.

Paper-based and administrative collections

As previously stated, none of the data sets performed well against all 11 criteria. Only one collection, BEACH, reported a diagnosis or problem managed. Being able to link management actions to a diagnosis is essential for determining whether those actions were appropriate and reflect the evidence base. Despite the advantages of excellent coverage and high data quality displayed by several of the administrative collections (for example, MBS and PBS), the usefulness of these data in terms of providing information to assess the quality of care is severely limited by the lack of a clinical diagnosis or reason for the service.

The population health surveys—although not providing information about the content of encounters between individuals and medical practitioners—provide valuable contextual information about the burden of disease and the potential need for services, as well as offering population-level assessments of quality of life, functioning, perceptions of health and, in some cases, satisfaction with health-care services. The ability to generate detailed information of this kind at the small area level (for example, by divisions of general practice) would greatly enhance the value of encounter-based data at the jurisdictional and regional levels for research and professional bodies.

Electronic collections

Several of the electronic collections performed well against the criteria. The encounter-based collections CONDUIT, GPRN and Medic-GP all provide a diagnosis, record detailed information about the care process and enable follow-up of individual patients over time. In addition, the CONDUIT collection incorporates linkage between general practice data and other health data, such as hospital records.

The aggregate data collections, although not performing as well as the encounter-based collections, nevertheless provide valuable information about specific issues, which is useful for monitoring and surveillance purposes as well as for supporting quality assessment and improvement processes within individual practices. These types of collections may be a useful way of generating topical data in an efficient and timely manner, in addition to a national 'core' encounter-based data collection.

Table 4.1: Summary of criteria testing for paper-based and administrative collections

	Demographic information	Workforce information	Problem managed	Comorbidities	Clinical outcomes	Adherence to guidelines	Best-practice care	Patterns of care	Patient perceptions	Potential for linkage	Data quality
GP–patient encounter collections											
BEACH	Yes	Yes	Yes	Limited	No	Yes	Limited	Some[(a)]	Limited	No	Very good
Population health surveys											
ALSWH	Yes	No	No	Yes	No	Limited	No	No	Yes	Yes	Very good
AusDiab	Yes	No	No	Limited	No	Limited	Some	No	Yes	Yes	Good
NATSIHS	Yes	No	No	Yes	No	No	No	No	Yes	No	Good
National health survey	Yes	No	No	Yes	No	Yes	No	No	Yes	No	Good
VPHS	Yes	No	No	NHPAs only	No	No	Some	No	Yes	No	Good
WA HWSS	Yes	No	No	Some	No	No	Some	No	Yes	No	Good
Administrative collections											
MBS	Some	Minimal[(b)]	No	No	Limited[(c)]	No	Limited[(c)]	No	No	Yes[(d)]	Excellent
PBS	Some	Minimal[(b)]	No	No	Limited[(c)]	Limited	No	No	No	Yes[(d)]	Excellent
PIP and SIP	No	Some	No	No	No	No	Some	No	No	No	Good
RPBS	Some	Minimal[(b)]	No	No	Limited[(c)]	Limited	No	No	No	Yes[(d)]	Excellent
Research and other collections											
HIT	No	Some	No	No	No	Limited	No	Limited	No	No	Good
NPS GP survey	No	Yes	No	No	No	Some	No	No	No	No	Unknown
NPS consumers	Yes	No	No	No	No	Some	No	No	Some	No	Unknown
TAPS	Yes	Minimal	No	No	No	Limited	No	No	No	No	Unknown

(a) Information on referrals written by GP, but no follow-up information.

(b) Service provider identified by individual code, so it may be possible to obtain further details.

(c) Information only available via linkage. Diagnosis inferred only.

(d) Conditions of linkage constrained by legislation.

Table 4.2: Summary of criteria testing for electronic collections

	Demographic information	Workforce information	Problem managed	Comorbidities	Clinical outcomes	Adherence to guidelines	Best-practice care	Patterns of care	Patient perceptions	Potential for linkage	Data quality
GP–patient encounter collections											
APCC	No	Some	Some	No	No	Some	Some	No	No	No	Fair
CONDUIT	Yes	Some	Yes	Yes[a]	Yes[a]	Yes	Potentially	Yes	No	Yes	Fair
GPRN	Yes	Some	Yes	Yes[b]	Yes[b]	Yes	Yes	Yes	No	Yes (int)	Good
Medic-GP	Some	Some	Yes	Yes	Yes	Yes	Yes	Yes	Some	Yes (int)	Fair
Collections of aggregate data											
ASPREN	Some	Some	No	No	No	No	No	No	No	No	Fair
NT AHKPI	Yes	No	No	No	No	No	Some	No	No	No	Unknown
PHA	Yes	Yes	No	No	No	Some	Some	Some	No	No	Good

(a) Information can be obtained via record linkage.

(b) Information available where patient treated by a participating GP.

Yes (int) signifies internal linkage only.

Strengths and limitations of the existing data

The existing evidence base around services provided in general practice is rich and varied. A wide range of data is able to be generated, which provides information about costs, throughput, management patterns and the frequency of presentation of various conditions to GPs. Several collections contain detailed information about problems managed, and the related management actions undertaken by GPs, which can be used in assessing the quality of care. In addition, some of the existing electronic collections merit further examination with regard to the future development of a national electronic data collection system.

The major limitations common to several of the existing collections are:

- the lack of a diagnosis/problem linked to the service
- the inability to follow the treatment of an individual over time in order to determine outcomes
- the inability to link general practice data with other relevant health information (such as mortality or hospital records)
- low level of participation in providing information, which is possibly caused by the time-consuming nature of some collections
- a 'fit-for-purpose' design that may not always lend itself to the broader picture.

The lack of information available to inform patient-centred management and analysis has a flow-on effect that limits our understanding of the patterns of prescribing, referrals and investigations used in general practice. As a consequence, there is no feedback loop to inform and stimulate general practice to become more involved in the collection and use of such data.

Fuelling the effects of low participation rates for some of the electronic collections is the difference between doctors in using the capabilities of their electronic clinical systems, which results in varying degrees of missing data. There is also inconsistency and variability associated with the use of coded terms and free text language in electronic clinical records, coupled with the mismatch across different medical software applications.

The combination of a diagnosis, longitudinal analysis, linkage to other health information and standardised coding—along with a record of management actions undertaken by the GP—enables assessment of the care provided against relevant best-practice guidelines. This will assist in the evaluation of patient outcomes and provide doctors, governments and the community with essential information to underpin the continual improvement of health services.

Determining the capacity to derive information to fulfil various elements of a collection requires an understanding of the patient–doctor encounter. An integral part of this relationship is the opportunity to collect data about the patient perspective (on their health and the health services they receive) and their compliance with the medical treatment and advice offered. Therefore, to inform discussion of the strengths and limitations of existing data collections, and the potential for future collections, it is prudent to examine real-life situations or encounters. The following chapter uses scenarios to illustrate the kind of data that might be collected during such encounters.

5 Scenario-based evaluation of existing data collections

In order to provide a more detailed examination of the utility of existing data collections, two scenarios were constructed with the advice of practicing GPs. Each of the scenarios presents a 'case study' (Herreid 1997) of an individual or a group and a particular situation commonly encountered in general practice.

What is a scenario?

A scenario is a brief narrative, or story, here used to describe the hypothetical use of one or more systems to capture relevant information for population health and/or problem management monitoring. For example, practice management systems manage the business of the general practice by recording patient details, managing bookings and attendances, and managing financial transactions, whereas clinical management systems may record information about the patient's health issues—current and past problems, conditions and treatments, including medications and diagnostic tests.

Expectations of the scenarios

The scenarios are designed to provide a complementary assessment of the usefulness of the existing data collections and also to illustrate some of the connectivity between these collections. In doing so, they highlight the data that need to be collected and extracted for reporting purposes.

Assessing collections against the scenarios

Each of the collections was assessed as to the extent to which the patient–general practitioner interactions, diagnoses and management actions were able to be recognised and from which the outcome for the scenario could be deduced.

A collection is deemed as a satisfactory starting point for an electronic collection only if it is able to provide these pieces of information—namely to satisfy criteria 1 and 3–9—and that the data collected is patient-based.

So, for patient encounters, it would be expected that information could be obtained about demographics (criterion 1), why patients come (problem managed) (criterion 3), what other conditions they present with (comorbidities) (criterion 4), and in managing the patients' care over the short and long term, what outcomes were achieved (criterion 5) and how these were achieved (criteria 6–8), and finally how satisfied the patients are with their care and/or their health status (criterion 9).

Scenario 1: Paediatric asthma

The policy and practice context for this scenario

In the context of the National Chronic Diseases Strategy (NHPAC 2006a), the approach for the management of asthma encourages coordinated action to manage the impact of the disease. In accordance with the National Asthma Strategy 2006–2008 (DoHA 2006) and the National Service Improvement Framework (NSIF) for Asthma 2005 (NHPAC 2006b), a GP would be expected to appropriately manage an occurrence of asthma by:

- correctly diagnosing the condition
- making an assessment of its severity
- devising a proper management strategy, including appropriate medication, patient education, and a written action plan
- providing for ongoing monitoring, including the scheduling of appropriate follow-up
- referring the patient, where appropriate, to a specialist.

An integrated and ambulatory model of care is seen as the best approach for the cost-effective management of chronic diseases. The goal is to prevent and manage such conditions in the home and community environment to avoid costly hospitalisations. For the delivery of optimal services for patients with asthma, critical intervention points for the management of asthma, as highlighted in the NSIF, could be monitored if the relevant data were collected. This could provide a means to monitor the extent to which evidence-based medicine is applied in practice. The monitoring of such intervention points could be used to assess the extent to which the burden of asthma in the community is reduced through effective primary health care.

The problem the scenario tackles

The information to be collected is about the encounter a GP has with a child exhibiting signs of asthma, as a first recognised occurrence. As an individualised written asthma action plan is an essential component of optimal self-management education—leading to clinically significant reductions in hospitalisations, emergency department visits and unscheduled visits to the doctor for asthma (National Asthma Council Australia 2000)—it is expected that this action would be able to be recognised using data collected from practice records.

The scenario

In this scenario, the patient presents to her local GP with a problem of not being able to get rid of her cough. The patient is a young child whose mother smokes. The GP belongs to a medium-sized metropolitan medical centre with sophisticated patient management and clinical management systems. The medical practice has an integrated suite of software to manage the business of the practice and encounters with its patients.

About the patient

Myra Anderson presents to her local medical centre to see her doctor about her daughter Vanessa's cough. Myra, a 32-year-old woman, is concerned that her daughter has got another chest infection and ongoing cough.

Vanessa, who has just had her seventh birthday, wants to go on her first school excursion. Myra is keen for Vanessa to go, but wants to make sure Vanessa is well enough to go for the long day of the excursion.

Register patient

Myra and Vanessa present at 9:30am to the front counter of the medical centre for Vanessa's appointment with Dr Ramone. Although Myra is registered as a patient of the centre, it is Vanessa's first visit to this medical centre. Myra is asked by the reception staff to fill out the patient registration form.

Data that would be collected by GP system	Data needing to be extracted for a national data collection
Patient details:	
Family Name	
Given Name	
Date of birth (D.O.B)	D.O.B
Country of birth	
Sex	Sex
Individual Health Identifier (IHI)	IHI
Indigenous status	Indigenous status
Address	Postcode
Contact details	
Carer details	
Medicare number	
Private health insurance fund code	
Date of encounter	Date of encounter
Time	

Understand problem (assess)

Dr Ramone asks what the problem is and Myra states Vanessa seems to have another cough which she cannot seem to shake. She coughs at night and she seems to be really tired of late. Myra has tried giving Vanessa some over-the-counter medication, which sometimes helps for a bit, but Vanessa's coughing is continuing.

Data that would be collected by GP system	Data needing to be extracted for a national data collection
Symptoms	Symptoms
Presenting problem	Presenting problem

Dr Ramone asks Myra to describe Vanessa's cough. Myra states that the cough sounds quite moist and that she thinks that it needs some antibiotics to clear it up.

Dr Ramone asks Vanessa how long she has been feeling this way and Myra states that it is about a month. Myra states "It seems as if it never really went away after the last cold she had".

Data that would be collected by GP system	Data needing to be extracted for a national data collection
Date of onset	Date of onset

Dr Ramone asks Vanessa to describe more about the cough, its pattern and what happens if she runs around or plays sport. Vanessa states she coughs at night time, sometimes a lot, and also when she runs around at school. Vanessa adds that sometimes she has to stop to cough.

Relevant past and family history

Dr Ramone gathers past history by asking Myra if Vanessa has had any previous illnesses or hospitalisations. Myra responds Vanessa has always been a bit chesty. Vanessa has been hospitalised once, when she was one, for gastroenteritis. Apart from that, Myra declares Vanessa has been well.

Dr Ramone asks Myra whether anyone in the family has asthma, hayfever or allergies. Myra says her brother had asthma when he was younger, and that she used to get bronchitis a lot. Myra adds that Vanessa's dad gets bad hayfever and she thinks he may have also had asthma as a child but she is unsure. Myra states her father also gets asthma.

Dr Ramone checks Vanessa's allergy and immunisation history is up to date.

Dr Ramone then to ask some more questions about Vanessa, including whether there are any recent changes at home, whether they have any pets, and if anyone at home is a smoker. Myra admits to smoking and Vanessa says this really makes her cough.

Data that would be collected by GP system	Data needing to be extracted for a national data collection
Exposure to ETS flag	Risk factor

Clinical examination

Dr Ramone takes Vanessa's temperature, looks at her throat, and looks in her ears. Dr Ramone asks Vanessa to cough and to take a couple of large breaths while he listens to her chest.

Dr Ramone observes Vanessa has expiratory wheeze in most zones and tends to cough after expiration. Her chest is slightly overexpanded, but she is not using additional muscle to help her breathe. She has no fever and her throat and ears are normal.

Identify condition

Dr Ramone advises Myra that Vanessa's cough sounds more like a mild asthma than infection. Antibiotics are not likely to help in this situation.

Diagnosis	Diagnosis

Dr Ramone explains that this is a common condition in children and in Vanessa's case is most likely due to her lungs remaining a bit inflamed following her recent cold. Dr Ramone also explains to Myra that her family history makes this more likely. He reassures Myra and Vanessa that this is a treatable condition.

Severity	Severity

Myra states she knows a little about asthma from her brother and other parents at the school who talk about their kids having asthma. Myra states she does not want Vanessa taking steroids and enquires about other medication.

Dr Ramone downloads a brochure G*ood Asthma Management for Everyone. A Guide for People with Asthma* and talks Myra through the key points about asthma, its symptoms and their causes and its triggers.

Dr Ramone also uses the opportunity to advise Myra that Vanessa being exposed to passive cigarette smoke in the house can also be a triggering factor and that perhaps they need to talk more about her smoking. He asks Myra to try to give up her smoking or at least try to smoke outside of the home to help Vanessa better cope with her condition. He invites her to return and discuss this at another time.

Dr Ramone advises Myra that there are different options to manage Vanessa's condition and they could try tablets or a non-steroid preventative puffer. Myra and Vanessa agree the puffer would be better for them.

Dr Ramone checks to see whether June, the practice nurse, can see Myra and Vanessa before they go home. Dr Ramone prescribes Tilade to be used morning and night via MDI and spacer and Ventolin to be used if required when she is coughing a lot or wheezing.

Data that would be collected by GP system	Data needing to be extracted for a national data collection
Medication Order Identifier	Medication Order Identifier

He arranges to see Myra and Vanessa in 2–3 weeks to ensure the cough has resolved and to discuss ongoing management.

