



## 7.17 Patient-reported experience and outcome measures

Patient-reported measures collect information about the experience of health services, and the outcomes of health services, as described by patients. They differ from many other measures of health service delivery which are based on information from providers of health services. Patient-reported measures can be used to measure health performance—for both national and local area monitoring—and to inform ongoing improvements in the quality of health services. Currently, their use is largely restricted to discrete health services and contexts (Thompson et al. 2016).

Interest is growing in strengthening and coordinating efforts to collect patient-reported information to benefit patients and the health system as a whole. To this end, patient reported measures have been included in the scope of the new Australian Health Performance Framework (AHPF) as measures for potential development to inform assessments of the appropriateness and safety of care in particular (NHPPC 2017).

This article presents information on the current and potential use of patient-reported experience and outcome measures in Australia.

### Patient-reported experience measures

Patient-reported experience measures (PREMs) are used to obtain patients' views and observations on aspects of health care services they have received. This includes their views on the accessibility and physical environment of services (for example, waiting times and the cleanliness of consultation rooms and waiting spaces) and aspects of the patient–clinician interaction (such as whether the clinician explained procedures clearly or responded to questions in a way that they could understand).

### Patient-reported experiences in Australia

The Australian Bureau of Statistics Patient Experience Survey (PES) is undertaken annually to report on patient experiences of health care services (in general) in Australia. This national population-based survey collects information on the use of, and experiences with, selected health service providers by people aged 15 and over.

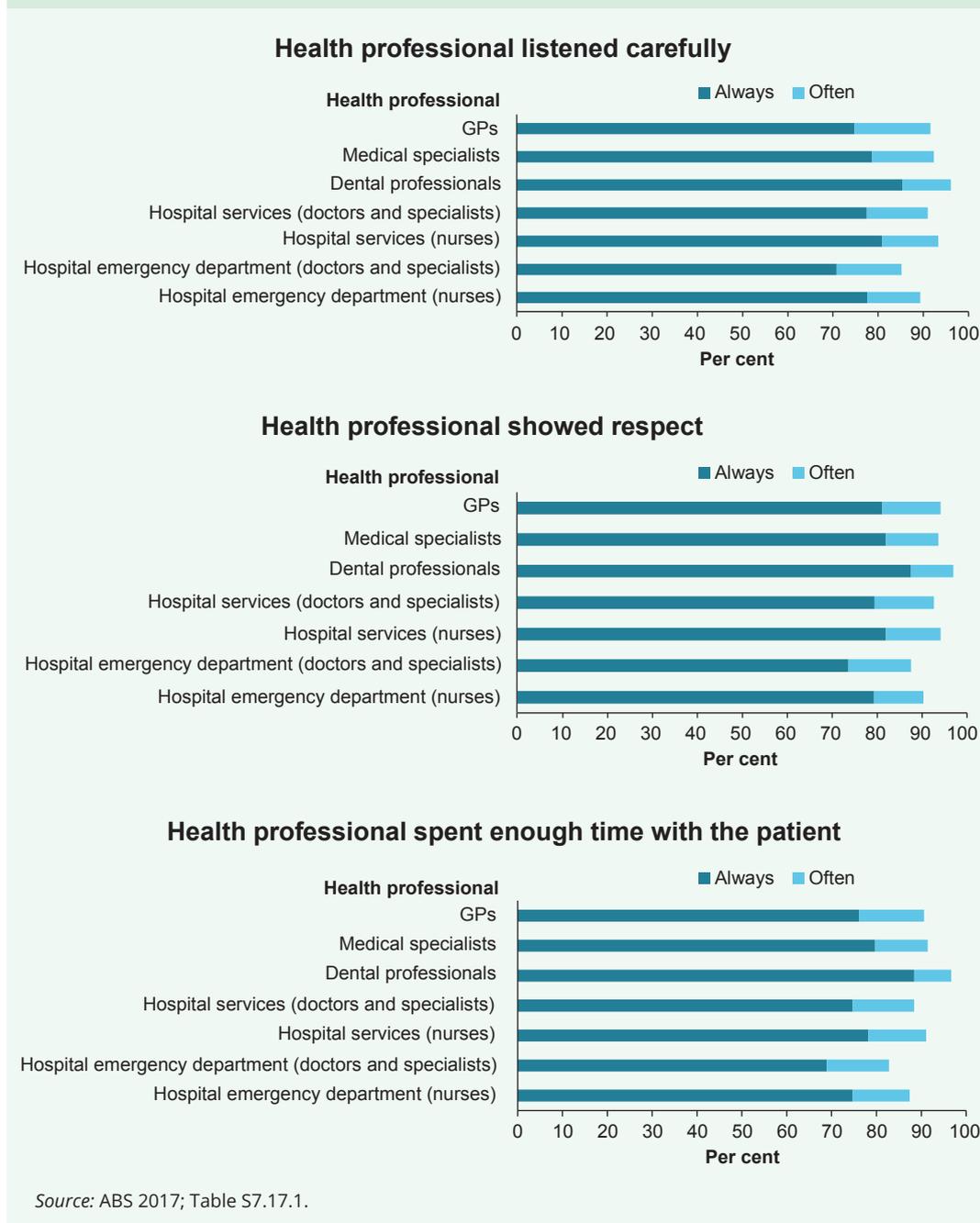
According to the PES, in 2016–17, 18% of people felt that they had waited longer than they felt was acceptable to get an appointment with a general practitioner (GP) in the last 12 months, and 21% had waited longer than they felt was acceptable for an appointment with a medical specialist.

