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**Australian Institute of
Health and Welfare**

The measurement of patient experience in non-GP primary health care settings

Discussion paper for the
National Health Standards and Statistics Committee

April 2014



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*Authoritative information and statistics
to promote better health and wellbeing*

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Australian Institute of Health and Welfare
Canberra

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- Office for Aboriginal and Torres Strait Islander Health
- Australian Bureau of Statistics
- Australian Medicare Local Alliance
- Consumers' Health Forum
- Child Welfare and Prisoner Health Unit, AIHW
- Dental Statistics and Research Unit, AIHW
- Winnunga Nimmityjah Aboriginal Health Service

Abbreviations

ABS	Australian Bureau of Statistics
ACSQHC	Australian Commission on Safety and Quality in Health Care
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
COAG	Council of Australian Governments
OECD	Organisation for Economic Co-operation and Development
NACCHO	National Aboriginal Community Controlled Health Organisation
NHPA	National Health Performance Authority
NHS	National Health Survey
NHISSC	National Health Information Standards and Statistics Committee
NHPF	National Health Performance Framework
NPHDC	National Prisoner Health Data Collection
PEIDWG	Patient Experience Information Development Working Group
RACGP	Royal Australian College of General Practitioners

Summary

Information about patient experience is important to guide health care quality improvement and may also be used for health performance reporting. While there have been developments in the capture of patient experience information in hospital and GP settings, little was known about the extent of data capture and in the broader non-GP primary health care sector.

To gain a better understanding of patient experience in the non-GP primary health care sector, the Australian Institute of Health and Welfare (AIHW) undertook this exploratory study to document current state/territory and nationally relevant data collections with a view to assessing options for compiling patient experience data in this sector.

The project was part of a broader 3-part project funded by the Australian Health Ministers' Advisory Council to develop patient experience data and indicators. This work was overseen by the National Health Information and Performance Principal Committee through its National Health Information Standards and Statistics Committee with broad input from the Patient Experience Information Development Working Group.

In undertaking this work, the AIHW consulted with relevant state/territory health authorities, the Australian Medicare Local Alliance, the Office for Aboriginal and Torres Strait Islander Health, the Consumers Health Forum and the Australian Bureau of Statistics.

Results

Overall, the study confirms that while there have been selected activities to validate and standardise patient experiences in the hospital and GP setting, there has been limited documentation of patient experiences within the non-GP primary health care sector.

Future options

If there is interest in measuring patient experience in non-GP primary health care settings, a number of options could be considered:

- Undertake further work to define primary health care and non-GP primary health care.
- Improve fundamental data capture of community health information, including patient experience data. One option could be to build on the Victorian Government's model, pending further development, validation, piloting and implementation of the Victorian patient experience tools.
- Build on the work of the Royal Australian College of General Practitioners accreditation process and/or the common hospital patient experience questions to develop standard agreed questions for adoption across primary health care settings.
- For a more population-based approach (as opposed to surveys of recent service recipients), priority non-GP primary health care services could be identified and the Australian Bureau of Statistics (ABS) Patient Experience Survey expanded to capture patient's experiences with a selection of these services. If adopted, it would be important to develop a consistent definition and understanding of what constitutes primary health care and, specifically, non-GP primary health care so that the population could respond consistently to questions on this subject.

A number of the above options could be pursued to help build a more complete picture of patient experience in non-GP primary health care settings.

1 Background to the current project

In 2012-13, the Australian Health Ministers' Advisory Council (AHMAC) provided funding to develop patient experience data and indicators. This work is overseen by AHMAC's National Health Information and Performance Principal Committee through its National Health Information Standards and Statistics Committee (NHISSC) and received input from the broadly representative NHISSC Patient Experience Information Development Working Group (PEIDWG).

The associated work program consists of 3 projects, including Patient Experience Data Set Specification Development (Project 1a), Implementation of core patient experience questions (Project 1b), Validation of core, common patient experience questions for same-day admissions to public and private day procedure centres (Project 2) and Patient experience in non-GP primary health care (Project 3). This project aims to document existing approaches for measuring patient experience within the 'non- General Practice (GP)' primary health care sector.

Purpose

Information about patient experience is an important tool for health care quality improvement and may also be used for health performance reporting. While there have been selected activities to standardise and validate patient experience information in hospital and GP settings, there has been limited documentation of patient experience information within the non-GP primary health care sector. This project will help inform future work in the area of patient experience in primary health care settings.