Review date	Review date

June explains how to use the use the MDI with the spacer and asks Myra to help Vanessa to take a dose of her prescription, as directed by Dr Ramone, when they get home.

June reiterates how passive smoke may be triggering some of Vanessa's attacks and provides some guidance for Myra to help her give up.

Review appointment

Dr Ramone asks Myra how Vanessa is going. Myra replies the cough seems to have settled and she is sleeping much better. She can also run around again without coughing. Myra has also not given Vanessa any ventolin for more than a week and she seems much better. Dr Ramone listens to Vanessa's chest and is satisfied that it is now clear.

Date of encounter	Date of encounter
Time	
Presenting problem	
Symptoms	
Diagnosis	Diagnosis
Severity	Severity

Dr Ramone reviews Myra's understanding of asthma and uses this opportunity to write out a set of instructions for Myra using a coloured Home Management of Asthma—Action Plan which he accesses from his letter templates. The Action Plan sets out written instructions about how to recognise asthma and what Myra is to do when Vanessa has symptoms. They decide to wean Vanessa off the Tilade over the next week and see how she goes.

Date action plan	Date of action plan

He suggests Myra contact the Asthma Foundation for further information and recommends <www.nationalasthma.org.au> for web-based resources.

	Data that would be collected by GP system	Data needing to be extracted for a national data collection
Dr Ramone again encourages Myra to quit smoking because it will bring benefits to both her and Vanessa and that she should try the Quit program.		
He asks Myra to book a follow-up appointment in 3–6 months.	Review date	Review date
Follow-up visit		
Vanessa and Myra return after 4 months—Myra has not quit smoking, but she does not smoke in the house or the car and she thinks this has helped her cut her smoking to no more than 10 per day. Myra is still trying to quit.	Date of encounter Time Presenting problem Symptoms	Date of encounter
Vanessa has had the occasional puff of ventolin when she started swimming lessons as she started coughing with this exercise. Recently, Vanessa had another cold and started Tilade as per her asthma management plan, which seemed to prevent her developing asthma or a prolonged cough on that occasion.	Diagnosis Severity	Diagnosis Severity

Data collected during the encounter

For this scenario, information about patient demographics (criterion 1), problems managed (criterion 3), the clinical outcome achieved (criterion 5), adherence to guidelines (criterion 6) and evidence of best-practice (criterion 7) can be collected. The patient did not present with comorbid conditions (criterion 4) nor were referrals (criterion 8) for specialist services or diagnostic tests ordered. No information is available about how the patient felt about her health or the quality of care that she was provided (criterion 9).

For this scenario, data captured during this encounter could be used to report information for the following indicators (ACAM 2007):

- doctor-diagnosed asthma
- symptoms of asthma in the last 12 months
- symptoms of a wheeze in the last 12 months
- smoking in the household where children with asthma reside
- written asthma action plan.

Commentary

Monitoring for the adoption of evidence-based practice would require data from all three encounters to be collected to ensure clinical interventions have been applied at critical points (NHPAC 2006b). The data extracted for each encounter, from the initial encounter to the review of the patient's adherence to the asthma action plan, would need to be linked to see if the action plan is having the desired effect for achieving a positive clinical outcome for the patient. Thus for the 'parent' record, where the condition was first diagnosed, the subsequent 'child' records would also need to be extracted.

Utility of existing data collections

The majority of the data collections described in this report would not be able to provide all of the required pieces of information; indeed, most would provide very little. CONDUIT, GPRN and BEACH do collect much that is relevant (demographics, symptoms, diagnoses, treatments provided) but not all. The connection between the first and subsequent encounter is the most problematic factor, as the linkage over time to follow treatment patterns is not yet possible in most cases. However, the method in use by CONDUIT has potential in this regard.

Scenario 2: Influenza vaccination

The policy and practice context for this scenario

It is estimated that influenza—a potentially fatal disease—causes more than one million consultations, 20,000–40,000 hospitalisations, 1,500 deaths and 1.5 million days off work each year in Australia (Influenza Specialist Group 2006).

To reduce this impact, an improvement in vaccination rates for target populations at high risk would have significant benefits to Australia because the need for health services, and therefore costs, would be reduced. Influenza and its associated complications, if not treated early, are one of the major reasons people in these high-risk groups are admitted to hospital.

The problem the scenario tackles

The information that needs to be collected relates to the encounter a GP has with an existing patient who was recalled for her influenza immunisation, but did not come to the practice influenza clinic.

A significant cause of illness, influenza greatly affects those people who suffer from chronic conditions such as heart disease, diabetes and lung disease. This group not only includes people over the age of 65, but many people below that age who, because of their health status, are at risk of severe illness, hospitalisation or death due to the effects of influenza.

As an annual influenza vaccination is an essential preventive treatment for people at risk, it is expected that the fact that the patient has not had her annual vaccination would be an item that could be recognised, that whether appropriate action is taken could be monitored and the associated data could be collected from GP system(s).

The scenario

In this scenario, the patient with a complex comorbid condition presents to her local GP with a problem of not being able to get sufficient sleep. The patient is recognised as belonging to an at-risk group aged less than 65—an annual influenza vaccination is recommended. The GP belongs to a medium-sized medical centre that has a clinical management system, but patient bookings are taken manually.

About the patient

Helen Lazaridis presents to her local medical centre to see her doctor about renewing her medication. Helen, a 52-year-old woman, has three teenage children, two of whom still attend school, while the oldest Anna helps her out in the shop. Helen's husband Nick was killed in a fishing accident 2 years ago.

Register patient

Helen presents at 4:30pm to the front counter of the medical centre for her appointment with Dr Rachael Cohen.

Dr Cohen calls Helen and they go to the consulting room.

Understand problem (assess)

Dr Cohen asks what seems to be the problem. Helen states she just needs a renewal of her medication.

Dr Cohen explores how Helen is going with her health care. Dr Cohen probes further about the general management of her health. Helen is not exercising sufficiently and is not sleeping very well. Helen also complains about her arthritis and that she has been taking paracetamol but recently moved to taking nurofen and glucosamine. Dr Cohen decides to review Helen's current medications and measure her weight, waist circumference and check her blood pressure.

Relevant past and family history

Helen's blood pressure is 120/78. Helen's history shows she has Type 2 diabetes, hypertension and hyperlipidaemia. Helen is also overweight, with a BMI of 29. Helen is a non-smoker and non-drinker. Dr Cohen notes her family history of diabetes and heart disease in her mother and that her father died of lung cancer. He also notes she was recalled for her influenza immunisation, but did not come to the practice influenza clinic. Helen's last diabetes screening was completed 4 months earlier and they had agreed a 6 month review of her care plan which would be due for review in 2 months time.

Clinical examination and identify condition

Dr Cohen advises Helen that he would like to review her medication to make sure she is not going to run into any problems. He organises a medication review for the pharmacist to visit her at home and go through all Helen's medication with her, including the tablets she is getting from the health food shop.

Data that would be collected by GP system	**Data needing to be extracted for a national data collection**
Patient details:	
Name	IHI
Date of birth (D.O.B)	D.O.B
Country of birth	
Sex	Sex
Indigenous status	Indigenous status
Address	Postcode
Contact details	
Carer details	
Medicare number	
Private health insurance fund code	
Date	Date of encounter
Time	
Reason for encounter	Reason for encounter
Symptoms	Symptoms
Presenting problems	Presenting problems
Risk level	Risk level

Dr Cohen uses the online referral network to see if there is an accredited pharmacist in her area. Dr Cohen completes the online e-referral form and sends the referral via the secure network (Argus) to Ryan's Pharmacy.

Dr Cohen advises Helen once she and the pharmacist have reviewed her medication and she gets Helen's Medication Review back, the practice will give her a ring and ask Helen to book an appointment to follow-up the results. Dr Cohen suggests it may also be a good time to review her care plan.

Data that would be collected by GP system	Data needing to be extracted for a national data collection
Planned review date	Planned review date
Medication Order Identifier	Medication Order Identifier

Before Helen leaves, Dr Cohen arranges for her to see the practice nurse and have her influenza vaccination.

Follow-up visit

Helen returns the following week. Dr Cohen and the pharmacist have reviewed the results of Helen's Medication Review (NPS Form) and Dr Cohen explains the plan of action in relation to Helen's medication regime with her.

Data that would be collected by GP system	Data needing to be extracted for a national data collection
Date	Date of encounter
Time	
Presenting problems	Presenting problem
Symptoms	
Diagnosis	
Severity	Risk level
Date medication management plan	Date medication management plan

Data collected during the encounter

For this scenario, information about patient demographics (criterion 1), problem managed (criterion 3), the presence of comorbid conditions (criterion 4), the clinical outcome achieved (criterion 5) and the adherence to guidelines (criterion 6) and evidence of best-practice (criterion 7), and referrals (criterion 8) for specialist services can be collected. No information is available about how the patient felt about her health or the quality of care that she was provided (criterion 9).

Data captured may be used to report against the following indicators:

- doctor-diagnosed influenza risk group
- vaccination (medication order identifier) dispensed.

Commentary

For this scenario, although other health conditions of the patient may need to be monitored, it is the data about the detection of a patient at risk and ensuring that the clinical investigation does not reveal the onset of symptoms of influenza—and hence that the desired prevention is put in place (vaccination is given)—that needs to be captured.

To monitor for the adoption of evidence-based practice, data from the first encounter may be all that is required to ensure clinical interventions have been applied at critical points.

Utility of existing data collections

As for Scenario 1, most of the existing data collections would provide very little of the required information. Again, the most promising candidates for further development appear to be CONDUIT, BEACH and GPRN, with the issue of connecting information from more than one encounter being a substantial hurdle to be overcome.

6 Summary and recommendations

Primary health care is a vital component of the Australian health-care system. General practice has a central role in this system, with general practitioners acting as coordinators of ongoing and comprehensive care across the life course. Obtaining reliable, accurate and comprehensive data about general practice, therefore, is essential for:

- determining the need for services
- highlighting inequities in access and outcomes
- assessing the uptake of best-practice guidelines and evidence-based practices
- evaluating the outcomes of interventions
- providing practitioners with evidence for clinical decision making
- informing policy and strategy development.

For the purposes of this report, a key goal for the management of primary health care in Australia is that, within 5 years, sufficient information will be available for monitoring the outcomes, effectiveness, quality, safety and value of services provided by the primary health care sector. Such information (for example, medical history, allergies and current medications) would enable health-care providers to make the safest and most appropriate decisions about individuals for the management of their treatment and care. This information—under the principle of collect once and use often—would also be valuable for research and quality assurance purposes. Hence, the ability to capture information connecting diagnosis, treatment, referral and outcomes over time, and between different levels and sectors of the health system, would also allow analysts to build comprehensive pictures of the factors affecting the provision and outcomes of care. Data about contextual factors, such as access to and availability of services, is also important for interpreting this information.

This review and evaluation of existing data collections relevant to general practice has highlighted the strengths and limitations of the current evidence base. It has also identified several collections that provide valuable information that could be used to assess the quality of care provided in general practice, and that have the potential to be expanded or further developed in the move towards a national electronic general practice data collection.

Evaluation results

At present, data for assessing the quality of care in general practice are limited. Although some parts of the picture can be filled in from various sources—for example, tracking the individual components of the annual cycle of care for diabetes through MBS data, or examining prescribing practices for certain conditions through BEACH—this is only possible in specific circumstances and for particular health conditions. One of the major limitations is the lack of data that can be used to follow the management of individual patients over time, and where management actions are linked to a specific diagnosis. Without the link between the management actions and the reason(s) for these actions (in terms of a diagnosis or symptom pattern), assessing whether the actions were appropriate is almost impossible.

A key requirement for a general practice data collection that could be used to assess the quality of care and the uptake of best-practice is that the data must be able to be analysed at the individual patient level. Additionally, the recording of interventions at each encounter must be able to be linked to trace their effects on both the patient and treatment of the disease. Of the 11 criteria used to assess the data collections, nine relate to patient-level data, while the other two criteria (Criterion 2 and Criterion 11, as described in Chapter 4) relate to information about the health-care provider and to the quality of the data collected, respectively. Of the 22 existing data collections examined, only four satisfy at least seven of the nine patient-level criteria—the base level of information considered adequate for the above purpose (Table 6.1).

Table 6.1: Summary of criteria-based evaluation results—the 'top four'

Collection	Criteria satisfied (n/9)	Notes
MEDIC-GP	9	Demographic information (criterion 1) and information about the patient's quality of life or satisfaction with care (criterion 9) is limited. This collection is no longer active. Large number of records from small sample of practices (150 GPs), from all states, but not geographically representative. Variety of clinical software systems supported.
CONDUIT	8	There is potential to derive evidence of best-practice care (criterion 7) from current information. Although no information about the patient's quality of life or satisfaction with care (criterion 9) is currently recorded, the system has the capacity to do this. Variety of clinical software systems supported. Small regional collection at present, but with capacity to expand. All health settings captured, with general practice as focus. Only computerised services are able to participate. Some problems with data quality and completeness, but good potential to resolve these issues. Collection has ethics approval and individual patient consent is obtained.
GPRN	8	No information about the patient's quality of life or satisfaction with care (criterion 9) is recorded. Only GPs using the clinical software 'Medical Director' are able to participate (randomly sampled). Large number of records from moderate number of GPs (currently around 400). Uncertain whether nationally representative. Good data completeness. No ethics oversight of collection, nor is explicit patient consent obtained.
BEACH	7	No information about outcomes (criterion 4) is recorded. Data are not able to be linked internally or externally (criterion 10). Information about best-practice care (criterion 7), patterns of care (Criterion 8) and the patient's quality of life or satisfaction with care (criterion 9) is limited. Paper-based survey allowing any GP to participate subject to a minimal level of Medicare claims. National random annual sample with some under-representation of younger GPs. Large number of records from relatively large GP sample (around 1,000 per year). Collection has ethics approval and patient consent is obtained.

Of these four collections, the first three are drawn from computerised extractions of clinical records. GPRN is based on an extraction tool developed specifically by and for a single clinical software provider—only GPs using this particular software are able to participate. MEDIC-GP was specific to pharmaceutical-related de-identified clinical records; a variety of clinical software systems were supported, but collection ceased in 2004. CONDUIT is supported by a sophisticated collection process where linked data from hospitals, general practices, pharmacies and other health services can be extracted and deposited into a secure data warehouse for further analysis; a variety of clinical software systems are supported.

A limitation common to all three collections is that the sample of GPs able to participate is of necessity limited to those who keep electronic patient records in a software system supported by the extraction tool; this will of course be the case for any electronic data collection system. The remaining collection, BEACH, is a compilation of manually completed surveys and so GPs don't need to have access to a computer, nor use a particular clinical software product, but this method too has its own limitations.

The types of electronic methods in use by CONDUIT and GPRN appear to be useful starting points for exploring an electronic data collection, though each of these still has specific limitations (detailed in Chapter 3) that need to be overcome. Considering the e-health agenda and the desire to enable linkage and transfer of clinical records between different health providers, the CONDUIT system has great potential. Useful lessons can also be learned from the Medic-GP collection, the Practice Health Atlas tool and from the variety of smaller-scale electronic collection activities occurring within specific divisions (for example, GPpartners and Canning). The BEACH team also has been involved in exploratory work relating to electronic collection methods and standards. Making the transition to electronic collection of general practice data will be a complex and time-consuming process. The experiences of all of the organisations and individuals involved in existing and past data collections are extremely valuable and should be considered in determining the best way forward.

The evaluation also demonstrated that collections other than those containing GP–patient encounter data may provide useful information about general practice. Specifically, survey data can provide information about patient satisfaction with health services, about functioning, quality of life and self-assessment of health, and about reasons for seeking, or not seeking, care when required. In addition, some surveys can provide data about receipt of care relevant to particular diseases: AusDiab data relating to tests undertaken as part of the annual cycle of care for people with diabetes is a good example of this.

