

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 unforeseen 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.