The AIHW has undertaken this exploratory work to document current state/territory and nationally relevant data collections, with a view to assessing options for patient experience data improvement in primary health care.

Scope

In-scope service types/settings

The scope of this project is to document existing approaches for measuring patient experience within non-GP primary health care settings, including but not limited to:

- maternal and child health services
- public dental health services
- allied health services
- community rehabilitation programs
- alcohol and other drug treatment services
- Indigenous community healthcare
- women's health services
- men's health programs (SCRGSP 2013).

The project drew on this definition from the Report on Government Services in the absence of any standard or agreed definition of what constitutes primary health care or non-GP primary health care in Australia. While the definition is useful for focusing attention on a narrower range of specific program areas, such as maternal and child health services, it does not address the fact that these services may be delivered in various settings and under a range of funding and management arrangements.

For the purposes of this report, the scope is largely limited to services that are funded and/or delivered by state/territory and/or Australian governments and excludes similar services delivered and funded by the private sector. This reflects a broader issue that there is no consensus on what constitutes primary health care in Australia in terms of the various service activities, settings, professional groups and funding streams that constitute the sector.

The project excludes patient experience measurement in general practice because the Royal Australian College of General Practitioners (RACGP) has already approved a number of validated patient experience questionnaires for use in these settings. While the results of the surveys are not publicly available, some information about these validated patient experience questionnaires are reviewed for contextual purposes as part of this project.

Approach

The AIHW undertook a desk-top analysis of current data collections of patient experience in the non-GP primary health care sector (including surveys of patients and the general population and other data collections). To obtain information about current surveys used to access information about patient experience in the above settings, the AIHW sent a detailed questionnaire to:

- relevant state/territory health authorities, through NHISSC members who were asked to identify appropriate respondents
- the Australian Medicare Local Alliance
- the Office for Aboriginal and Torres Strait Islander Health
- the Consumers Health Forum
- the Australian Bureau of Statistics
- relevant areas within the AIHW.

In-scope data collections

It was requested that respondents provide information about relevant population surveys (e.g. state/territory population surveys) and surveys of specified patient groups (e.g. follow-up surveys of patients who have attended a community health centre).

Report structure

Subsequent chapters of this report are structured as follows:

- Chapter 2 provides contextual information about primary health care and measurement of patient experience in Australia
- Chapter 3 describes the methods adopted for the review
- Chapter 4 outlines the results of the review and options for areas of improvement.
- Chapter 5 provides an overview of findings.

2 Primary health care and patient experience measurement in Australia

Chapter 2 presents background information about primary health care in Australia, its importance in the overall health system, patient-centred care and the role of patient experience in understanding and improving the quality and performance of the health system. This general information is provided as context to guide the remainder of the report.

2.1 What is primary health care?

Primary health care is commonly viewed as the first level of health care or the entry point to the healthcare system for consumers (AIHW 2009). It can include care delivered by general practitioners, nurses, allied health providers, indigenous health workers, pharmacists, dentists, health promotion officers and paramedics working in the community (as opposed to those working in hospitals or other institutions) (AIHW 2008).

The primary healthcare workforce, based on people employed in general practice medical services and community-based dental, allied health and pharmacy services, including nurses, is estimated to be around 137,600 (DoHA 2013). Healthcare professionals providing services in the non-GP primary health care sector include physiotherapists, social workers, nurses, osteopaths, optometrists, psychologists, pharmacists, speech pathologists, audiologists, dietitians and radiographers among others. The number of professionals working in these non-GP primary health care settings has not been estimated.

Most health care in Australia is provided in primary healthcare settings. Some people may receive care from only one primary healthcare provider but many people visit a range of primary healthcare providers or teams, across a range of different disciplines.

Results from the 2007–08 National Health Survey show that 46% of Australians consulted a health professional other than a medical practitioner or dentist in the previous 12 months (AIHW 2010). The most commonly consulted health professionals were opticians or optometrists, pharmacists and physiotherapists. People older than 65 were more likely to consult other health professionals than those aged 15–24 (DoHA 2013).

Box 2.1: What is primary health care?

The Australian Primary Health Care Research Institute defines primary health care as: *'socially appropriate, universally accessible, scientifically sound first level care provided by health services and systems with a suitably trained workforce comprised of multi-disciplinary teams supported by integrated referral systems in a way that:*

- *gives priority to those most in need and addresses health inequalities*
- *maximises community and individual self-reliance, participation and control*
- *involves collaboration and partnership with other sectors to promote public health.*

Comprehensive primary health care includes health promotion, illness prevention, treatment and care of the sick, community development, and advocacy and rehabilitation.'(APHCRI 2005)

2.2 Why is primary health care important?

A strong primary health care system has been shown to improve patient health outcomes, reduce costs, increase efficiencies, lower hospitalisation rates, reduce health inequities, increase patient satisfaction and produce better health outcomes. It helps people better manage their health and plays an important role in preventing disease (Wong 2013, Starfield 2008, DoHA 2009, DoHA 2011).