For people who had seen a GP for urgent medical care at some stage in the last 12 months, 63% were able to see the GP within 4 hours of making an appointment at their most recent visit, but a quarter (25%) waited for 24 hours or more.



PES respondents reported that a high proportion of health professionals 'always' or 'often' listened carefully, showed respect, and spent enough time with them in their communications. Dental professionals were identified as most likely to always display these characteristics, with doctors and specialists in emergency departments least likely to do so (Figure 7.17.1). This may reflect the different nature of these health care interactions, and the circumstances in which these different services might be accessed.

Figure 7.17.1: Key patient experience measures, selected health professionals, 2016–17





The PES is useful to obtain a picture of how patients' view their experiences in accessing key health care services, and their satisfaction with aspects of the clinical interaction in general. The data it provides are used in national health performance assessment—for example, as reported in the *Report on Government Services* (SCRGSP 2018). However, they cannot be specifically used to support service improvement because they:

- relate to all relevant services provided in the last 12 months (and so do not necessarily relate to experiences with a single service provider or organisation)
- do not identify the specific service provider(s) used (and so information cannot be fed back to them)
- are not restricted to assessment of recent experiences; the information may be collected up to 12 months after the service was provided, which may influence responses provided.

## Using patient experiences data for service improvement

There are several programs in Australia where patient experience data are collected for specific services, and then fed back to service providers to drive continuing improvement of those services. Data may also be aggregated to allow some overarching monitoring of services. One such program is the Your Experience of Service survey, which has been adopted in some parts of the public mental health sector; the program aims to help mental health services and consumers work together to build better services (see Box 7.17.1).

There are a number of other standardised PREMs developed for general use across health services. Examples include the United Kingdom's National Health Service surveys, the Canadian Patient Experiences Survey and the Victorian Healthcare Experience Survey (CIHI 2018; Picker Institute Europe 2018; Victorian DHHS 2017a).

In relation to hospital care, the Australian Hospital Patient Experience Question Set (AHPEQS) has recently been developed. It is a nationally consistent tool for assessing patient experiences in the hospital sector in a way that can be fed back to providers. The AHPEQS is a set of 12 questions about a person's recent experience in a private or public hospital or day procedure service, regardless of their condition or the type of treatment they receive. The questions cover a range of aspects of their care and experience—such as patient involvement, responsiveness to needs, clear communication, patient safety, and harm and distress (ACSQHC 2017a). The questions were based on focus group discussions with Australian health care consumers, which identified the key dimensions seen to be important influences on the quality of their experience (Figure 7.17.2).