Data collection principles

In exploring electronic collection of patient-level data, it is important to establish a set of guidelines around the supply of such data. At the consultation meetings, stakeholders suggested the need for a set of principles around the collection and use of general practice data. These principles would form the foundation for the future collection, storage and use of information about general practice activity.

One of the central themes of the discussion around data collection through general practice was the incentive for GPs and practices to participate. GPs and representatives of relevant organisations expressed a general willingness to participate in data collection activities if it could be demonstrated that the resulting information would be used to improve health and health-care services, for example, by enabling research or informing policy decisions.

Principles discussed in consultation meetings included:

Implementation

- The process should be efficient—collect once, use often.
- Start small and simple—be realistic about what information is needed, manage expectations and use testing phases to refine the process before implementing on a large scale.
- Minimise collector burden, and make sure information is being collected from the most appropriate person.

Data access and use

- Focus on information sharing not information gathering—data should be useful, accessible and fed back to those who collected it.
- Enable data linkage and secondary uses of routine data where possible.

Governance

- Establish a clear governance framework, for example, through a dedicated data agency.
- Balance data access with data security and protection of individual privacy.

Resourcing

- Provide appropriate resources to make data collection and reporting ongoing and sustainable.

In making the transition to a national electronic patient-level collection about services provided in general practice, it is important that stakeholders are able to put the principles they have declared into context. There are several issues that need to be dealt with in this transition process to ensure that sufficient and necessary information is made available for its intended purpose(s).

The transition to an electronic collection

The primary purpose of patient information recorded by a GP—whether stored on paper or electronically—is to support the care of the patient. The information it contains contributes to the future care of the patient by their GP. It may also be communicated to (and from) other health professionals where care for the patient is required. Although it acts primarily as an 'aide memoir' to the GP for that patient, it also has considerable value for epidemiology and service planning.

Other uses for patient health information include:

- billing
- evidence of the provision of care
- reviews of quality and performance through clinical audits, accreditation, and so on
- education
- research
- public health reviews
- policy development.

Because patient notes have often been inadequate for these other functions, specific requests from interested stakeholders have been required. Historically, information sought for these purposes has been gathered through paper-based data collection tools.

A structured paper form prompts all participants involved in collecting patient data to answer direct questions in the manner requested by the intended data recipient. Individual pieces of information, similarly labelled, can be organised in a manner that permits the linking of any of the concepts captured. If specific information is required, a data collection tool can be designed and distributed to data collectors (in this scenario, GPs), which, on completion, will theoretically answer the topic in question. This may well include information not stored in a patient's medical record, and which is unknown by the GP until such information is actively sought from the patient during a consultation.

Although the inclusion of a data element into the design of a structured paper instrument infers that a response is required, the number of items ultimately completed remains at the discretion of the GP.

Electronic collection of data generated by GPs is a potential alternative to the traditional paper-based survey methods currently in use. The main challenge to the successful change of data collection format is to ensure that data collected either passively or actively from a patient's electronic record is at least as accurate and complete as that collected on paper, so that valid, reliable results can be inferred via appropriate analyses.

Active data collection usually involves asking a pre-determined set of questions. If active data collection is involved, the difference in format (paper versus computer screen) affects only the capacity of the GP to contribute: if a GP has a computer, the same information can be collected via an electronic 'form' designed with a software program as can be collected on paper. Either format is open to the same discretionary behaviour of the participant in terms of the number of items completed.

To capture this type of information from a patient's record in a passive manner seems similar on the surface, but is actually very different. Active data collection involves asking a sample of GPs to provide specific pieces of information—which are identically labelled and defined—about a patient or condition. Passive data collection involves sorting through previously recorded information in the hope that the specific items sought may already exist in a recognisable format. Where the record has some type of structure, it is more likely that specific items have been included because the GP has been prompted accordingly. Records that consist of short notes taken on blank paper are almost useless for secondary purposes—even should adequate information be recorded, the amount of time and resources needed to process it is prohibitively large.

For this reason, active collection has been the preferred method of information gathering for most data collectors. For example, if information was required about patients with Type 2 diabetes, a tool would be designed that would ask GPs to actively report specific elements, such as a patient's age, sex, HbA1C level, and current medication regimen for diabetes management. There have been occasions where (paper) patient records have been manually examined to obtain this information, but this has proven a laborious, time-consuming and often costly process, with no guarantee that the information sought has been recorded at all and, where it has, that it was recorded consistently, either between GPs or within a GP's own records. Where items are recorded, there is at best an assumption that GPs record and interpret concepts in a similar manner, given the absence of definitions—for example, what is meant by 'reason for visit' or 'reason for prescription'. The absence of definitions, the inconsistency of completeness and the lack of inter- and intra-recorder reliability are significant methodological flaws.

The introduction of patient records in an electronic format offers the potential to collect useful patient data passively. The present situation is that there are approximately 35 different providers of clinical software to GPs in Australia. Recently, several companies have developed tools capable of extracting data from some software products; some work on a single software system and some have broader capability and can extract from several different systems. It appears on the surface that the transition from paper to electronic data collection should therefore be a relatively simple process. However, there are a number of issues that need to be tackled if valid, reliable, representative general practice data are to be obtained from computerised patient records.

Issues for Australia

Desired functionality and adoption of standards

For all GPs to be able to contribute to the collective pool of patient information, all software products need to have the capacity to allow the capture, extraction and transfer of data. Currently there are many competing vendors, each with their own products. Clinical programs have been designed in isolation—in an environment of competition for vendors who aim to keep their customers 'locked in' to their product. Interoperability allows the 'freedom' for customers to take their business elsewhere, with no disruption to their practice processes, so there is little incentive for software developers to produce compatible products.

To date, there are no standards or regulations to which developers are required to adhere—resulting in products that in some cases have 'significant gaps in functionality' (Coiera & Westbrook 2006). Some investigations of functionality have reported incidences of defaults that caused the maximum number of repeats, or a 'do not substitute generic drugs' message, to be printed on prescriptions. On testing four popular software packages, the NPS found that some missed serious drug–drug interactions, and others produced numerous clinically unimportant alerts that ultimately led the GP to turn off all alerts (Harvey 2005). Presently, in Australia, the software embedded in, or linked to, clinical devices is tightly regulated, but clinical decision-support software such as prescribing programs are not considered 'therapeutic goods' and are not subject to regulation (Coiera & Westbrook 2006).

Communication infrastructure

There are still gaps in the telecommunications infrastructure that deny all members of the GP workforce the opportunity to participate in an electronic primary care data collection requiring electronic transfer of data. Broadband access is being improved, but no definitive timeline has been set. As has been experienced in other countries, large projects of this nature are often delayed because of unforseen technical problems.

Legal and ethical issues—ownership, privacy and consent

Legal issues for users remain contentious—even around the software itself. For example, in the event that errors result from a design flaw in a software update, who is liable if system problems lead to an adverse event: the designer, the vendor or the user? Questions of data privacy and security have not been satisfactorily answered, and no decision has yet been made about where data would be stored, and indeed who owns them. In addition, many of the existing collections do not obtain patients' consent to collect their information, and ethical oversight of its use is lacking.

Infrastructure for the storage and transfer of data also requires development. Australian information security technologies are presently inadequate and require improvement for the security of EHRs (Crompton 2004; Win 2005; Win et al. 2006). GPs will be less likely to give access to their data if they fear litigation, and patients will be less inclined to agree if they fear privacy breaches.

Rate of technology uptake

Encouraging clinicians to use the technology may take some time, given that computerisation is more common among younger GPs. Natural turnover of the GP workforce may resolve this situation, but the falling numbers of young doctors entering general practice in recent years (Britt et al. 2008) means that the workforce will remain dominated by older practitioners for some time. This means that some type of incentive or education process will be necessary to encourage all GPs to use electronic records and to complete the data entry to an appropriate level. There is evidence from a UK study that computers encourage 'minimalist record keeping'. Paper records contained more symptoms reported at the consultation, better recording of absent symptoms and better recording of severity of symptoms (Hamilton et al. 2003). As discussed in Chapter 3, there is evidence that GPs are selective about their use of computers in their clinical activity, and reliable data can only be extracted from a computer if it has been entered in the first place.

Encouraging participation in data collection

Australian GPs are independent practitioners, and participation in data collection could not be mandated by government. Participation would need to be encouraged, for example through education and raising awareness of the value of the data. GPs and GP groups involved in the stakeholder consultations expressed a willingness to participate in data collection if the value and usefulness of the data could be demonstrated to them. It is also important that participation not be burdensome; automatic data extraction tools and structured data entry within clinical software may assist with this. Engagement with software developers may also enable the use of standard data items, coding and terminologies that could simplify both data entry and data extraction.

The privacy and security concerns for both patients and GPs, as noted above, will also need to be tackled if adequate participation levels are to be achieved.

An ideal for Australia

In an 'ideal' data collection environment, general practices would be encouraged and enabled to capture reliable client and service data as part of their normal business activities. This should include data about the patients (demographics), data about the patients' health profile (problems and comorbidities), data that provides the ability to understand the demand for services (reason for service and patterns of care), data about the results of the care provided (patient outcomes and satisfaction), and data about the workforce. This information is essential for informing the planning of future health care services. Consequently, informed decision making is heavily reliant on the collection of accurate, relevant and reliable patient, service and provider data.

The implementation of this ideal under the principles for data collection would involve:

Stewardship and analysis of data (governance framework)

- Identification of core data requirements to enable program planning at a government level.
- Specifying principles around the collection, storage, transfer and security of client information that will form part of the core data collection.
- Nominating an independent body to have 'custody' of the de-identified patient data.
- Analyses to be performed by appropriate personnel, skilled and experienced in the methodology, statistical analyses and interpretation of primary care data.

Standards, structure and capacity (business processes)

- The use of a problem-oriented structure in the electronic record that allows both longitudinal follow-up of a patient over time holistically and for individual problems. Both aspects are of equal importance—it is not possible to measure outcomes for individual patients unless follow-up of specific problems are linked over time (and therefore can be observed); neither can any judgements be made about the quality of care producing those outcomes without the full holistic view of the patient's total morbidity pattern.

- Standards agreed for use in primary care need to be adopted in every clinical system. These would include standards for classification and terminology for morbidity and management, for classification of pharmaceutical substances, and for messaging between all external health care providers.
- Standard labelling of data elements; that is, an agreed set of data elements need to be defined and named such that the receiver of transferred data can ascertain that the elements labelled are all referring to the same piece of information.
- Development of a data dictionary, aligned with the National Health and Community Services Data Dictionaries, to establish the core set of data elements that are required to meet sector performance measures. A defined minimum data set for use in electronic records should be offered so that all GPs are collecting the same 'amount' of information. This is needed to identify 'missing' data to determine true numerators and denominators, without which no inferences can be drawn with any reliability.
- Ability to link data elements; that is the ability to link medications, referrals, pathology, imaging, and so on, with a specific morbidity and a patient encounter.
- Standards for hardware and software to ensure that the hardware systems in use can operate the software selected by the practice. Systems need to be compatible between practices for true interoperability across the primary care network.
- Interoperable data extraction tools, to include all GP data regardless of the software used to collect it.
- Sufficient telecommunications infrastructure so that all GPs have the capacity to be sampled and truly representative data from across the nation can be collected.
- Options for the handling of 'legacy' data—at whatever point a fully interoperable system is implemented in Australia, there is the real possibility that the data currently held in many GP systems will not be accessible because of the limitations of the systems in which they are currently housed.

Privacy, security and legal issues (data access and use)

- A unique patient identifier—although this has privacy implications, until patients can be uniquely identified in a secure manner, we will not be able to realise the benefits of complete longitudinal information where all visits by one person to any GP can be collated through a common identifier. (Design, building and testing of a unique identifier is being undertaken by NeHTA and Medicare Australia.)
- Secure data storage.
- Resolution of data ownership and access issues.
- Clear guidelines around the requirement for and obtaining of patient and practitioner consent to participate in data collection for various purposes.
- Clarification of, and education about, legislation describing responsibility for breaches of security or privacy, and where errors involving electronic system failures occur, for protection of both the patient and the GP.

- Ethical oversight of all bodies—both public and corporate—using data for any purpose other than direct patient care. Ethical oversight and the resolution of consent, privacy and security issues would encourage GP and patient participation in non-clinical uses of their data.
- A reliable de-identification process before patient data is transferred from the practice, except when identifiable collection is authorised by a relevant ethics committee. Any re-identification process should occur in the originating practice so that longitudinal records can be updated and again de-identified before transfer to external bodies for analysis and reporting.
- Specification of the reporting arrangements and collection methodology.

Support and education (resourcing)

- Streamlining of the funding strategy across multiple initiative and projects so that this can be used as a means for a staged national approach.
- Establishing a coordination process to minimise duplication of effort across multiple initiative and projects.
- Adequate, timely IT support for practices. Historically some vendors have only supplied ongoing support in order to maintain their client base.
- GP education processes to improve computer literacy in general and in the use of coding systems once standards are chosen and in place. These should be ongoing programs.
- Incentives for GPs to complete a patient record—if time constraints apply this may need ultimately to be undertaken by trained coding staff, as occurs in hospitals.

Recommendations for progressing towards national electronic collection

The review and evaluation of existing data collections revealed a variety of electronic data collection projects being undertaken across the country, both nationally (for example, the GP Census) and in small regions (for example, the Brisbane Health Record Exchange Program). Although each of these collections has its own strengths and limitations, there are lessons to be learned from them in terms of methods, implementation and stakeholder engagement.

In the context of the requirements for data to answer particular questions, the existing infrastructure and the 'ideal' outlined above, the following recommendations are made:

R1 A minimum data set specification for patient-GP encounters should be defined, in consultation with all stakeholders, which builds on work already undertaken in this area.

The evaluation criteria and scenarios demonstrate that a discrete set of data elements should enable detailed analysis of data for a variety of purposes, including the assessment of quality of care. Work on detailing these data elements and establishing the functionality required within clinical software for supporting quality care and collecting relevant data has already been done under the auspices of the General Practice Computing Group (GPCG 2004; Miller et al. 2005); the experiences of these working groups will be valuable in specifying a national minimum data set.

Inherent in defining this national minimum data set would be the development and endorsement of standards for the collection and coding of the data elements; this would integrate with the work of the National e-Health Transition Authority.

R2 The options established as potential starting points for an electronic collection should be explored with all stakeholders to formulate an agreed approach for implementing collection of this minimum data set at the national level.

This report has identified several examples of electronic data collection that have the potential to be applied at the national level. Ongoing engagement with the jurisdictions, the GP networks, clinical software vendors and the wider community will ensure that the needs of all parties are considered, and enable the development of a national implementation plan to be informed by the experiences of existing and previous data collection teams. A variety of collection methods, including stratified sampling and 'modular' collection of additional data items, should be considered. The plan should involve small-scale testing phases to refine the collection process before rolling out at the national level.

In developing and implementing any such collection, it is implicit that issues around consent, ethical oversight, governance, data security and protection of privacy need to be resolved.

R3 Where existing collections provide useful data, they should continue to be supported during the transition period and, where appropriate, afterwards.

A transition to fully electronic data collection in general practice will be a complex process, and it will take some time and considerable resources before an electronic collection system is able to be implemented on a national scale. The low rate of uptake of fully electronic clinical record keeping in general practice will continue to limit the number of GPs able to participate in such a system.

Several of the existing data collections provide valuable information that is not otherwise obtainable. It may be appropriate to expand the scope of some of these collections to provide a more representative sample or additional data items. These sources can continue to provide national data during the transition period, and may also be of use as a validation mechanism during testing and implementation of an electronic collection system.