2.3 How is primary health care organised and monitored in Australia?

Service delivery

Primary health care services can be delivered in a range of healthcare settings across urban, rural and remote areas of Australia, both within the public and private sectors. Settings include general practices, dental practices, community health centres, Aboriginal Community Controlled Health Services, pharmacies, private allied health practices, residential aged care facilities, homes, schools, workplaces and non-health-based community settings (such as shopping centres and community halls).

Primary health care in Australia operates as one component of the broader health care, community and aged care service system. Through the initial contact, individuals can be directed from one primary health care service provider to another, from primary health care into secondary or specialist health care (such as specialist medical care provided by a cardiologist or specialist mental health or drug and alcohol treatment) or from primary health care to hospital (including for outpatient, emergency department or admitted patient services).

Figure 2.1 uses primary health care settings to broadly illustrate the central role of primary health care (the settings depicted inside the dotted line) in the Australian health care system and the key health, community and aged care services with which it interacts.

Funding

As with the overall health system, primary health care is funded via complex arrangements involving Australian, state/territory and local governments, insurers and individuals. For example, physiotherapy services can be provided via private practices, community health centres, Aboriginal Medical Services, and hospital outpatient departments.

General practice activity is funded predominantly through fee-for-service and incentive payments (known as blended payments). Community health centres are generally funded by state/territory health authorities, Aboriginal Medical Services predominantly by Commonwealth funding and some fee-for-service payments and outpatient departments by state/territory health authorities in combination with fee-for-service payments.

Monitoring

Despite the importance of the primary health care sector, it has not experienced the same national focus on data capture, collation and reporting as other parts of the health system, such as hospitals. As a result, there are no nationally-consistent primary health care data

collections that describe the services comprising the sector, the users of these services or their experiences in any systematic way.

Unlike hospitals where a set of data is agreed and provided by each jurisdiction to gain a national picture, there is no nationally coordinated approach to primary health care data collection. Consequently, there is a lack of information about why someone went to a health professional, what occurred during the consultation, what treatment was recommended and what outcome was achieved. It is therefore difficult to obtain a clear understanding of the use of primary health care services nationally.

Primary healthcare delivery has been described as ‘fragmented’ and ‘fractured’ (ACSQHC 2011a). Primary health care service providers, governance and funding mechanisms are varied, as are reporting systems and requirements.

‘A coordinated approach to reporting requirements, standards and data collection would help fill the picture of primary health care in Australia for research and health decision-making purposes’ (AIHW 2012).