In the future, it is intended that the AHPEQS will provide a nationally consistent method to monitor and benchmark patient experience across Australia, for both public and private health care services. These data can then be used within services to drive improvement and, will, potentially, be a data source for the patient experience indicators anticipated in the AHPF.



### Box 7.17.1: Your Experience of Service Survey

Monitoring consumer and carer experiences of service is an action under the Fifth National Mental Health and Suicide Prevention Plan (The Fifth Plan) (CHC 2017).

All levels of government have had a long-standing interest in developing a standardised national measure of mental health consumer experiences of care that would support quality improvement, service evaluation and benchmarking between mental health services.

The Your Experience of Service (YES) survey was developed for use with public mental health services. It asks questions about patients' perceptions of their treatment and the care they received (for example, did they feel welcomed, respected and safe; were they provided with information about the service, their rights and responsibilities; and was a suitable care plan developed).

The YES survey is currently used in three states (New South Wales, Victoria and Queensland). In general, the survey form (which identifies the service provider) is offered to patients at discharge or at other appropriate intervals, and they complete it anonymously. Data are collated centrally, and an aggregated data report is provided to services to encourage review and continuous improvement.

Individual states have publicly reported on YES data. Some of the key findings presented in their reports are detailed here:

- In Victoria, nearly two-thirds (65%) of people who attended a clinical mental health service in the previous 3 months rated their experience as excellent or very good. The main factor associated with positive experiences was 'staff showing respect for your feelings', which was further influenced by 'feeling welcome', 'staff making an effort to see you when you wanted', 'staff showing hopefulness for the future' and 'respect for individual values and feeling safe' (Victorian DHHS 2017b).
- In New South Wales, 39% of people rated their overall experience as excellent and 28% as very good in 2016–17. Composite score data (based on responses to all relevant questions) in that state are also presented for local health districts/ specialty health networks and hospitals—which identify those services that have scores that are significantly more positive than the state average, and those that are significantly lower (NSW Ministry of Health 2017).
- In Queensland, 44% of people rated their overall experience as excellent, and 26% as very good in 2016. Across the state, the most positive scores were related to 'showing respect', 'ensuring safety and fairness' and 'supporting active participation'. Lower scores were given for 'providing information and support' and 'making a difference' (Queensland Health 2017).

These data are used at the statewide level to monitor services in general. The data for individual services are used by those services to compare their results with those of others, and to prioritise improvement activities.

The Fifth Plan commits governments to national pooling and reporting of YES survey data in the future.

Figure 7.17.2: Dimensions of patient experience (hospital care)



## Patient-reported outcome measures

As well as interest in activities aimed at expanding the use of PREMs, there is also strong interest in promoting and coordinating the use of patient-reported outcome measures (PROMs, see Box 7.17.2)—both in Australia and other countries.

The International Consortium for Health Outcomes Measurement (ICHOM), established in 2012, aims to promote the collection and reporting of common data for patients with identified health conditions, and to support international efforts to share data and improve health internationally. The ICHOM assembles global teams of stakeholders (including patients) to review existing instruments and recommend those that are valid and appropriate for use in a range of cultures. As well, they recommend additional data that should be collected and used in conjunction with health outcomes data (for example, information about the age of the patient and comorbidities that may affect expected outcomes).

Building on the work of the ICHOM, the Organisation for Economic Co-operation and Development (OECD) has prioritised activities to promote the coordinated use of standardised questionnaires within OECD member countries (including Australia) among priority population groups. This international coordination may provide opportunities for international comparison and data sharing in addition to national use. In the first instance, this work is focusing on patients who have undergone hip or knee replacement surgery, and patients who are receiving treatment for cancer or mental illness (OECD 2017).