In addition, some collections will continue to provide contextual and non-clinical information (such as data about the primary health care workforce or patient satisfaction) that will not be collected as part of the minimum data set. It is important that collection of these data continues into the future.

Appendix 1: Primary care data and information needs discussion starter

Potential areas of information need and example questions (as presented to stakeholders)

In order to assess how useful existing data are for providing information about GP services in Australia, we need to know what it is that people would like to use the data for. We would like to get your perspective on the importance of having good information about various issues, and what would be the questions you would like to be able to answer.

Listed here as an example are some of the major issues that have an impact upon general practice services, and some specific questions that could provide insight into these issues. The list is not exhaustive, but is intended to prompt consideration and discussion of a broad range of issues about which information may be needed.

We would appreciate your views on:

- the importance of these issues, and any others you would like to add
- the relevance or usefulness of the questions listed under each issue
- any additional specific questions you would like to see answered.

Accessibility and availability

Before issues surrounding the quality of care can be considered, patients must be able to consult with a GP. This means that services must be available where and when they are needed, and be accessible to all within the community. They should also be affordable. In addition, patients may be more likely to seek care, and be satisfied with the care received, if they are able to attend a GP of their choice (for example, women having access to a female GP regarding sexual and reproductive health issues). Other factors that might impact on accessibility and sustainability—particularly in rural and remote areas—are the size of the local practice, the hours worked and the ages of the practicing GPs.

GP characteristics may also affect the types of patients seen (for example, their age, sex, cultural background or particular health problems) and types of care delivered, so are important to consider when examining geographic differences or changes over time.

Questions that may provide relevant information about these issues include:

- What proportion of non-referred GP attendances are bulk-billed? (by geographic area)
- What proportion of practices are taking on new patients? (by geographic area)
- What proportion of practices provide or participate in out-of-hours care? (by geographic area)
- What proportion of practices offer home visits? (by geographic area)
- What proportion of GPs are aged 50 years or over? (by geographic area)
- What is the age–sex distribution of GPs? (by geographic area)
- What proportion of GPs work part-time? (by geographic area)

- What proportion of GPs are in solo practice? (by geographic area)
- What proportion of practices have a practice nurse? (by geographic area).

Prevention and detection

In addition to providing treatment for acute conditions and ongoing management for chronic conditions, GPs are well placed to prevent disease through promoting healthy behaviours and managing risk. This includes both opportunistic and regular screening and risk assessment, as well as targeted attention to those who are at high risk or are less likely to seek preventive care (for example, Indigenous Australians or men in rural areas).

Questions that may provide relevant information include:

- What proportion of GPs have relevant risk factor information for each patient (age-appropriate)? (such as SNAP, body weight, BP, cholesterol, blood sugar, family history, occupation)
- What proportion of practices have, or participate in, a register/recall system:
  - (a) for Pap smears
  - (b) for management of diabetes
  - (c) for immunisations?
- What proportion of eligible older people have received an EPC annual voluntary health assessment? (by area and patient demographics).

Quality, safety and appropriateness

Both patients and practitioners want to know that the care provided by GPs is safe, appropriate and in line with best-practice. A variety of schemes address this issue, including practice accreditation, the Practice Incentives Program (PIP), and 'quality use' programs (such as QUM and QUP).

Questions that might provide insight into these issues include:

- What proportion of practices are accredited? (by geographic area)
- What proportion of practices participate in each of the PIP incentives? (by geographic area)
- What proportion of the population are currently taking more than X prescription medications? (by age group).

Use of guidelines

Guidelines for practitioners provide a guide to best-practice, based on the available evidence. A large number of guidelines are available for GPs, covering such topics as management of Type 2 diabetes, use of antidepressant medications in children and preventive activities. However, despite the resources devoted to preparing these guidelines, we know little about whether and how they are used by GPs, and what impact they have on patient outcomes or practitioner workloads.

Questions that may provide information about these issues include:

- What proportion of GP are aware that best-practice guidelines exist? (for a particular health problem)
- What proportion of GPs are using these guidelines as a basis for care decisions/practices?
- Is the care provided to a patient with a particular condition consistent with the guidelines for that condition? For example: what proportion of patients with diabetes are receiving a complete annual cycle of care?

- Does use of the guidelines lead to better outcomes for patients? For example: are asthmatics with a care plan less likely to be admitted to hospital for respiratory problems than those without a care plan?
- What do GPs use for decision support when no guidelines are available?

Use of new technologies

Advances in computing power and electronic information transmission have great potential to streamline clinical processes and improve patient care. Although the majority of GPs have computing facilities available, it is unclear how these tools are being used and what their impact is on practice and on patient outcomes.

Developments in diagnostic and treatment technologies are also changing the way GPs deliver care and manage cases, but again the impact of these changes is unclear.

Questions that may provide relevant information include:

- What proportion of GPs keep electronic patient records?
- What proportion of GPs use electronic prescribing?
- What proportion of GPs use an electronic decision-support system in their consultations?
- What proportion of GPs use electronic systems for:
    - (a) referral
    - (b) imaging
    - (c) pathology?
    - Of these, what proportion have the results returned electronically?
- What proportion of practices make use of point of care pathology testing (PoCT)?

Appendix 2: Participants in consultations and surveys

Table A2.1: Participants in stakeholder consultation meetings

Participant	Affiliation
Dr Roshmeen Azam	Health Professional Team, National Prescribing Service
Mr Richard Bartlett	Manager, Primary Care Policy, Department of Veterans' Affairs
Mr Richard Bialkowski	Chief Executive Officer, ACT Division of General Practice
A/Prof Helena Britt	Director, Family Medicine Research Centre, University of Sydney
Mr Andrew Bruce	Reimbursement Strategies Manager, Medicines Australia
Mr Brenton Chappell	Executive Officer, Adelaide Hills Division of General Practice
Ms Catherine Dalton	Director, Primary Care Performance Section, DoHA
Ms Judy Daniel	Assistant Secretary, Primary Care Chronic Disease Branch, DoHA
Dr Peter Del Fante	Chief Executive Officer, Adelaide Western General Practice Network
Ms Elizabeth de Somer	Regulatory Affairs Manager, Medicines Australia
Ms SallyAnn Ducker	A/g Assistant Secretary, Primary Care Policy and Analysis Branch, DoHA
Mr Andre du Toit	Health Care Safety and Quality Unit, AIHW
Mr Paul Giacometti	Project Manager, e-Health Program, Australian General Practice Network
Ms Karen Gibson	General Manager, Project Coordination, NeHTA
Mr Hitendra Gilhotra	Assistant Director, Performance, Safety and Quality Section, DoHA
Dr Ann-Louise Hordacre	Research Fellow, Primary Health Care Research and Information Service (PHC RIS), Flinders University
Mr Warwick Hough	Senior Manager, General Practice, Legal Services and Workplace Policy, Australian Medical Association
Mr Niall Johnson	Australian Commission for Safety and Quality in Health Care
Dr Chris Kelman	A/Prof in Population Health, Australian Primary Health Care Research Institute, Australian National University
Mr Roger Kilham	Economic Consultant, Australian Medical Association
Mr Phil Lowen	Principal Adviser, e-Health, Australian General Practice Network
Ms Lisa McGlynn	Assistant Secretary, e-Health Branch, DoHA
Dr Graeme Miller	Medical Director, Family Medicine Research Centre, University of Sydney
Mr Simon Moore	Team Leader, General Practice Systems Improvement Team, GPpartners, Brisbane
Dr Christopher Mount	Director, eHealth Clinical Communication Section, DoHA
Ms Louise O'Rance	Health and Hospital Reform Commission Indicator Development Team, AIHW
Dr John Primrose	Medical Officer, Pharmaceutical Benefits Division, DoHA
Dr Steve Riddell	Program Evaluation Officer, National Prescribing Service
Ms Maxine Robinson	Secretary, Drug Utilisation Sub-Committee, Pharmaceutical Benefits Division, DoHA
Professor Nigel Stocks	Head, Discipline of General Practice, University of Adelaide

Table A2.2: Electronic data collections survey

Collection	Responsible organisation	Responded
Annual Survey of Divisions	AGPN	Yes
APCC	Improvement Foundation Australia	Yes
ASPREN	University of Adelaide	Yes
CARDIAB	CARDIAB Alliance	No
CONDUIT	University of Melbourne	Yes
GP Census	AGPN	Yes
GPRN	Health Communication Network Ltd	Yes
IMS	IMS Health	No
MEDIC-GP	University of Adelaide	No
NT AHKPI	NT Department of Health	No
Practice Health Atlas	Adelaide Western General Practice Network	Yes
Prescribing market data	Cegedim Strategic Data	No
Various	NPS	No

Appendix 3: Comparison of data collections

Table A3.1: Comparison of advantages and limitations of data collections

DATA SOURCE	INFORMATION	PURPOSE	ADVANTAGES	LIMITATIONS
PAPER-BASED, ADMINISTRATIVE and CATI COLLECTIONS				
GP–patient encounter				
BEACH	Random sample of GPs surveyed • GP and patient characteristics • reasons for encounter • problems managed • management techniques used	A national survey of general practice activity collecting data from the GP–patient encounter.	Data covers problems presented in practice and their management—medications, referrals, and tests. Random ever-changing sample. Data collected on patient encounters and medication regardless of Medicare and PBS eligibility. Large continuous time series	
Population health surveys				
ALSWH	• GP visits/patterns of use • Diagnoses/medications • GP advice on lifestyle • Serious Illnesses • Specialist/allied health items • Female GP • Health service access • GP satisfaction/cost • BP/cholesterol checks	National survey of women to ascertain the use of health services by women and to explore the factors influencing women's health.	Large longitudinal study. Over-sampling in rural and remote areas. Consumer views of GP quality of care. Age group representativeness. Can be consensually linked with MBS and PBS data. Good response rate (70%+).	Response bias in terms of overrepresentation of women with tertiary education and under-representation of some groups. Differences in those giving consent to data linking and those who do not. Reduced sample size linked data may affect some in-depth analysis.
AusDiab	• Diabetes status • Health service use • Discussions with GP about health • Other chronic health conditions • Demographics	National survey of diabetes mellitus prevalence and associated risk factors in people aged 25 years and over.	Large national diabetes prevalence study. Provides a resource for the study of the prevalence and possible causes of diabetes and establishing possible risk factors. Baseline survey in 1999–2000 followed up in 2004–05.	Comparisons with the 1998 Australian population estimates showed younger age respondents were under-represented at the biomedical examination and the middle and older age groups were over-represented. Purpose-built as a diabetes collection: it may not be comparable to other reasons for health service use and quality of care.

(continued)

Table A3.1 (cont'd): Comparison of advantages and limitations of data collections

DATA SOURCE	INFORMATION	PURPOSE	ADVANTAGES	LIMITATIONS
NATSIHS	Relevant data collected on: • self-reported conditions. • visits to GP/specialist	Information collected on the health status of Indigenous Australians, their use of health services and facilities and health-related aspects of their lifestyle.	Information collected on Indigenous Australians in remote and non-remote areas of Australia who see a GP regularly and the type of medication used for their condition.	The reason for consultation was not recorded. Consultation information is 'as reported' by respondents.
National health survey	Relevant data collected on: • self-reported conditions. • visits to GP/specialist	A national population survey collecting data from households on a range of health-related issues.	Provides data about diagnosis, medications prescribed for selected conditions. Large random sample	Very limited data on the GP–patient encounter—medication for selected conditions. Consultation information is self-reported.
VPHS	Use of and level of satisfaction with community health centres Self-reported diagnoses BP, cholesterol, diabetes/high sugar level and bowel cancer screening	A state-based (Vic) annual population survey collecting data from households on a range of health-related issues. Population health indicators gathered can assist in state government policy development.	Based on a core set of question modules, allows for comparability. Over-sampling in non-metropolitan areas allows for comparisons with metropolitan areas.	Collection item relates to use of community health centres, which include GPs, but also a number of other allied health professionals. Diagnoses data are self-reported. Limited to households with a landline phone connection.
WA HWSS	• Demographics • GP diagnosis of NHPA condition • Blood pressure (BP) or cholesterol checked • GP diagnosis of high BP or high cholesterol • Medications taken for high BP or high cholesterol • Risk factors • Health service use in past 12 months (primary health, hospital, allied health) • Seen GP in last 4 weeks for psychological distress • Influenza/pneumonia vaccination in last 12 months (over 65s)	A state-based (WA) monthly survey monitoring the health status of the population of WA. Collects data to inform policy decisions and assist in the provision of health services.	Large sample size. Excellent response rate (80% approx). Continuous sampling.	Includes English speaking respondents only. Small Indigenous sample.

(continued)

Table A3.1 (cont'd): Comparison of advantages and limitations of data collections

DATA SOURCE	INFORMATION	PURPOSE	ADVANTAGES	LIMITATIONS
		Administrative		
MBS	Provider information: • name and address • speciality by qualification • registered major speciality • derived speciality based on type of claims • sex Patient information: • name, address of cardholder • date of birth • sex	The MBS is an administrative collection that deals with the payment of subsidies for services rendered by GPs and some other health professionals.	Data are based on items in the MBS and can be broken down by patient gender and age group. Medicare data include records of referrals and investigations that can provide an insight into the presenting clinical problem. PBS and MBS data may be linked.	No information on non-fee-for-service general practice components. No information about the reason for the consultation or the diagnosis. Data only on those services eligible for Medicare benefits.
PBS	Information about the drug and cost: • quantity • supply date • repeats • prescriber details • patient details	The PBS is an administrative collection that deals with the supply of pharmaceutical medicines subsidised by the Australian Government. Data are collected through pharmacy electronic records when the prescription is filled.	Possible to link PBS data with MBS.	Only collects data for claims on PBS subsidised drugs. Drugs outside the subsidy threshold, or where there is no subsidy, are not included in the collection.
PIP and SIP	Incentive payments cover: • information management and technology • access to A/H care • rural practice support • practice nurse employed • prescribing behaviour improvements • cervical screening • asthma and diabetes cycles of care	Incentive program to assist GPs improve their quality of care.	Data readily available on those practices and GPs that have provided services.	No record of consultation. Assumption that all GPs have provided the same level of service in meeting the PIP and SIP

(continued)

Table A3.1 (cont'd): Comparison of advantages and limitations of data collections

DATA SOURCE	INFORMATION	PURPOSE	ADVANTAGES	LIMITATIONS
RPBS	Information about the drug and cost • quantity • supply date • repeats • prescriber details • patient details	The RPBS is an administrative collection that deals with the supply of pharmaceutical medicines subsidised by the Australian Government for the treatment of veterans and war widows. Data are collected through pharmacy electronic records when the prescription is filled.	Can be internally linked to examine use of medications by individuals	Only collects data for claims on RPBS subsidised drugs for patients with an entitlement card. Drugs outside the subsidy threshold or where there is no subsidy are not included in the collection.
SAR	• Practice size • Services provided • Use of computers • Number of episodes of care and client contacts	To collect data on service activity, staffing profiles and client numbers of Australian Government funded Aboriginal and Torres Strait Islander primary health-care services.	Provides information about preventive activities such as screening and vaccinations Two views of service provision—episodes and client contacts	No information about content of episodes of care, diagnoses or treatments Only includes those services that receive Australian Government funding
Other surveys and research				
HIT	Use of computers by GPs generally. Use of computerised clinical functions e.g. prescribing, drug–drug interactions, health summaries and progress notes, recall systems.	A national survey to determine the use of computers for prescribing and maintaining electronic health records. Provides a snapshot of how GPs are using information technology for clinical purposes.	Good representation of rural and remote GPs. Provides a recent picture regarding the use of computers as a practice aid.	Low response rate (39.5%). Survey responses are self-reported.
NPS	GP survey: • prescription medicines • information sources • computerised prescribing • view on generic medicines Pharmacist survey: • use of IT • patient communication Consumer survey: • prescription and non-prescription medicine use • attitudes to medicine use and medicine information sources	Surveys of GPs, pharmacists and consumers to determine knowledge relevant to medication use and NPS activities to encourage better use of medicines. Drug data analysed to provide independent information about medicines to health professionals and consumers, and to encourage and support cross-discipline and cross-sector collaborations that promote QUM	Provides data about the quality use of medicines (QUM), GPs level of knowledge about QUM and their understanding of changes in the use of medicines.	Low response rates to GP and pharmacist mail surveys (<50%).