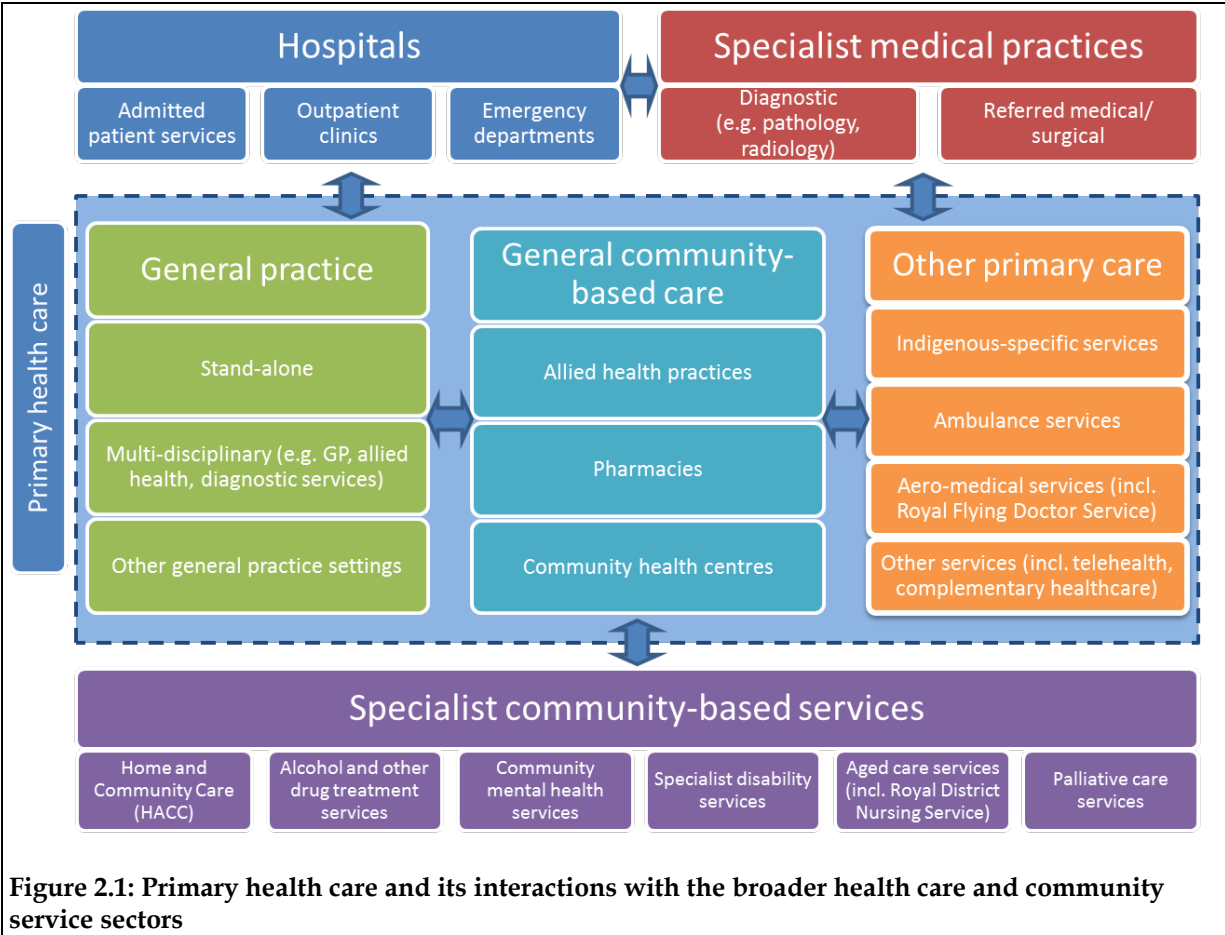


Figure 2.1: Primary health care and its interactions with the broader health care and community service sectors

2.3 What is patient-centred health care?

Patient-centred care is health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers (ACSQHC 2013). Its underlying principles include:

- treating patients, consumers, carers and families with dignity and respect
- encouraging and supporting patients, carers and families to participate in shared decision-making
- communicating and sharing information with patients, carers and families
- encouraging collaborations with patients, carers, families and health professionals in the development of programs and in the delivery and evaluation of health services.

A variety of national service-level initiatives, strategies and policies set out a patient-centred approach to health care, including:

- Australian Charter of Healthcare Rights
- Australian Safety and Quality Framework for Health Care
- National Primary Health Care Strategy
- National Chronic Disease Strategy
- Fourth National Mental Health Plan
- Fifth Community Pharmacy Agreement
- Current Aboriginal and Torres Strait Islander policies, which also reflect patient-centred principles, and focus on family and community.

These strategies recognise that a patient-centred approach to health care is needed to improve health care quality in Australia (ACSQHC 2011a).

2.4 Why is patient-centred health care important?

Patient-centred care is increasingly being recognised as a measure of high quality health care. It has been shown to lead to improvements in health care quality and outcomes by increasing safety, cost effectiveness and patient, family and staff satisfaction (ACSQHC 2013). Enhanced measurement of consumers' experience of, and satisfaction with, their healthcare is of great interest to many stakeholders including consumers (CHF 2012).

The patient's experience with the health system is an important and meaningful measure of quality of care relevant to all domains of health system performance. Information about patient experience provides a different perspective of performance for policy makers and service providers to consider. This information can be useful for both quality improvement and performance monitoring purposes.

The cornerstone for assessing patient-centred care is to understand how patients experience their care. This work is commonly guided by the Picker framework. Picker Europe pioneered the use of carefully designed survey instruments to obtain detailed reports of patient experience and identify areas for improvement (Picker Institute Europe 2013). These survey instruments differ from patient satisfaction surveys which have a more subjective focus.

The 8 Picker principles of patient-centred care include:

- access to reliable health

- effective treatment by trusted professionals
- participation in decisions and respect for preferences
- clear, comprehensive information and support for self-care
- attention to physical and environmental needs
- emotional support, empathy and respect
- involvement of and support for family and carers
- continuity of care and smooth transitions.