Within Australia, the Australian Commission on Safety and Quality in Health Care is currently leading the development of a national approach to the routine use of PROMs to inform local evaluations and improvement. This will be based on three types of evidence:

- what has been shown to be effective (and ineffective) in health systems internationally where PROMs are already extensively used
- what is already happening in terms of PROMs use in the Australian health sector
- what Australian consumers and other stakeholders want and need.



#### Box 7.17.2: What are patient-reported outcome measures?

PROMs are used to obtain information from patients on their health status, usually using standardised and validated questionnaires. When used before and after a health care intervention (or at points throughout a longer term therapeutic intervention), information on the self-reported changes in health status associated with these interventions are considered to be measures of health outcomes.

The questionnaires can be designed either for use with all patients—regardless of their health condition or the type of treatment they may be receiving—or for use with specific patient groups (for example, cancer patients).

Typically, PROMs for general use measure aspects such as overall health and wellbeing (or 'health-related quality of life'), the severity of symptoms such as pain, measures of daily functioning (activities required for self-care and to support social interactions) and psychological symptoms. The most common questionnaires used range in length from 5 to 36 questions, and typically ask respondents to assess attributes of their health and functioning on a rating scale.

Examples of general purpose PROMs in common use include the Short Form-36 (SF-36), Patient-Reported Outcomes Measurement Information System (PROMIS) and the World Health Organization Quality of Life Instrument (WHOQoL-BREF) (HealthMeasures 2018; Ware & Sherbourne 1992; WHO 2018).

Disease- or condition-specific PROMs are designed to assess aspects of health that might be more specifically associated with a particular health condition (Williams et al. 2016). For example, a measure designed for use in people who experience inflammatory bowel disease might include questions on bowel symptoms, as well as more general questions about pain and discomfort, fatigue, and ability to participate in activities.

The two types of PROMs have different uses. Generic PROMs can be used to compare the health gains across different health conditions. Condition-specific PROMs may be more useful in settings where the aim is to compare outcomes associated with different treatments for a specific condition.

## What are the potential benefits of using PROMs?

PROMs have long been used in research settings as part of the evaluation of health interventions. Their systematic use in real-world health care delivery settings is proposed to improve health systems on a number of levels (see, for example, Black 2013; Williams et al. 2016).

At the patient level, the collection of PROMs data can influence the patient–clinician interaction. It does this in two ways: by focusing attention on important aspects of patients' lives that might be affected by their health condition, and by providing a means to prompt discussion between the health care provider and the patient. This, in turn, can enhance information sharing (including about patients' priorities for their health care) and support shared decision making about treatments. In particular, aggregated PROMs



data could enhance shared decision making with patients by providing evidence-based information on expected outcomes at specific times after a health intervention (for example, at 2 weeks, 4 weeks and 3 months after a knee replacement). This information could help patients to make informed choices about their care.

At the service level, these data can be used for performance reporting and benchmarking by individual clinicians and/or health care services. In this way, providers can ensure that the outcomes achieved overall for their patients are comparable with those achieved by others (when adjusted for relevant patient characteristics). This information can then be used to review systems, processes and approaches to care (where poorer outcomes are seen), or to support sharing of information about good practices with better outcomes.

Another key potential use for PROMs lies in the ability of data—if available at the aggregate level and for a wide range of health services—to inform health care decisions at the system level. Specifically, if data were available about the improvements to health, quality of life and functioning status associated with specific health interventions or procedures (or the extent to which they slowed a decline in health status), this could substantially help the health system to re-focus on those interventions that deliver the best value for patients and for the system as a whole.

## Examples of the use of patient-reported outcome measures in health care delivery

This section describes some specific areas where there has been some cooperative effort in Australia to collect and share information about health outcomes (including patient-reported outcomes) associated with care. These are the Palliative Care Outcomes Collaboration (PCOC) and the Prostate Cancer Outcomes Registry.

### Palliative Care Outcomes Collaboration

The PCOC is a national program open to all palliative care service providers (providing either admitted patient or community-based services). It was set up in 2005. Participation is voluntary; in a recent period (January–June 2017), 127 services contributed data.