(continued)

Table A3.1 (cont'd): Comparison of advantages and limitations of data collections

DATA SOURCE	INFORMATION	PURPOSE	ADVANTAGES	LIMITATIONS
TAPS	Demographics. RRMA area. Error report items: • event • contributing factors • outcome • preventative options	A state survey of GPs in NSW to determine the incidence of errors reported by GPs in the state.	Estimated error prevalence in general practice presented. Contributes to better understanding safety and quality of care in general practice. Data collected form urban, regional and rural/ remote areas of NSW.	Low response rate (26%, n= 84) Small sample size GPs are likely to under-report adverse drug events—other patient safety threats may also be under-reported.
ELECTRONIC COLLECTIONS				
APCC	Diabetes, CHD and better access to health care are the focus of the current program.	The Collaboratives program aims to achieve improvements across a broad range of clinical and practice business issues. Find and implement better ways to provide good quality primary health-care services.	Program can assist to improve patient care. Increased best-practice care through better use of information systems. Data can be collected from most clinical software programs in use. Data may be able to be linked to other sources	Small proportion of general practices nationally. Practices must apply to join the program and pass certain criteria. Practices are required to commit time and resources to program implementation and participation in it. Limited to practices working in the subject areas.
ASPREN	Collects data on influenza-like illness and other conditions seen in general practice. Data collected on: • influenza • gastroenteritis • chicken pox • shingles	The network is part of the Australian Government bio-surveillance strategy for preparedness for emerging communicable diseases	Electronic (web-based) ongoing submissions of de-identified patient data on influenza like illnesses mainly. Retention rate of GPs in the network is very high (95%) Quick, easy data entry operation.	Limited focus on a few specific diseases. Small volunteer sample of GPs submitting data. Needs more GPs in rural and regional areas to give better representation. Difficult to recruit and maintain GP participation

(continued)

Table A3.1 (cont'd): Comparison of advantages and limitations of data collections

DATA SOURCE	INFORMATION	PURPOSE	ADVANTAGES	LIMITATIONS
CONDUIT	Opportunistic sampling of GPs collecting data items such as: **GP/practice:** demographics number of GPs in the practice practice nurse available **Patient:** demographics Indigenous status reason for visit diagnosis medication prescribed pathology, imaging referrals procedures	Enables data from various sources to be analysed and linked into a single platform to provide a complete patient picture.	Data can be collected from various types of clinical software. Data can be linked with other data sources. Collects information about repeat visits linked to the initial visit/problem for longitudinal analysis.	Small divisional collection. Data collected from computerised practices only. Data quality issues mainly in regard to complete structured data components.
GPRN	• GP characteristics • Patient characteristics • Encounter characteristics • Scripts	Develop an electronic, longitudinal, patient-based data set—to improve MD and support educational and research initiatives. Data are used to assist in improving • training for MD users • functionality of future decision-support systems • quality assurance activities • communication channels.	Large longitudinal database. Prescription details regardless of PBS eligibility. GPs can compare their practice against 'best-practice standards' and those of peers Potential for medication/drug adverse events and treatment outcome studies	Sample selected from users of Medical Director (MD) software in computerised practices. Lower representation of older GPs (possibly due to lower computer use). Not able to link to external data. Variations in GP's computer use capability.

(continued)

Table A3.1 (cont'd): Comparison of advantages and limitations of data collections

DATA SOURCE	INFORMATION	PURPOSE	ADVANTAGES	LIMITATIONS
MEDIC-GP	• Assessment • Treatment plan • Medications prescribed • Pathology investigations • Diagnostic imaging • Adverse reactions • Specialist referrals	Electronic data collection forming a pharmacoepidemiological database. Can offer investigation of research questions from a longitudinal perspective	Comprehensive clinical data collected over a decade. Integrated longitudinal perspective of patient clinical data in general practice.	A selected sample of nine computerised practices. No information as to whether scripts are filled. Not able to link to external data Collection has ceased
NT AHPKI	• Sex • Age group • Indigenous status • Locality (establishment) and reporting period • Health services	Will provide a baseline collection of key indicators that can assist health centre functions and government policy development	Can provide a primary health care performance reporting system for capturing and reporting Northern Territory Aboriginal primary health care key performance indicators data. Indigenous centred data collection.	Collection limited to state run community health centres. Aggregated data includes consultations with persons other than GPs, mainly Aboriginal health workers
PHA	• Demographics • Indigenous status • Medications • Height, weight • Diagnosis • Blood pressure, cholesterol levels	Collection of practice-level data within a divisional geographical area for use as a decision-support tool. Used to assist practices improve their clinical and business performance.	Data collected is mapped to the NHDD. Data integrated with other data sources e.g. Census. Minimal involvement of practice staff after initial establishment.	Data are collected when requested from computerised MD user practices. About one-third of the practices in the area involved. Data are not collected on GP–patient encounters only as information per patient.

Table A3.2: Data collections—summary and contacts for further information

DATA SOURCE	TYPE	CURRENT SIZE	TIME SERIES	CONTACT INFO
		PAPER-BASED, ADMINISTRATIVE and CATI COLLECTIONS **GP-patient encounter collections**		
BEACH	National annual paper-based GP survey. Approximately 20 GPs providing data each week.	• 1000 GPs per year • 100,000 encounters per year • 1,000,000+ encounters to date	1998–now	Helena Britt T: (02) 9845 8150 E: beach@fmrc.org.au W: www.fmrc.org.au/beach.htm
		Population health surveys		
ALSWH	Longitudinal population based paper survey, conducted at three yearly intervals for each age cohort.	40,000 women	1995–now	T: (02) 4913 8872 E: whasec@newcastle.edu.au W: www.alswh.org.au
AusDiab	Population-based paper questionnaire plus physical measurements.	• 20,000+ persons completed questionnaire • 11,000+ participated in physical tests in 1999–2000 and • 6,500 in 2004–05	1999–2000 and 2004–05	T: (03) 9258 5050 E: research@diabetes.com.au W: www.diabetes.com.au
NATSIHS	Electronic 6-yearly Indigenous population based survey.	10,000+ interviews in 2004–05	1995, 2001, 2004–05	National Information and Referral Service 1300 135 070 or Katrina Poyser (08) 8943 2131. W: abs.gov.au
National health survey	Electronic 3-yearly population based survey.	25,000+ interviews in 2004–05	1989–90, 1995, 2001, 2004–05, 2007–08.	Jane Griffin-Warwicke (02) 6252 6535. E: jane.griffin-warwicke@abs.gov.au W: abs.gov.au
VPHS	Population-based annual CATI state survey.	7,500 interviews in 2006.	2001–now	Loretta Vaughan Phone: (03) 9096 5286 E: loretta.vaughan@dhs.vic.gov.au W: www.health.vic.gov.au/healthstatus/vphs
WA HWSS	Monthly population-based CATI state survey	550 surveyed each month 27,000+ (at Dec 2006) in total since 2002	2002–now	Alison Daly E: alison.daly@health.wa.gov.au W: www.health.wa.gov.au

(continued)

Table A3.2 (cont'd): Data collections—summary and contacts for further information

DATA SOURCE	TYPE	CURRENT SIZE	TIME SERIES	CONTACT INFO
		Administrative		
MBS	Continuous electronic data collection from GPs.	107,000,000+ services recorded in 2006–07	1984–now	T: 1800 101 099 E: statistics@medicareaustralia.gov.au W: www.medicareaustralia.gov.au
PBS	Continuous electronic data collection from pharmacists.	2 billion + prescriptions recorded between 1992 and 2007	1984–now	T: 1800 101 099 E: statistics@medicareaustralia.gov.au W: www.medicareaustralia.gov.au
PIP and SIP	Continuous electronic data collection from GPs.	4800+ participating practices (as at November 2007).	1999–now	T: 1800 222 032 E: statistics@medicareaustralia.gov.au W: www.medicareaustralia.gov.au/provider/incentives/pip
RPBS	Continuous electronic data collection from pharmacists	179,000,000+ prescriptions recorded between 1992 and 2007	1984–now	E: statistics@medicareaustralia.gov.au W: www.medicareaustralia.gov.au
SAR	Annual paper-based survey of Australian Government-funded Aboriginal and Torres Strait Islander primary health services	Around 140 health services surveyed each year	2000–now	T: 1800 678 445 E: oatsih.enquiries@health.gov.au W: www.health.gov.au
		Other surveys and research		
HIT	National one-off paper-based GP survey	1186 GPs	2005	Keith McInnes T: 02 9556 7240 E: keith@gp.med.usyd.edu.au E: mcinnes@hcp.med.harvard.edu
NPS	Paper-based surveys of GPs (biennial), pharmacists and phone survey of consumers (annual/biennial).	• 800–900 GPs • 650+ pharmacists • 1200 consumers	1999–now	Neil Donnelly T: 02 8217 8700 E: NDonnelly@nps.org.au W: www.nps.org.au
TAPS	One-off NSW GP survey. Data reported electronically.	84 GPs 490,000+ encounters 400+ error reports	2003–04	Dr Meredith A B Makeham T: (02) 9818 1400 E: makeham@ozemail.com.au

(continued)

Table A3.2 (cont'd): Data collections—summary and contacts for further information

DATA SOURCE	TYPE	CURRENT SIZE	TIME SERIES	CONTACT INFO
		ELECTRONIC COLLECTIONS		
APCC	Electronic data lodgement by general practices.	480+ general practices	2005–now	Sarah Wrz T: (08) 8422 7466 E: apcc@improve.org.au W: www.apcc.org.au
ASPREN	Weekly electronic data collection from GPs all year round.	90 GPs	1991–Sept 2006 (paper-based system) Sept 2006–current (electronic reporting)	Dr Nigel Stocks T: (08) 8303 7583 E: nigel.stocks@adelaide.edu.au W: www. racgp.org.au/aspren
CONDUIT	Electronic data collection from GPs	12 GPs 5000 encounters	2006–now	Professor Siaw-Teng Liaw E: t.liaw@unimelb.edu.au W: www.grhanite.com/
GPRN	Electronic data collection from around 200 GPs each week.	• 400 GPs currently enrolled • 800 GPs in total • 5 million patients • 17 million encounters	1999–now	Andy Muchhala T: 1 800 622 678 E: andy.muchhala@hcn.com.au W: www.hcn.com.au/doctors/gprn.asp
MEDIC-GP	Monthly electronic data submission by GPs.	• 150 GPs • 99,000 patients • 2-million clinical records	1994–2004	Katherine Duszynski T: (08) 8303 3467 E: katherine.duszynski@adelaide.edu.au W: www.adelaide.edu.au/health/gp/units/medic-gp/
NT AHKPI	Electronic or web-based data collection from Community Health Centres.	Due to commence in July 2008.	Nil	Richard Inglis T: (08) 8999 2628 E: ahkpi.communications@nt.gov.au W: www.nt.gov.au/health/ahkpi
PHA	Annual electronic data collection from GPs.	30 general practices (approx). 60,000+ patients.	Data collected for the purpose of the PHA is destroyed after the PHA is constructed.	Julian Flint Phone: (08) 82443822 E: julian.flint@awgpn.org.au W: www.awdgp.org.au

Appendix 3: Comparison of data collections

Appendix 4: Results of criteria testing

BEACH survey

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects sex, date of birth, postcode, NESB status, Indigenous status and concession card status
Workforce information	Yes
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Collects sex, age, years in practice, practice size, sessions, hours worked (direct and on call) per week, practice postcode, graduation country, after-hours availability, computer use, FRACGP status.
Problem managed	Yes
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	Collects both patient's reason(s) for encounter and diagnoses recorded.
Comorbidities	Limited
Is information about the patient's comorbid conditions available?	Only those managed at the same encounter generally recorded. Specific information may be obtained through SAND studies.
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No longitudinal data available for individuals.
Adherence to guidelines	Yes
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Collects medication name, dose and repeats, related to a specific diagnosis and patient details. More detail for specific issues available through SAND studies.
Best-practice care	Limited
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Data are collected for a single encounter, so some capacity to investigate care in a cross-sectional manner. No follow-up or tracking of care cycles possible. Results of tests, and so on. not available. More detail for specific issues available through SAND studies.
Patterns of care	Some
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	Records to whom referrals/orders were written, but results unknown.
Patient perceptions	Limited
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No regular information available from the patient perspective. This information may be gathered through SAND studies.
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No identifying information is collected; neither internal nor external linkage possible.
Data quality	Very good
Is the sample nationally representative?	Random sample of 1,000 GPs per year. Some under-representation of younger GPs. Annual data are weighted to account for this.
Are the data reliable? Are the data complete?	Good evidence of reliability and completeness of data.

ALSWH

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	All females. Collects age, country of birth, marital status, education, employment status, income, Indigenous status.
Workforce information	No
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	No information is collected about specific health service encounters.
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No, reports of health-care visits are not connected to a diagnosis/reason for attendance.
Comorbidities	Yes
Is information about the patient's comorbid conditions available?	Collects data on presence of a wide variety of chronic and acute conditions.
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No
Adherence to guidelines	Limited
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	All cohorts report types of medications taken in the 4 weeks before the survey. Older and mid age cohorts have reported names of all medications taken. These are matched with PBS data.
Best-practice care	No
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	No information about specific treatment or management is available in the core surveys. Information about management of specific conditions is available through sub-studies.
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No information about contents of health-care visits available.
Patient perceptions	Yes
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	Surveys have included SF-36, satisfaction with GP care, access to health care, stress, feelings about weight, mental health, life events, social interaction, control over own health, physical functioning.
Potential for linkage	Yes
Does the database contain information to enable (i) internal linkage (ii) external linkage?	Yes, both internal and external linkage (to MBS, PBS, DVA and National Death Index) enabled.
Data quality	Very good
Is the sample nationally representative?	Total sample of 40,000 women. Broadly representative of women in relevant age groups. Some over-representation of tertiary-educated and English speaking women. Non-urban women deliberately over-sampled to allow comparisons.
Are the data reliable?	High completeness. Due to longitudinal nature of survey, missing responses are often able to be imputed.
Are the data complete?	Low frequency of non-logical responses to items over time.

AusDiab

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects age, sex, marital status, education, Indigenous status, country of birth, languages spoken at home, income, employment.
Workforce information	No
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	No information is collected about specific health service encounters.
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No, reports of health-care visits are not connected to a diagnosis/reason for attendance.
Comorbidities	Limited
Is information about the patient's comorbid conditions available?	Data on diabetes, heart disease, stroke, hypertension, high cholesterol, kidney problems.
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No
Adherence to guidelines	Limited
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Follow-up survey collected information on prescription medications taken, dose and strength.
Best-practice care	Some
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be recognised (ii) are the results of individual components of the cycle available?	Contains some information on cycle of care components for diabetes.
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No information about contents of health-care visits available.
Patient perceptions	Yes
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	Collected SF-36 and patient's impression of their quality of life.
Potential for linkage	Yes
Does the database contain information to enable (i) internal linkage (ii) external linkage?	Some linkage to the National Death Index (NDI)
Data quality	Good
Is the sample nationally representative? Are the data reliable? Are the data complete?	Sample over 11,000 with biomedical data. Represents a national population 25 years and over who agreed to biomedical examinations. Younger age respondents under-represented, middle/ older age groups over-represented. Purpose designed for collecting diabetes data Report includes those who participated in the questionnaires and biomedical tests providing better reliability, accuracy and completeness.