Some public and private hospitals in Australia use a modified Picker survey, while others have used these domains to develop questions suited to the Australian context. It is also generally possible to map the questions in various patient experience surveys to the Picker principles or domains to assess their comprehensiveness and to assist in comparing survey content or results.

2.5 How can patient experience information inform quality improvement and performance monitoring?

Information on patient experience helps inform two important functions:

- quality improvements, for example in response to various Australian Commission on Safety and Quality in Health Care (ACSQHC) documents and RACGP guidelines, and
- health performance reporting, for example in the National Healthcare Agreement (national and state/territory performance) and the Performance and Accountability Framework (Medicare Local level).

'A quality improvement approach refers to a deliberate and organised set of actions within a practice or organisation involving planning, implementation and assessment designed to improve the safety and quality of care' (ACSQHC 2011b).

A key element to quality improvement is access to a reliable flow of useful information to support monitoring and improvement in safety and quality across all levels of a healthcare organisation. Quality improvement processes usually rely on:

- information from a number of sources, including quality indicators generated from routinely collected datasets, and practice audits and case reviews
- qualitative approaches for collecting information and feedback.

This information allows health-service managers and individuals providing care to understand the reasons for variations in quality, and to identify where quality can be improved.

'A well-constructed primary health care survey offers a window into patients' perceptions that is otherwise unavailable. Patients are uniquely positioned to report on their care experiences and they are often the only common thread across disparate health care settings' (Wong 2013).

Performance monitoring is generally designed to assess differences in a specified performance indicator (e.g. proportion of people rating a service as high quality) or to identify examples of high or poor quality service, either over time or between different settings, agencies or jurisdictions.

Performance monitoring may or may not be made publicly available but, as with quality improvement, information is gathered with the intention that differences in the performance indicator measure can be readily interpreted and provides a useful guide for action.

For both performance monitoring and quality improvement purposes, the existence of a transparent process to respond to negative comments in a timely way and investigate them impartially, and sometimes independently, are equally important.

The expectations of the data used for these two purposes can be different. Patient experience information for quality improvement purposes may need less emphasis on the comparability of questions across different settings, agencies or jurisdictions. In this instance, data are mainly used to monitor an individual organisation's performance over time and questions and response processes must be comparable enough to generate useful information on which to base further quality improvement actions or responses to negative comments. In contrast, data for performance monitoring and reporting requires questions to be comparable between organisations and states/territories and over time to allow effective comparisons to be made.

Examples of quality improvement processes and frameworks relevant to patient experience in primary health care are highlighted in Box 2.2.

Box 2.2: Quality improvement processes and frameworks relevant to patient experience in primary health care

National Safety and Quality Health Service Standards

The Australian Commission on Safety and Quality in Health Care (ACSQHC) has developed National Safety and Quality Health Service Standards to improve the quality of health service provision in Australia. These standards provide a nationally consistent statement of the level of care consumers should expect from health services.

Of the ten standards developed, the second Standard – Partnering with Consumers – recognises the importance of patient experience. It describes the systems and strategies to create a consumer-centred health system by including consumers in the development and design of quality health care.

These standards form the basis of many of the accreditation programs provided for Australian health care professionals. For example, the Australian Council on Healthcare Standards (ACHS), an authorised accreditation agency with the ACSQHC, is authorised to accredit healthcare organisations to the National Safety and Quality Health Services Standards.

Australian Safety and Quality Framework for Health Care

The Australian Safety and Quality Framework for Health Care, developed by the ACSQHC, describes a vision for safe and high-quality care for all Australians. It specifies three core principles; that care is consumer centred, driven by information and organised for safety. The framework aims to promote discussion with patients, clinicians, managers, researchers and policy makers about how they might best form partnerships to improve safety and quality.

Royal Australian College of General Practitioners' Standards

The RACGP has developed *Standards for General Practice* focusing on quality care and risk management. These standards require practices to systematically gather and use information about patient experiences as a meaningful part of their quality improvement and accreditation process.

Box 2.2: Quality improvement processes and frameworks relevant to patient experience in primary health care (Cont.)

Practice-level Indicators of Safety and Quality for Primary Health Care

The Australian Commission on Safety and Quality in Health Care has developed specifications for a recommended set of practice-level indicators of safety and quality for primary health care. One of the main dimensions focuses on acceptability/patient participation and comprises 7 indicators, including a patient experience survey.