The program was established to promote the routine use of standardised, validated clinical assessment tools in clinical practice. One of the instruments used that is designed to be reported by patients is the Symptom Assessment Scale (Aoun et al. 2011), which measures distress associated with a range of symptoms. The instrument also allows assessment by proxy (for example, a carer) if the patient is unable to give the relevant rating directly.

Assessments are conducted daily for admitted patients, or at contact for hospital consultative and community-based settings. Assessments can be done face to face or by telephone, as appropriate to the setting.



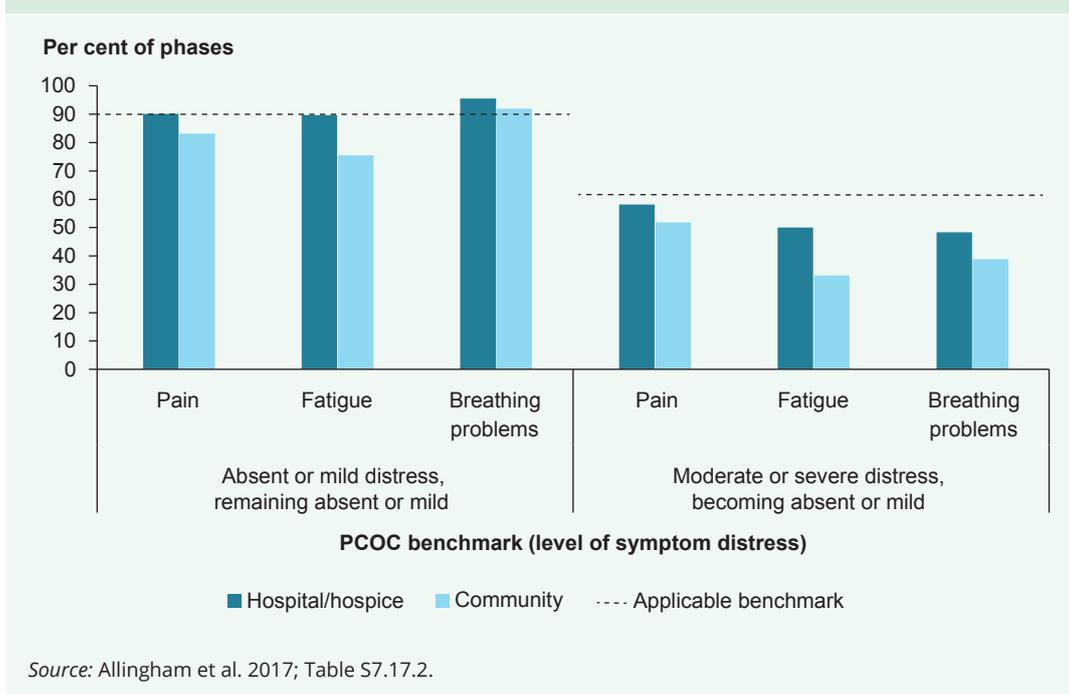


In this program, the data are primarily used as a benchmarking tool, rather than to formally evaluate different types of interventions. Outcomes data are collated, along with information about the patient's demographic profile, episode and setting of care, and phase of care (which provides information on the patient's needs and their clinical condition); these added data form an important context for analysis of the patient health status data. Summary reports are then returned to individual service providers to help in benchmarking. State, territory and national reports are also published. These reports compare aggregated data on a range of benchmarks that have been developed in consultation with participating services. For example, in relation to pain, fatigue and breathing problems, relevant benchmarks aim that:

- at least 90% of patients with absent or mild distress associated with the symptom (as measured by the Symptom Assessment Scale) at the start of their phase of palliative care have absent or mild distress at the end of the phase
- at least 60% of patients with moderate or severe distress associated with the symptom at the start of their phase of palliative care have absent or mild distress at the end of the phase (PCOC 2014).

