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.

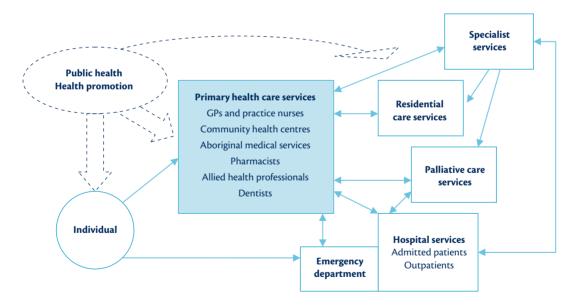
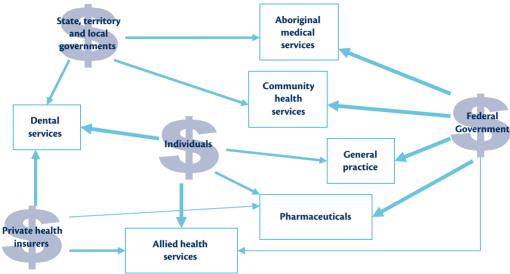


Figure 1.1: The role of primary health care in the Australian health system: a simplified framework

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.