NATSIHS

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects age, sex, marital status, education, Indigenous status, main language spoken at home, income, employment.
Workforce information	No
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	No information is collected about specific health service encounters.
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No, reports of health-care visits are not connected to a diagnosis/reason for attendance.
Comorbidities	Yes
Is information about the patient's comorbid conditions available?	Collects data on various disease states.
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No
Adherence to guidelines	No
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Data only about whether medications were used
Best-practice care	No
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	No information about specific treatment or management is available
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No information about contents of health-care visits is available
Patient perceptions	Yes
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	Collects data on self-rated health, mental health and reasons for not seeing a doctor when needed
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No
Data quality	Good
Is the sample nationally representative?	Nationally representative of the Indigenous population, total sample 10,000.
Are the data reliable?	Self-reported nature of data affects reliability and accuracy, as does the inherent nature of the survey in having sampling and non-sampling error. Good completeness.
Are the data complete?	

National health survey

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects age, sex, marital status, education, Indigenous status, country of birth, main language spoken at home, income, employment.
Workforce information	No
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	No information is collected about specific health service encounters.
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No, reports of health-care visits are not connected to a diagnosis/reason for attendance.
Comorbidities	Yes
Is information about the patient's comorbid conditions available?	Collects data on various disease states.
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No
Adherence to guidelines	Yes
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Collects names and types of medication for selected conditions
Best-practice care	No
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	No information about specific treatment or management is available
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No information about contents of health-care visits available
Patient perceptions	Yes
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	Collects data on self-rated health, mental health and reasons for not seeing a doctor when needed
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No
Data quality	Good
Is the sample nationally representative?	Nationally representative of the population, total sample 25,000.
Are the data reliable? Are the data complete?	Self-reported nature of the data affects reliability and accuracy, as does the inherent nature of the survey in having sampling and non-sampling error. Good completeness.

VPHS

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects age, sex, marital status, education, Indigenous status, country of birth, main language spoken at home, income, employment.
Workforce information	No
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	No information is collected about specific health service encounters.
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No, reports of health-care visits are not connected to a diagnosis/reason for attendance.
Comorbidities	NHPAs only
Is information about the patient's comorbid conditions available?	Collects data on NHPA conditions
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No
Adherence to guidelines	No
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	No medication data collected
Best-practice care	Some
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Limited data collected for asthma, diabetes, BP, cholesterol
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No information about contents of health-care visits available
Patient perceptions	Yes
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	Self-rated health, mental health, satisfaction with care (not GP)
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No
Data quality	Good
Is the sample nationally representative?	State-based CATI collection, general to Victoria but limited national representativeness. Total sample 7,500.
Are the data reliable? Are the data complete?	Self-reported nature of data affects reliability and accuracy, as does the inherent nature of the survey in having sampling and non-sampling error. Good completeness.

WA HWSS

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects age, sex, marital status, education, Indigenous status, Australian born, income, employment.
Workforce information	No
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	No information is collected about specific health service encounters.
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No, reports of health-care visits are not connected to a diagnosis/reason for attendance.
Comorbidities	Some
Is information about the patient's comorbid conditions available?	Collects data on NHPA conditions.
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No
Adherence to guidelines	No
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Data only about whether medications were used for BP or cholesterol
Best-practice care	Some
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Some data collected for BP, cholesterol. Influenza and pneumonia vaccinations (for 65 years and over)
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No information about contents of health-care visits available
Patient perceptions	Yes
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	Self-rated health, QoL, mental health, control over own health
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No
Data quality	Good
Is the sample nationally representative?	State-based CATI collection, general to WA but limited national representativeness.
Are the data reliable?	Self-reported nature of data affects reliability and accuracy, as does the inherent nature of the survey in having sampling and non-sampling error. Good completeness.
Are the data complete?	

MBS

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects name, sex, date of birth, geographical location
Workforce information	Minimal
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Service provider identified by individual code, may be possible to obtain detail
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	Reports of health-care visits are not connected to a diagnosis/reason for attendance.
Comorbidities	No
Is information about the patient's comorbid conditions available?	No
Clinical outcomes	Limited
Can the treatment of a specific problem in an individual be followed over time?	Information only available via linkage. Diagnosis inferred only.
Adherence to guidelines	No
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	No
Best-practice care	Limited
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Where cycle or components of care result in claims
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	Information not collected
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No information from the patient perspective is collected
Potential for linkage	Yes
Does the database contain information to enable (i) internal linkage (ii) external linkage?	Internal linkage possible. May be linked with the PBS subject to legislation
Data quality	Excellent
Is the sample nationally representative?	Yes, essentially a 'census' although not all GP–patient encounters are captured.
Are the data reliable?	Data considered very reliable. Excellent completeness.
Are the data complete?	

NPS GP survey

Criterion	Results
Demographic information	No
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	No data collected about the patient in this survey
Workforce information	Yes
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Some provider data collected
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No encounter data collected
Comorbidities	No
Is information about the patient's comorbid conditions available?	No patient data collected
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No patient data collected
Adherence to guidelines	Some
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Collects data about GPs knowledge of the quality use of medicines
Best-practice care	No
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	No data collected
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No encounter data collected
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No data collected about the patient in this survey
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No
Data quality	Unknown
Is the sample nationally representative?	No, under-representation of male GPs and those in the less than 35 age category and over-representation of GPs over the age of 45.
Are the data reliable? Are the data complete?	Data relate to GPs' knowledge and thus may not represent actual practice. Level of completeness unknown.

NPS consumer survey

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects age, sex, geographical location
Workforce information	No
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	No data collected about the provider in this survey
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No encounter data collected
Comorbidities	No
Is information about the patient's comorbid conditions available?	Collects data on various disease states.
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No encounter data collected
Adherence to guidelines	Some
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Data only about whether medications were used
Best-practice care	No
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	No data collected
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No encounter data collected
Patient perceptions	Some
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	Data collected on self-rated health, attitudes to medicines, consumer awareness
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No
Data quality	Unknown
Is the sample nationally representative?	Unknown.
Are the data reliable?	Accuracy of self-reported information about medication use is uncertain.
Are the data complete?	

PBS

Criterion	Results
Demographic information	Some
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects age, sex, geographical location
Workforce information	Minimal
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Service provider identified by individual code, may be possible to obtain detail
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No encounter data collected
Comorbidities	No
Is information about the patient's comorbid conditions available?	No encounter data collected, but may be inferred by pattern of medications prescribed
Clinical outcomes	Limited
Can the treatment of a specific problem in an individual be followed over time?	No encounter data collected, but may be inferred for longitudinal analysis
Adherence to guidelines	Limited
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	No reason for prescribing recorded, but polypharmacy can be investigated
Best-practice care	No
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	No encounter data collected
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No encounter data collected
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No subjective patient data collected
Potential for linkage	Yes
Does the database contain information to enable (i) internal linkage (ii) external linkage?	Internal linkage possible. May be linked with the MBS subject to legislation
Data quality	Excellent
Is the sample nationally representative? Are the data reliable? Are the data complete?	Yes, although only includes data about medications where a government subsidy was paid (about 80% of all prescriptions). Data considered very reliable and complete.

PIP and SIP

Criterion	Results
Demographic information	No
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	No patient data collected
Workforce information	Some
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Collects some provider data for the purpose of claiming the incentive payments
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No encounter data collected
Comorbidities	No
Is information about the patient's comorbid conditions available?	No encounter data collected
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No encounter data collected
Adherence to guidelines	No
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	No data collected on medications
Best-practice care	Some
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Some information collected when a PIP is claimed; for example, for a cycle of care
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No encounter data collected
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No patient data collected
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No
Data quality	Good
Is the sample nationally representative?	Yes
Are the data reliable?	For the purpose of making an incentive payment claim the data are reliable.
Are the data complete?	

RPBS

Criterion	Results
Demographic information	Some
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects age, sex, geographical location
Workforce information	Minimal
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Service provider identified by individual code, may be possible to obtain detail
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No encounter data collected
Comorbidities	No
Is information about the patient's comorbid conditions available?	No encounter data collected, but may be inferred by pattern of medications prescribed
Clinical outcomes	Limited
Can the treatment of a specific problem in an individual be followed over time?	No encounter data collected, but may be inferred for longitudinal analysis
Adherence to guidelines	Limited
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	No reason for prescribing recorded, but polypharmacy can be investigated
Best-practice care	No
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	No encounter data collected
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No encounter data collected
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No subjective patient data collected
Potential for linkage	Yes
Does the database contain information to enable (i) internal linkage (ii) external linkage?	Internal linkage possible. May be linked with the MBS subject to legislation
Data quality	Excellent
Is the sample nationally representative?	Representative of war veterans and war widows.
Are the data reliable?	Data considered very reliable and complete.
Are the data complete?	

HIT

Criterion	Results
Demographic information	No
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	No patient data collected
Workforce information	Some
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Collected sex, age, country of training, practice location
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No encounter data collected
Comorbidities	No
Is information about the patient's comorbid conditions available?	No encounter data collected
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No encounter data collected
Adherence to guidelines	Limited
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Collects data on whether an electronic prescribing tool was used and whether recorded reasons for prescribing
Best-practice care	No
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	No encounter data collected
Patterns of care	Limited
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	Some information collected on whether electronic referral was used by the GP
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No patient data collected
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No
Data quality	Good
Is the sample nationally representative?	Broadly representative with over-sampling of non-urban GPs
Are the data reliable? Are the data complete?	Self-reported data affects reliability and accuracy, as does the inherent nature of the survey in having sampling and non-sampling error.

TAPS

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collected age, sex, Indigenous status, NESB
Workforce information	Minimal
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	RRMA group
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	No encounter data collected
Comorbidities	No
Is information about the patient's comorbid conditions available?	No encounter data collected
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No encounter data collected
Adherence to guidelines	Limited
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Collected information about errors in general practice
Best-practice care	No
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Assessed incidence of errors in the general practice environment
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	No encounter data collected
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No patient data collected
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No
Data quality	Unknown
Is the sample nationally representative?	Regional data collection representative of GPs in NSW
Are the data reliable?	Self-reported data affects reliability and accuracy, as does the inherent nature of the survey in having sampling and non-sampling error
Are the data complete?	

APCC

Criterion	Results
Demographic information	No
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	No patient data collected
Workforce information	Some
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Practice postcode, number of GPs in practice, accreditation of practice, practice nurse, provider number
Problem managed	Some
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	Collects encounter data about the problem/diagnosis, medication prescribed, pathology ordered
Comorbidities	No
Is information about the patient's comorbid conditions available?	No data collected about the patient and any comorbidities
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	No patient data collected to enable follow-up
Adherence to guidelines	Some
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Collects some medication prescription data
Best-practice care	Some
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Collects encounter data for the purpose of benchmarking and developing and implementing practice improvements.
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	Some pathology data collected to analyse chronic disease management
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No patient data collected
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	Not currently, but may be linkable to other sources
Data quality	Fair
Is the sample nationally representative?	Small sample, lacks national representativeness
Are the data reliable?	Reliability checks are conducted
Are the data complete?	Good level of data completeness

CONDUIT

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects age, sex, postcode, cultural background, HCC status, Veterans' Affairs status and patient status to practice (i.e. new or seen before)
Workforce information	Some
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Collects age, sex; practice postcode, number of GPs in practice, practice nurse, provider number and bulk-billing status.
Problem managed	Yes
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	Information collected about the problem/diagnosis, medication prescribed, pathology ordered and imaging ordered.
Comorbidities	Yes
Is information about the patient's comorbid conditions available?	Information can be linked
Clinical outcomes	Yes
Can the treatment of a specific problem in an individual be followed over time?	Information is recorded for repeated visits linked to the initial visit and problems/illnesses can be followed over time.
Adherence to guidelines	Yes
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Collects medication prescription data
Best-practice care	Potentially
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Data collected provides information that could be used to assess patient care
Patterns of care	Yes
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	Referrals and procedures are recorded
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	Not currently, but there is the capacity to add to the collection
Potential for linkage	Yes
Does the database contain information to enable (i) internal linkage (ii) external linkage?	Patient data can be linked to a practice, but may include information from more than one GP. External linkage with hospitals, pharmacies and other health-care services
Data quality	Fair
Is the sample nationally representative?	Small regional collection
Are the data reliable?	Lacks completeness
Are the data complete?	Accuracy checks conducted

GPRN

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects age, sex, HCC status, Veterans' Affairs status and Indigenous status
Workforce information	Some
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Collects age, sex, practice postcode, number of GPs in practice, number of years in practice, provider number and year of graduation.
Problem managed	Yes
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	Data are collected on reason for visit, problem/diagnosis and medication prescribed
Comorbidities	Yes
Is information about the patient's comorbid conditions available?	Data are available when patient is treated by a participating GP
Clinical outcomes	Yes
Can the treatment of a specific problem in an individual 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.
Adherence to guidelines	Yes
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Collects medicine name, dose, reason for prescribing, dosage and repeats
Best-practice care	Yes
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Collects patient medical record data
Patterns of care	Yes
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	Data collected about pathology ordered, imaging ordered, referrals and procedures
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No
Potential for linkage	Yes
Does the database contain information to enable (i) internal linkage (ii) external linkage?	Internal linkage only. Patient data can be linked to a practice, but may include information from more than one GP
Data quality	Good
Is the sample nationally representative?	Representative of users of clinical software package Medical Director. May not be nationally representative. 400 GPs currently participating; cluster effect may be considerable.
Are the data reliable?	Checks are conducted for accuracy
Are the data complete?	Good level of data completeness

MEDIC GP

Criterion	Results
Demographic information	Some
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Collects age and sex
Workforce information	Some
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Collects age, sex, employment status (FT or PT)
Problem managed	Yes
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	Collects data from the doctor–patient encounter
Comorbidities	Yes
Is information about the patient's comorbid conditions available?	Collects clinical assessment data including comorbidities
Clinical outcomes	Yes
Can the treatment of a specific problem in an individual be followed over time?	Within the 10-year period of the life of the collection
Adherence to guidelines	Yes
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Collects data about medications prescribed, changes in medications or their regimen, procedures and treatment plans.
Best-practice care	Yes
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Collects patient medical record data
Patterns of care	Yes
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	Collects information on pathology investigations and diagnostic imaging ordered and associated results, and specialist referrals
Patient perceptions	Some
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	Some information is collected about the patient perspective of the presenting problem and additional information relating to changes in health status
Potential for linkage	Yes
Does the database contain information to enable (i) internal linkage (ii) external linkage?	Internal linkage only
Data quality	Fair
Is the sample nationally representative?	Small sample. Representative of patients in terms of age and gender.
Are the data reliable?	Reliability of the recorded diagnosis is under question
Are the data complete?	As patient medical record data, the accuracy and completeness is limited by what has been recorded by the GP

ASPREN

Criterion	Results
Demographic information	Some
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Sex
Workforce information	Some
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Sex, practice postcode and number of GPs at the practice
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	Only those cases reported include reasons for encounter, problem/diagnosis and pathology ordered
Comorbidities	No
Is information about the patient's comorbid conditions available?	Comorbidities not collected with the reported case
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	Information is recorded for repeated visits for a patient, but does not link the problem within the record over time.
Adherence to guidelines	No
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	No medication data collected
Best-practice care	No
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	As a reporting collection, ASPREN does not collect information to assess the care of the patient.
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	Pathology tests are recorded
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No subjective patient data collected
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No
Data quality	Fair
Is the sample nationally representative?	Low numbers of rural and regional participants. May not be nationally representative.
Are the data reliable?	No checks conducted to ensure accuracy or reliability
Are the data complete?	Good level of data completeness