National Health Performance Framework

The National Health Performance Framework (NHPF), created under the auspices of the Australian Health Ministers' Advisory Council, contains 14 health dimensions grouped under three broad domains: health status, determinants of health and health system performance. In the NHPF, information about patient experiences with the health system can be used to measure various dimensions of health system performance.

3 Methods

The AIHW undertook to document existing approaches for measuring patient experience within the non-GP primary health care sector, including:

- maternal and child health services
- public dental health services
- allied health services
- community rehabilitation programs
- alcohol and other drug treatment services
- Indigenous community healthcare
- women's health services
- men's health programs.

To obtain information about current surveys used to access information about patient experience in the above settings, the AIHW contacted:

- state/territory health authorities (via NHISSC members)
- Australian Medicare Local Alliance
- Office for Aboriginal and Torres Strait Islander Health
- Consumers Health Forum
- Australian Bureau of Statistics
- other relevant areas within the AIHW.

A detailed list of contacts is at Appendix A. Stakeholders were asked to provide a synopsis of any current patient experience data collections, noting scope, key domains, methodologies, administration and reporting methods. A template was provided (Appendix B) to obtain details of data sources collecting relevant patient experience information from the general population (population surveys) or patients/clients of specific services where appropriate.

This information was compiled into a brief stocktake synopsis (Table 4.1) about current non-GP primary health care patient experience data collections. All completed surveys received are at Appendix C.

In addition, the AIHW undertook a targeted review of the literature to identify other potential approaches for measuring patient experience within non-GP primary health care settings within the Australian context.

4 Results

Section 4.1 describes the results from the questionnaires received by AIHW and Section 4.2 describes the results of additional research into other relevant data collection activities (i.e. in related sectors or internationally) that help to provide a more complete picture for measuring patient experience within non-GP primary health care settings.

While some surveys include a combination of patient experience and patient satisfaction questions, none exclusively measure patient experience in the non-GP primary health care setting.

4.1 Reviewed patient experience collections and approaches

The AIHW received 15 responses to the questionnaire sent to key contacts (at Appendix A) seeking to document existing approaches for measuring patient experience within the non-GP primary health care sector. These responses, described in Table 4.1, show:

- most jurisdictions do not currently collect data on patient experience in non-GP primary health care settings
- generally, it was not possible for respondents to describe existing data sources in terms of the Picker domains of patient experience
- some community health services conduct patient satisfaction surveys (see Box 4.1)
- some jurisdictions have future plans to introduce indicators for community health services, including measures relevant to patient experience, such as access, care planning, communication and continuity of care
- specific surveys, such as the 2002 National Dental Telephone Interview Survey and National Prisoner Health Data Collection, collect some data relevant to patient experience, including indicators to monitor access to care, respect for patients' values, communication and continuity of care.

Responses received noted that many primary health care programs include both GP and non-GP components, and occur in both community and hospital settings, making it difficult to accurately define 'non-GP' primary health care services.

Box 4.1: What is the difference between patient experience and patient satisfaction surveys?

Patient experience surveys require patients to give factual responses to reflect actual experiences during an episode of treatment. These surveys aim to avoid value judgements and the effects of existing expectations. Response options to questions are usually 'yes' or 'no'. For example, 'Did you get an appointment within two working days?'

Patient satisfaction surveys often include subjective and non-specific questions. For example, 'How satisfied are you with the appointment system?' Response options generally use some form of rating scale, such as a range from 'poor' to 'excellent'.

Table 4.1: Stakeholder responses regarding the measurement of patient experience in non-GP primary health care