For palliative care phases that ended between January and June 2017, relevant benchmarks were achieved (nationally) for patients who had absent or mild pain-related distress at the start of the care phase for hospital/hospice care only, and for patients who had absent or mild distress associated with breathing problems (for both hospital/hospice and community based care) (Figure 7.17.3). Nationally, relevant benchmarks were not met in the other areas, though these benchmarks were met in some individual services (Allingham et al. 2017).

Figure 7.17.3: Proportion of palliative care phases where patient care met relevant PCOC benchmarks, by care setting, January–June 2017





## Prostate Cancer Outcomes Registry

Clinical quality and population (disease- or condition-specific) health registries also provide a context in which patient-reported health outcomes data can be collected and used to assess treatments and services provided by specific health service providers (Williams et al. 2016).

One example is the Prostate Cancer Outcomes Registry–Australia and New Zealand. Established in 2013, it tracks the treatment and outcomes of men with prostate cancer (PCOR–ANZ 2016). Participating sites (distributed across most states and territories in Australia, and throughout New Zealand) recruit men diagnosed with prostate cancer to provide information about their treatment and other clinical data. Participants are then asked to periodically complete standardised questionnaires that capture data on their health-related quality of life. This includes reporting on symptoms that may be specifically associated with prostate cancer and its treatment (such as urinary continence and sexual functioning).

This information can be used to describe the patterns of treatment for patients (including those receiving no treatment, but who are under active surveillance) and enables monitoring of trends and benchmarking for all participating sites through public reporting at an aggregate level. As well, the data support activities to improve quality: reports sent back to participating sites and clinicians are framed in a way that allows them to compare their clinical practices and outcomes achieved for similar patients. The data can also be used to advise patients on the likelihood of symptoms associated with specific treatments and help them to understand how these might change over time.

As well, the data are made available to researchers, under specific conditions, to explore specific research questions.

### What is missing from the picture?

As already noted in this article, work is going on across the health sector to collect and report patient reported data on experiences of care and health outcomes; this is currently mainly restricted to selected settings and sectors. The value of these activities could be greatly enhanced by introducing more nationally coordinated technical and governance arrangements and by introducing improved data infrastructure. These activities could ensure that the data collected on outcomes and experiences are aligned (wherever possible). They also could establish a potential for national sharing of data or linkage arrangements to enable improvements in the delivery of health care at a range of levels.

### Where do I go for more information?

More information about the current use of PROMs in Australia and the AHPEQS is available at <[www.safetyandquality.gov.au](http://www.safetyandquality.gov.au)>.

More information on the YES survey for the mental health sector (including sample survey forms and application forms for use) is available in *Mental health services in Australia*, which is available for free download.