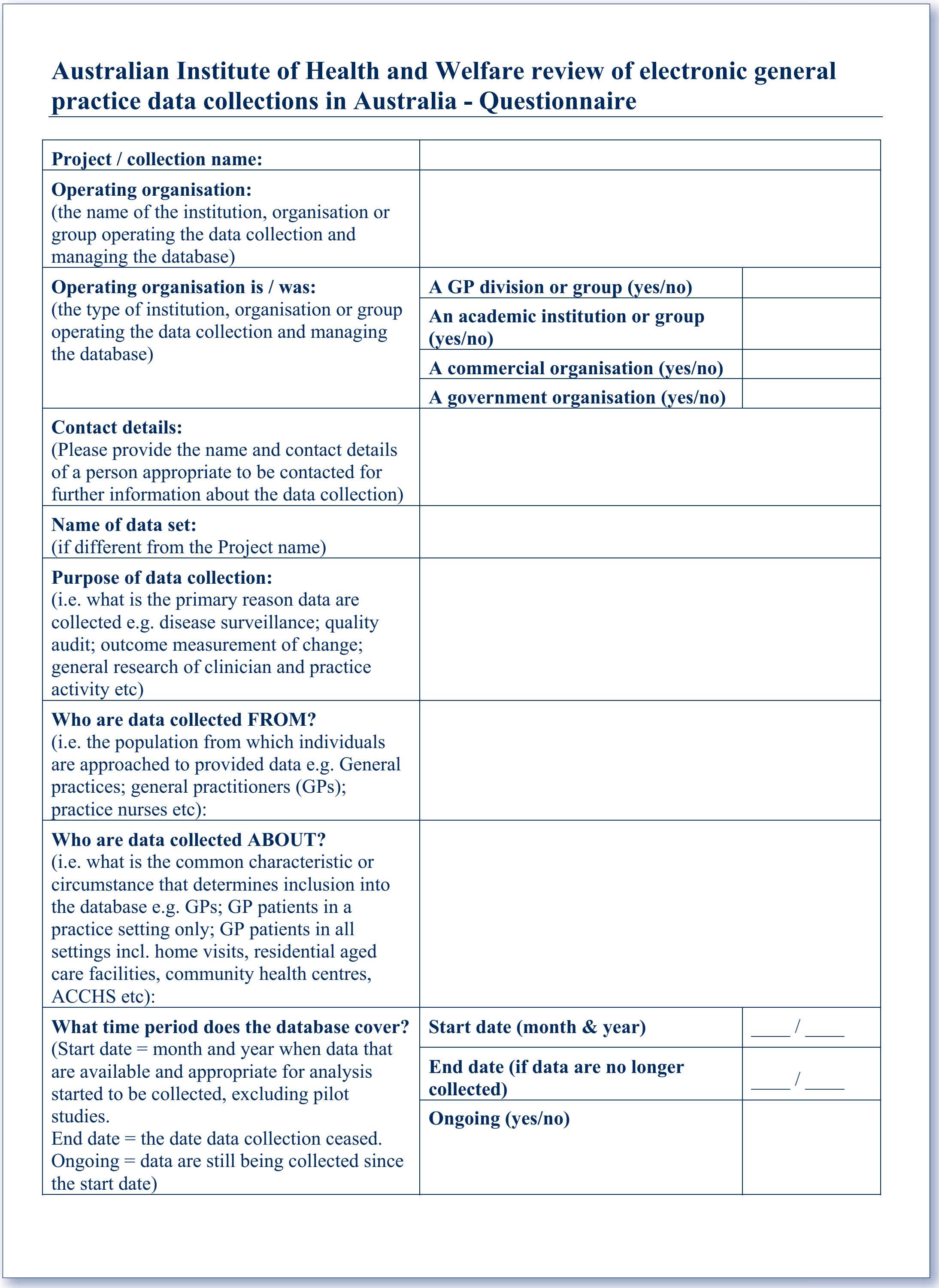
NT AHKPI

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Age, sex, Indigenous status, locality
Workforce information	No
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Some administrative data will be collected
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	Actual encounter data not collected
Comorbidities	No
Is information about the patient's comorbid conditions available?	Actual encounter data not collected
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	Actual encounter data not collected
Adherence to guidelines	No
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Actual encounter data not collected, but some medication indicators collected for the population
Best-practice care	Some
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Actual encounter data not collected, but some health-care indicators collected for the population
Patterns of care	No
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	Actual encounter data not collected, but some tests data collected for the population
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No subjective patient data to be collected
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	No
Data quality	Unable to assess
Is the sample nationally representative? Are the data reliable? Are the data complete?	Collection to commence in July 2008. Will cover Aboriginal Health Services in NT only.

PHA

Criterion	Results
Demographic information	Yes
Does the database contain basic demographic information about the patient? (age, sex, geographical location, Indigenous status)	Age, sex, postcode of residence, DVA card holder status, pensioner status and Indigenous status
Workforce information	Yes
Does the data set provide information about the service provider? (age, sex, specialty/occupation, FTE, location, Australian or overseas trained, after-hours availability, use of clinical software)	Sex, practice postcode, number of GPs at the practice, practice accreditation status, practice nurse, practice address, areas of special interest, opening hours and languages spoken by GPs
Problem managed	No
Can each encounter/prescription/service be connected with a diagnosis or problem managed?	Diagnostic data not connected to each encounter
Comorbidities	No
Is information about the patient's comorbid conditions available?	Data not available to link conditions
Clinical outcomes	No
Can the treatment of a specific problem in an individual be followed over time?	Information is recorded for repeat visits for a patient but does not link the problem within the record over time.
Adherence to guidelines	Some
Does the database provide information to examine use of medications? (medication name, dose, reason for prescribing, patient age and sex, number of medications taken, whether an electronic prescribing tool was used)	Collects data on medication prescribed and/or provided
Best-practice care	Some
Does the database provide information to assess best-practice care in patients with chronic illnesses? For example, for patients with diabetes: (i) can completion of an annual cycle of care be identified (ii) are the results of individual components of the cycle available?	Collects some data to measure health care in the practice and for business modelling purposes
Patterns of care	Some
Is information about referrals written and tests ordered in relation to an occasion of service available? (reason for referral, to whom referred, whether an electronic referral was used, results of tests/specialist consultation)	Collects data on pathology results, height, weight, blood pressure, foot/eye examination and date performed.
Patient perceptions	No
Does the database contain any information about the patient's quality of life, functioning, satisfaction with care or feelings about their own health?	No subjective patient data collected
Potential for linkage	No
Does the database contain information to enable (i) internal linkage (ii) external linkage?	Not for linking patient encounter data but is linked with Census and mapping data.
Data quality	Good
Is the sample nationally representative?	'Collection' is based on a single practice or group of practices, not intended to be more widely representative.
Are the data reliable?	Data are as entered within the clinical record system. Accuracy checks are conducted.
Are the data complete?	Low level of completeness

Appendix 5: Electronic collections survey



Australian Institute of Health and Welfare review of electronic general practice data collections in Australia - Questionnaire

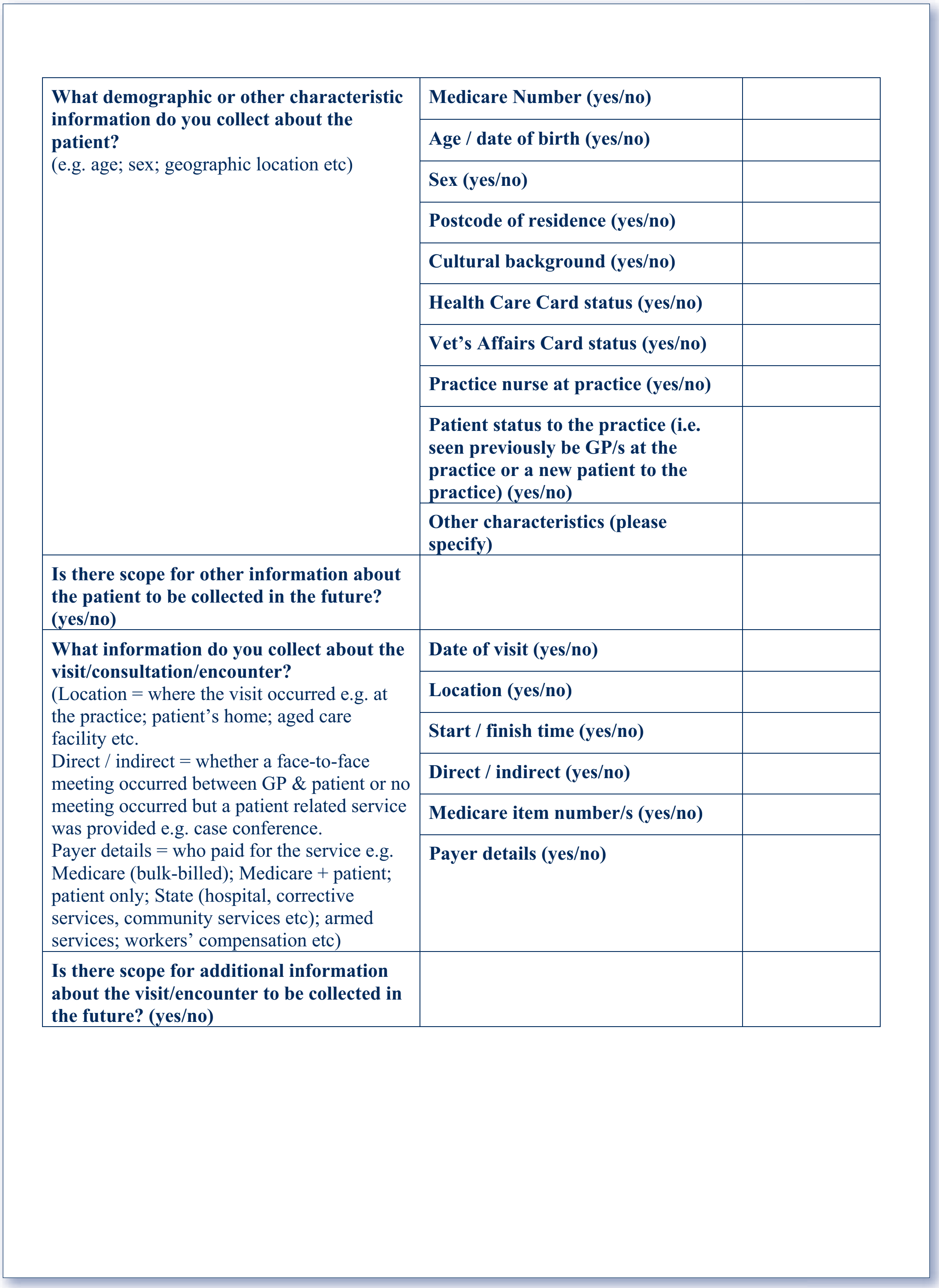
Project / collection name:		
Operating organisation: (the name of the institution, organisation or group operating the data collection and managing the database)		
Operating organisation is / was: (the type of institution, organisation or group operating the data collection and managing the database)	**A GP division or group (yes/no)**	
	An academic institution or group (yes/no)	
	A commercial organisation (yes/no)	
	A government organisation (yes/no)	
Contact details: (Please provide the name and contact details of a person appropriate to be contacted for further information about the data collection)		
Name of data set: (if different from the Project name)		
Purpose of data collection: (i.e. what is the primary reason data are collected e.g. disease surveillance; quality audit; outcome measurement of change; general research of clinician and practice activity etc)		
Who are data collected FROM? (i.e. the population from which individuals are approached to provided data e.g. General practices; general practitioners (GPs); practice nurses etc):		
Who are data collected ABOUT? (i.e. what is the common characteristic or circumstance that determines inclusion into the database e.g. GPs; GP patients in a practice setting only; GP patients in all settings incl. home visits, residential aged care facilities, community health centres, ACCHS etc):		
What time period does the database cover? (Start date = month and year when data that are available and appropriate for analysis started to be collected, excluding pilot studies. End date = the date data collection ceased. Ongoing = data are still being collected since the start date)	**Start date (month & year)**	____ / ____
	End date (if data are no longer collected)	____ / ____
	Ongoing (yes/no)	

What design method of data collection is/was used? (Periodic cross-sectional = recruitment of individuals for inclusion over set periods, with gaps in recruitment between periods e.g. three months repeated every year. Periodic longitudinal = follow-up of original participants for inclusion over set periods, with gaps in data collection between reporting periods e.g. three months repeated every year):	**Continuous cross-sectional (yes/no)**	
	Continuous longitudinal (yes/no)	
	Periodic cross-sectional (yes/no)	
	Periodic longitudinal (yes/no)	
	One-off (yes/no)	
	Other method (please specify)	
What physical method is/was used to collect the data?	**Paper-based survey (yes/no)**	
	Manual extraction from clinical records (yes/no)	
	Extraction from electronic records (yes/no)	
	Internet hosted survey (yes/no)	
	Desktop-based survey tool (yes/no)	
	Other (please specify)	
Is/was the study approved/overseen by an Ethics body? (yes/no)		
If data are collected electronically or extracted from an electronic record, what types/brands of clinical software is/are used?		
What data extraction tool is used?		
Can the data collection tool be used with more than one type of software? (yes/no)		
If 'NO', what is the potential for the tool to be altered for future use with other types or brands of clinical software?		
In what format are data downloaded? (i.e. free text; coded; encrypted; coded and encrypted etc)		
Are the data linked to other data sources? (yes/no): (e.g. Medicare; other research studies etc)		
Could the data be linked to other data sources? (yes/no): (e.g. Medicare; PBS; other research studies etc)		
What size is the database currently? (i.e. the number of individual GPs / patients / patient encounters / patients with specific condition etc, in the database that are available for analysis)	**GPs: (number)**	
	Patients/encounters/visits (number)	
	Other (please specify below) ________________________ **(number)**	

THE GP STUDY POPULATION		
Describe the GP study population (e.g. is the study national, regional, Divisional etc?):		
What type of sampling is used? (e.g. random sample of all GPs; random sample of GPs using specific software; opportunistic sample of all GPs; opportunistic sample of GPs at specific settings etc):		
How is GP participation / consent to participate decided?	**Signed consent obtained for each period of participation (yes/no)**	
	Signed consent obtained at first period of participation which includes subsequent episodes of participation (yes/no)	
	Verbal consent obtained for each period of participation (yes/no)	
	Verbal consent obtained at first period of participation which includes subsequent episodes of participation (yes/no)	
	Neither written nor verbal consent is obtained (yes/no)	
What is the level of participant consent? (i.e. the level of information given to participants about how their data will be used, to which they have consented?)	**Participants were/are informed individually of data collection, the storage of data in a database and the uses of the data for particular purposes (yes/no)**	
	Participants informed collectively of data collection, storage of data in a database and uses of data for particular purposes (yes/no)	
	Participants not informed explicitly of data collection, storage or uses (yes/no)	
Does the study include all types of GPs? (yes/no) (If no, please specify which groups are included e.g. new graduates; VR GPs; non-VR GPs; OMPs; full-time GPs; part-time GPs; locums etc):		**If no, please specify:**
GP participants can include …	**Individual GPs from a practice (yes/no)**	
	Multiple GPs from a practice (yes/no)	
	All GPs from a practice (yes/no)	

