

## 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).

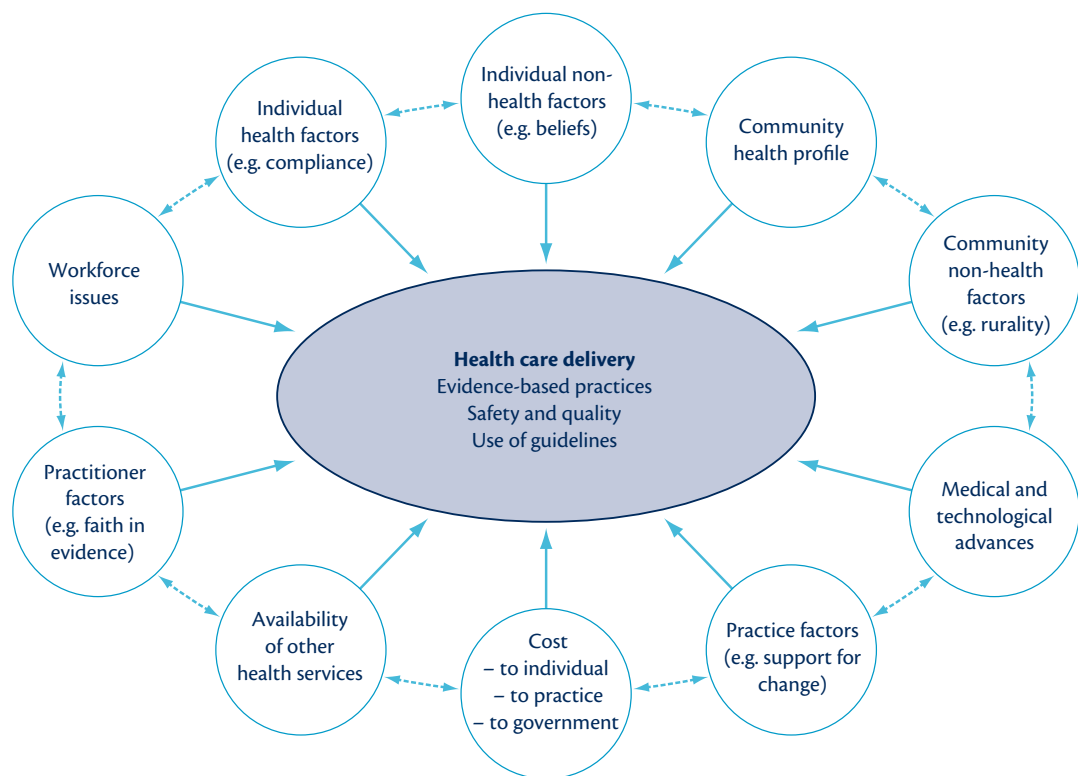
**Linkage: enabling data linkage**

- 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
<b>GP–patient encounter collections</b>											
BEACH	Yes	Yes	Yes	Limited	No	Yes	Limited	Some <sup>(a)</sup>	Limited	No	Very good
<b>Population health surveys</b>											
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
<b>Administrative collections</b>											
MBS	Some	Minimal <sup>(b)</sup>	No	No	Limited <sup>(c)</sup>	No	Limited <sup>(c)</sup>	No	No	Yes <sup>(d)</sup>	Excellent
PBS	Some	Minimal <sup>(b)</sup>	No	No	Limited <sup>(c)</sup>	Limited	No	No	No	Yes <sup>(d)</sup>	Excellent
PIP and SIP	No	Some	No	No	No	No	Some	No	No	No	Good
RPBS	Some	Minimal <sup>(b)</sup>	No	No	Limited <sup>(c)</sup>	Limited	No	No	No	Yes <sup>(d)</sup>	Excellent
<b>Research and other collections</b>											
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
<b>GP-patient encounter collections</b>											
APCC	No	Some	Some	No	No	Some	Some	No	No	No	Fair
CONDUIT	Yes	Some	Yes	Yes <sup>(a)</sup>	Yes <sup>(a)</sup>	Yes	Potentially	Yes	No	Yes	Fair
GPRN	Yes	Some	Yes	Yes <sup>(b)</sup>	Yes <sup>(b)</sup>	Yes	Yes	Yes	No	Yes (int)	Good
Medic-GP	Some	Some	Yes	Yes	Yes	Yes	Yes	Yes	Some	Yes (int)	Fair
<b>Collections of aggregate data</b>											
ASPEN	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.