## References

- ABS (Australian Bureau of Statistics) 2017. Patient experiences in Australia: summary of findings, 2016–17 data cubes. ABS cat. no. 4839.0. Canberra: ABS. Viewed 24 January 2018, <<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4839.02016-17?OpenDocument>>.
- ACSQHC (Australian Commission on Safety and Quality in Health Care) 2017a. Australian Non-proprietary Hospital Patient Experience Question Set (AHPEQS): status update. Viewed 20 December 2017, <<https://www.safetyandquality.gov.au/wp-content/uploads/2017/09/AHPEQS-update-for-web-September-2017.pdf>>.
- ACSQHC 2017b. Summary of development and testing of the AHPEQS, December 2017. Sydney: ACSQHC.
- Allingham S, Clapham S, Quinsey K, Mastroianni F & Foskett L 2017. Patient outcomes in palliative care: national results for January–June 2017, detailed report. Wollongong: Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong.
- Aoun SM, Montessoro L, Kristjanson LJ & McConigley R 2011. Measuring symptom distress in palliative care: psychometric properties of the Symptom Assessment Scale. *Journal of Palliative Medicine* 14(3):315–21.
- Black N 2013. Patient reported outcome measures could help transform healthcare. *British Medical Journal* 346:f167.
- CHC (COAG [Council of Australian Governments] Health Council) 2017. The Fifth National Mental Health and Suicide Prevention Plan. Canberra: Department of Health.
- CIHI (Canadian Institute for Health Information) 2018. Patient experience. Ottawa: CIHI. Viewed 24 January 2018, <<https://www.cihi.ca/en/patient-experience>>.
- HealthMeasures 2018. PROMIS. Evanston: Northwestern University. Viewed 24 January, <<http://www.healthmeasures.net/explore-measurement-systems/promis>>.
- NHIPP (National Health Information and Performance Principal Committee) 2017. The Australian Health Performance Framework. Viewed 16 February 2018, <[www.coaghealthcouncil.gov.au/Portals/0/OOS318\\_Attachment%201.pdf](http://www.coaghealthcouncil.gov.au/Portals/0/OOS318_Attachment%201.pdf)>.
- NSW Ministry of Health 2017. Your Experience of Service: what consumers say about NSW mental health services, 2016–17. Viewed 11 December 2017, <<http://www.health.nsw.gov.au/mentalhealth/Documents/yes-survey-report-2016-2017.pdf>>.
- OECD (Organisation for Economic Co-operation and Development) 2017. OECD work on health. Paris: OECD. Viewed 24 January 2018, <<http://www.oecd.org/health/Health-Brochure.pdf>>.
- PCOC (Palliative Care Outcomes Collaboration) 2014. Palliative Care Outcomes Collaboration: clinical manual. Wollongong: Australian Health Services Research Institute, University of Wollongong.
- PCOR–ANZ (Prostate Cancer Outcomes Registry–Australia and New Zealand) 2016. Prostate cancer outcomes Australia, 2016. Melbourne: Monash University. Viewed 24 January 2018, <[https://pcor.com.au/wp-content/uploads/2016/06/PCOR-ANZ-Annual-Report\\_2016\\_FINAL.pdf](https://pcor.com.au/wp-content/uploads/2016/06/PCOR-ANZ-Annual-Report_2016_FINAL.pdf)>.
- Picker Institute Europe 2018. NHS surveys. Oxford: Picker Institute Europe. Viewed 24 January 2018, <<http://www.nhssurveys.org/>>.
- Queensland Health 2017. Your Experience of Service: statewide report, 2016. Queensland Health: Brisbane.
- SCRGSP (Steering Committee for the Review of Government Service Provision) 2018. Report on government services, 2018. Part E, Chapter 10: Primary and community health. Viewed 29 March 2018, <[www.pc.gov.au/research/ongoing/report-on-government-services/2018/health/primary-and-community-health](http://www.pc.gov.au/research/ongoing/report-on-government-services/2018/health/primary-and-community-health)>.
- Thompson C, Sansoni J, Morris D, Capell J & Williams K 2016. Patient-reported outcome measures: an environmental scan of the Australian healthcare sector. ACSQHC: Sydney.
- Victorian DHHS (Victorian Department of Health and Human Services) 2017a. Victorian Healthcare Experience Survey—VHES. Melbourne: Victorian DHHS. Viewed 24 January 2017, <<https://www2.health.vic.gov.au/hospitals-and-health-services/quality-safety-service/patient-experience-survey>>.
- Victorian DHHS 2017b. Victoria's mental health services annual report, 2016–17. Victorian DHHS: Melbourne.
- Ware JE & Sherbourne CD 1992. The MOS 36-item Short Form Health Status Survey (SF-36): 1, conceptual framework and item selection. *Medical Care* 30:473–83.
- Williams K, Sansoni J, Morris D, Grootemaat P & Thompson C. 2016. Patient-reported outcome measures: literature review. ACSQHC: Sydney.
- WHO (World Health Organization) 2018. WHO Quality of Life-BREF (WHOQOL-BREF). Geneva: WHO. Viewed 24 January 2018, <[http://www.who.int/substance\\_abuse/research\\_tools/whoqolbref/en/](http://www.who.int/substance_abuse/research_tools/whoqolbref/en/)>.