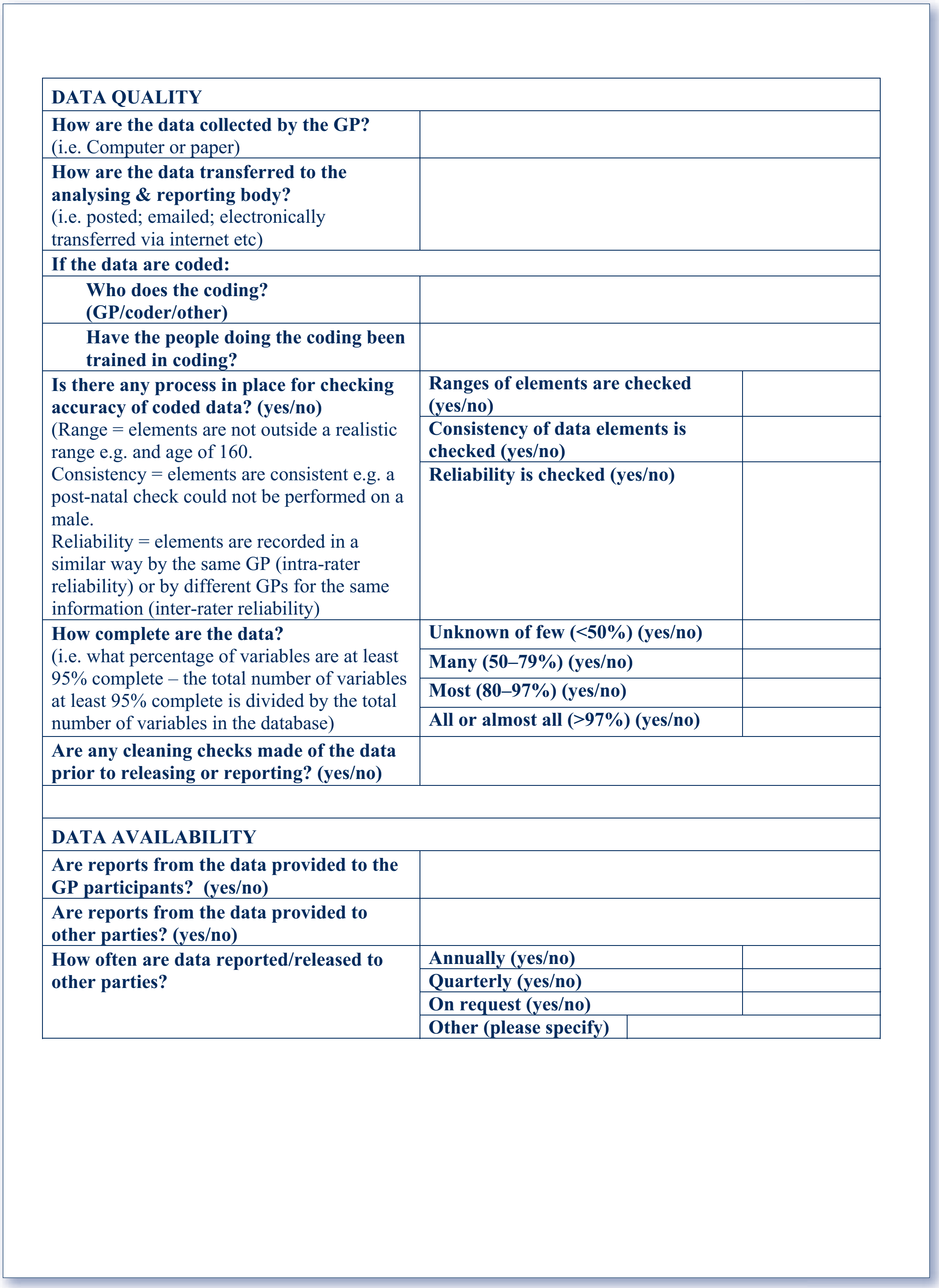
To what extent is the participant sample representative of the GP population? (i.e. the extent to which the sample population can be generalised to the reference population)	**No evidence or unlikely to be representative (yes/no)**	
	Some evidence that eligible population is represented (yes/no)	
	Good evidence that eligible population is represented (yes/no)	
	Total eligible population included (yes/no)	
What demographic or other characteristic information do you collect about the GP or the practice? (e.g. age; sex; location of practice etc)	**No GP characteristics (yes/no)**	
	Age (yes/no)	
	Sex (yes/no)	
	Practice postcode (yes/no)	
	No of GPs in practice (yes/no)	
	No of years in practice (yes/no)	
	Accreditation of practice (yes/no)	
	Practice nurse at practice (yes/no)	
	Bulk-billing status (yes/no)	
	Business model (i.e. solo GP, partnership, corporate owned etc) (yes/no)	
	Provider number (yes/no)	
	Other characteristics (please specify)	
Is there scope for additional information about the GP or practice to be collected in the future (yes/no)?		
Are individual GPs identifiable? (Identifiable = individuals can be identified as one or more of the following are included: name; address; date of birth; provider number. Reversibly anonymised = individual identifiers have been removed or encrypted so that those using the data cannot identify individual GPs. A unique individual ID (either number or code) has been assigned by project management such that it is possible to reverse the anonymisation if required for data linking purposes. Irreversibly anonymised = No individual GP identifiers are stored on the database).	**Identifiable (yes/no)**	
	Reversibly anonymised (yes/no)	
	Irreversibly anonymised (yes/no)	

Are there any other characteristics of the study population that should be noted?		
THE PATIENT STUDY POPULATION		
Describe the patient study population (i.e. all patients included; a sample of all patients; only patients with specific morbidity e.g. diabetes; only patients at ACCHSs etc?):		
Patient participants include …	**Selected individual patients from a practice (yes/no)**	
	A designated number of consecutive patients from a practice (yes/no)	
	All patients from a practice over a specified time period (yes/no)	
How is patient participation / consent to participate decided? (i.e. how is subject consent obtained?)	**Signed consent obtained for data to be recorded at each episode (yes/no)**	
	Signed consent obtained only at first participation but that includes subsequent episodes (yes/no)	
	Verbal consent obtained - patients are given the option to opt-in and are only included if they choose to participate (yes/no)	
	Verbal consent obtained - patients are given the option to opt-out and are included unless they choose not to participate (yes/no)	
	Neither written or verbal consent obtained and patients are not given the option to opt-in or opt-out of the database (yes/no)	
Are individual patients identifiable? (Identifiable = individuals can be identified as one or more of the following are included: name; address; date of birth; provider number. Reversibly anonymised = individual identifiers have been removed or encrypted so that those using the data cannot identify individual patients. A unique individual ID (either number or code) has been assigned by project management such that it is possible to reverse the anonymisation if required for data linking purposes. Irreversibly anonymised = No individual patient identifiers are stored on the database).	**Identifiable (yes/no)**	
	Reversibly anonymised (yes/no)	
	Irreversibly anonymised (yes/no)	

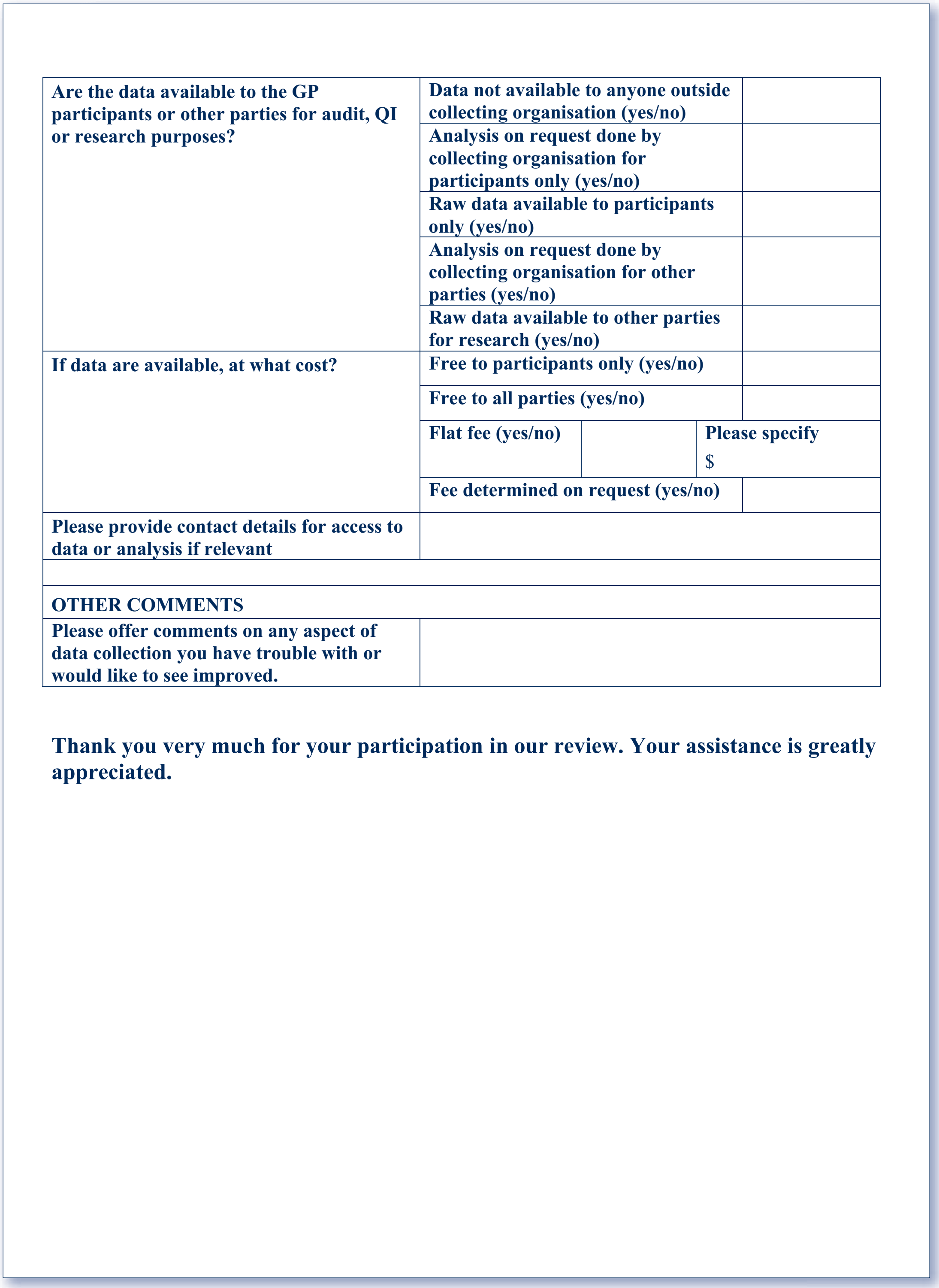


What demographic or other characteristic information do you collect about the patient? (e.g. age; sex; geographic location etc)	**Medicare Number (yes/no)**	
	Age / date of birth (yes/no)	
	Sex (yes/no)	
	Postcode of residence (yes/no)	
	Cultural background (yes/no)	
	Health Care Card status (yes/no)	
	Vet's Affairs Card status (yes/no)	
	Practice nurse at practice (yes/no)	
	Patient status to the practice (i.e. seen previously be GP/s at the practice or a new patient to the practice) (yes/no)	
	Other characteristics (please specify)	
Is there scope for other information about the patient to be collected in the future? (yes/no)		
What information do you collect about the visit/consultation/encounter? (Location = where the visit occurred e.g. at the practice; patient's home; aged care facility etc. Direct / indirect = whether a face-to-face meeting occurred between GP & patient or no meeting occurred but a patient related service was provided e.g. case conference. Payer details = who paid for the service e.g. Medicare (bulk-billed); Medicare + patient; patient only; State (hospital, corrective services, community services etc); armed services; workers' compensation etc)	**Date of visit (yes/no)**	
	Location (yes/no)	
	Start / finish time (yes/no)	
	Direct / indirect (yes/no)	
	Medicare item number/s (yes/no)	
	Payer details (yes/no)	
Is there scope for additional information about the visit/encounter to be collected in the future? (yes/no)		

THE PATIENT DATABASE			
What data elements are collected about the patient's visit? (If data elements are coded, please name the coding system used e.g. Docle, ICPC-2 PLUS etc)	**Collected? (Yes/No)**	**Coded? (Yes/No)**	**Coding system used**
Reasons for visit/encounter			
Problem/diagnosis			
Medication prescribed			
Medication provided			
Medication advised for purchase			
Pathology ordered			
Imaging ordered			
Referrals			
Procedures - diagnostic			
Procedures - therapeutic			
Administrative (e.g. medical certificate)			
Other			
Is there scope for other data elements to be collected in the future? (yes/no)			
Can the GP and patient data be linked? (i.e. can data from a specific patient be linked to a specific GP)	**Patient data can be linked to a practice but may include information by more than one GP (yes/no)**		
	Patient data can be linked to a single GP only (yes/no)		
To what extent can individual problem and its management be followed for each patient over time? (i.e. linking of initial and subsequent visits so that progress of problem/illness can be observed):	**Information is recorded for single visit/encounter only (yes/no)**		
	Information is recorded for repeated visits for a patient but does not link the problem within the record over time (yes/no)		
	Information is recorded for repeated visits that are linked to the initial visit and problems/illnesses can be followed over time (yes/no)		
What if the name of the problem/diagnosis changes over an episode? (i.e. if the diagnosis label is initially a symptom which is later better defined e.g., headache, sore throat progress to diagnosis of strep infection; a headache progresses to diagnosis of migraine, then to brain tumor?)			



DATA QUALITY		
How are the data collected by the GP? (i.e. Computer or paper)		
How are the data transferred to the analysing & reporting body? (i.e. posted; emailed; electronically transferred via internet etc)		
If the data are coded:		
Who does the coding? (GP/coder/other)		
Have the people doing the coding been trained in coding?		
Is there any process in place for checking accuracy of coded data? (yes/no) (Range = elements are not outside a realistic range e.g. and age of 160. Consistency = elements are consistent e.g. a post-natal check could not be performed on a male. Reliability = elements are recorded in a similar way by the same GP (intra-rater reliability) or by different GPs for the same information (inter-rater reliability)	**Ranges of elements are checked (yes/no)**	
	Consistency of data elements is checked (yes/no)	
	Reliability is checked (yes/no)	
How complete are the data? (i.e. what percentage of variables are at least 95% complete – the total number of variables at least 95% complete is divided by the total number of variables in the database)	**Unknown of few (<50%) (yes/no)**	
	Many (50–79%) (yes/no)	
	Most (80–97%) (yes/no)	
	All or almost all (>97%) (yes/no)	
Are any cleaning checks made of the data prior to releasing or reporting? (yes/no)		
DATA AVAILABILITY		
Are reports from the data provided to the GP participants? (yes/no)		
Are reports from the data provided to other parties? (yes/no)		
How often are data reported/released to other parties?	**Annually (yes/no)**	
	Quarterly (yes/no)	
	On request (yes/no)	
	Other (please specify)	



Are the data available to the GP participants or other parties for audit, QI or research purposes?	Data not available to anyone outside collecting organisation (yes/no)		
	Analysis on request done by collecting organisation for participants only (yes/no)		
	Raw data available to participants only (yes/no)		
	Analysis on request done by collecting organisation for other parties (yes/no)		
	Raw data available to other parties for research (yes/no)		
If data are available, at what cost?	Free to participants only (yes/no)		
	Free to all parties (yes/no)		
	Flat fee (yes/no)		Please specify $
	Fee determined on request (yes/no)		
Please provide contact details for access to data or analysis if relevant			
OTHER COMMENTS			
Please offer comments on any aspect of data collection you have trouble with or would like to see improved.			

Thank you very much for your participation in our review. Your assistance is greatly appreciated.

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