No	Stakeholder	Response
1	New South Wales Health	<p>From 2007 to 2011, the NSW Ministry of Health conducted an annual survey of patient experiences with Community Health services. The definition of Community Health Services used was all non-hospital services, including home visits, clinics, etc. not considered to be clinical outpatient or mental health outpatient services. The questionnaire was 80 questions in length, with a response rate between 31.5% (2010) and 37.6% (2007).</p> <p>From 2010 to 2011, the Ministry conducted a survey of patient experiences with Outpatient Mental Health services (otherwise known as community mental health). The scope was defined as all non-admitted patients for mental health services, including clinics, outreach/home visits/community mental health/consultation liaison and emergency patients. The survey instrument was 66 questions long and the results published in October 2013 (http://www.bhi.nsw.gov.au/publications/patient_perspectives).</p> <p>From 2007 to 2011, the Ministry conducted a survey of patient experiences with non-admitted outpatient health services. The definition of Outpatient services used was all non-admitted patients in a hospital setting, including specialty/procedural clinics such as diabetes, gastro, respiratory, cardiology and allied health, excluding mental health outpatients and services provided in community health settings. The survey instrument was 79 questions long, with a response rate between 34.6% (2010) and 41.1% (2008). The results were published in August 2011 (http://www.bhi.nsw.gov.au/publications).</p> <p>In July 2012, the Bureau of Health Information took responsibility for managing the Patient Survey Program for NSW Health. The Bureau is currently reviewing survey tools and sampling strategies and developing an outpatient survey for roll out in 2014. There are no immediate plans to develop a new community health survey, although the Bureau is interested in any developments in this area.</p>
2	Department of Health, Victoria	<p>Currently, non-GP primary health care patient experience data from the Victorian Department of Health funded community based health services are not routinely collected. However, all Community Health Services (CHSs) conduct patient satisfaction surveys, including a previous Department survey tool, and report on this in their annual public quality of care report.</p> <p>In 2015, the Department will conduct patient experience surveys in a variety of community based health care settings, under the new Victorian Healthcare Experience Survey program. Services will include community health services, public residential aged care services and specialist clinics (out-patients at hospitals). The sampling methodology is currently being developed and the Department is willing to share this information with PEIDWG members. The 4 new patient experience surveys under this Survey program in 2014-15 are:</p> <ul style="list-style-type: none"> • Community Health Service clients (primarily non-GP primary health care clients, such as nursing, counselling, allied health and dental) will be surveyed using a tool based on the National Health Service's (NHS) Primary Care Survey • Adult and child specialist clinic patient experience data will be collected using a tool based on the NHS Adult Outpatient Survey and Picker Europe's Paediatric and Parent/Guardian Outpatient Survey • Public residential aged care residents and carers will be surveyed using a tool developed on the NHS Primary Care Survey and Australian patient experience surveys. <p>These 4 new surveys will be conducted annually from 2015 over a three month collection period. All surveys are being developed with service provider, consumer and carer working groups; cognitively tested with consumers (and, where appropriate, carers); piloted through a sample of the appropriate service type; and will include verbatim comments thematically streamed from survey respondents.</p> <p>The Department has a licence agreement with Picker Europe to use its suite of paediatric and carer surveys; a memorandum of understanding with the NHS Care Quality Commission to use its surveys; and a licence with the National Research Corporation Picker US to use its adult in-patient experience questions. In addition to the above surveys, the Victorian Healthcare Experience Survey program includes continuous surveying of discharged adult and paediatric (and carer) in-patients and emergency department consumers and maternity clients from April 2014. The surveys will be publicly reported on the new Departmental website <http://www.health.vic.gov.au/vhes>.</p> <p>Another local source of questions for the CHS client survey are the indicators for CHSs, introduced to support agencies with their Continuous Quality Improvement projects and activities. All indicators are consistent with the ACSQHC's Practice-Level Indicators of Safety and Quality for Primary Health. These indicators measure a number of practices identified as important by clients and carers, including access, care planning, goal setting by clients/carers, communication between providers and the percentage of clients/carers whose experience has been evaluated. Work has also commenced on developing a number of immediate outcome or impact indicators of services with clients who present with chronic and complex conditions. These indicators, developed in consultation with consumers, carers and clinicians, measure outcomes consistent with major chronic disease management frameworks, particularly the <i>Wagner Chronic Care Model</i>, which pose questions directly to clients.</p>

Table 4.1 (Continued): Stakeholder responses regarding the measurement of patient experience in non-GP primary health care

No	Stakeholder	Response
3	ACT Health Department	<p>In relation to formal data collections of specific Patient Experience measures in the Health Directorate, the ACT Government collects a biannual survey of a range of patient satisfaction measures, including some measures consistent with patient experience type markers. This survey is sent to all patients who have had an episode of care with a Health Directorate service in the preceding 6 months. This is the only formal survey type approach taken, and given its biannual nature, is under currently review to assess its timeliness and ability to assess patient experience.</p> <p>All projects and Quality Improvement activities conduct a one off evaluations at completion to check for improvement and the impact on the patient experience.</p> <p>The Health Directorate also has a robust Patient Experience narrative collection program. A range of projects and programs regularly interview recent patients and their carers to obtain the patient's view on their experience in their own words. These narratives are then analysed against the Picker Institute Principles of Patient Centred Care. Additional specific issues can also be explored during the analysis stage, such as effectiveness of discharge planning.</p>
4	Queensland Health	Patient experience in non-GP primary health care is not currently conducted.
5	WA Health	Patient experience in non-GP primary health care is not currently conducted.
6	SA Health	Patient experience in non-GP primary health care is not currently conducted.
7	Department of Health and Human Services, Tasmania	<p>The difficulty of defining primary health care was noted, with the suggestion to review selected primary health care services where it is possible to accurately count episodes of service delivery. Without accurate counts of service delivery, it is not feasible to measure patient experience.</p> <p>In Tasmania, some limited patient experience work is undertaken for alcohol and drug services, oral health, and ambulance and patient transport services (although not clear the extent to which this is considered 'non-GP primary health care').</p>
8	Department of Health and Families, NT	Patient experience in non-GP primary health care is not currently conducted.
9	Office for Aboriginal and Torres Strait Islander Health	Provided information on some domains of patient experience currently reported in the Aboriginal and Torres Strait Islander Health Performance Framework 2012 Report. Noted that it is preferable to draw on research specific to the interests of Aboriginal and Torres Strait Islander people, as surveys and other quantitative instruments used for national reporting do not currently collect patient experience information.
10	Australian Bureau of Statistics	The ABS Patient Experience Survey is conducted annually and collects national data on access and barriers to a range of health care services, including general practitioners, medical specialists, dental professionals, imaging and pathology tests. Data are also collected on aspects of communication between patients and health professionals. This is a population survey not a survey of providers. See Attachment C for further details.
11	Australian Medicare Local Alliance	Patient experience in non-GP primary health care is not currently conducted.
12	Consumer Health Forum	Provided information on the Euro Health Consumer Index which could inform this project. The aim of the index is to measure and compare consumer experiences against indicators relating to consumer rights and information, eHealth, waiting times for treatment, outcomes, range and reach of services and the provision of pharmaceuticals.
13	Child Welfare and Prisoner Health Unit, AIHW	The National Prisoner Health Data Collection is the only national source of information on the health of prisoners in Australia, covering a broad range of health issues and social determinants of health. Paper-based data collection forms are completed in the context of routine health assessments and service provision, by prison health services. This collection monitors a set of agreed indicators—aligned to the National Health Performance Framework—to help ensure appropriate health services are in place to meet the needs of the prisoner population. The indicators monitor access to care, respect for patients' values, preferences and expressed needs and transition and continuity of care. See Attachment C for further details.

Table 4.1 (Continued): Stakeholder responses regarding the measurement of patient experience in non-GP primary health care

No	Stakeholder	Response
14	Dental Statistics and Research Unit, AIHW	The Dental Satisfaction Survey, conducted by the AIHW Dental Statistics Research Unit jointly with the 2002 National Dental Telephone Interview Survey, examined differences in the levels of satisfaction with dental care in a cross-sectional survey and changes over time in dental satisfaction levels of health cardholders, particularly those receiving public-funded dental care. The domains of patient experience surveyed included dental professional and services received, communication, facilities/clinic staff, affordability, clinic location/appointments, service results, and unnecessary costs plus conceptually unrelated items.
15	Winnunga Nimmityjah Aboriginal Health Service	<p>The difficulty of defining primary health care was noted. Winnunga, like many Aboriginal Community Controlled Health Services is accredited against both RACGP and Quality Improvement Council standards and so patient feedback and survey mechanisms are in place.</p> <p>Recommended having Aboriginal and Torres Strait Islander or NACCHO representation as part of future plans for measuring patient experience in primary health care.</p> <p>Aboriginal Community Controlled Health Services provide culturally competent comprehensive primary health care in services developed and governed by Aboriginal people, for Aboriginal people. Positive patient experiences have been shown in these settings compared with mainstream services. The National Aboriginal Community Controlled Health Organisation (NACCHO) and affiliates have been discussing ways of better assessing patient experience.</p> <p>The experience of Aboriginal and Torres Strait Islander people in the healthcare system is unique and may not be picked up in standard data collections, particularly in identifying issues of cultural competence, discrimination and institutional racism.</p>

4.2 Further relevant patient experience measurement approaches

National population health surveys

Australian Bureau of Statistics Patient Experience Survey Series

Much of the Australian evidence on patient experience comes from the ABS Patient Experience Survey series. The survey series investigates patients' experiences involving multiple levels of the health care system, including GP services, medical specialist services, dental care, and hospital admissions. The survey, conducted annually, collects national information from individuals aged 15 and over about their experiences with selected aspects of the health system in the 12 months before interview.

The Patient Experience Survey forms part of the ABS's Multipurpose Household Survey, a supplement to the monthly Labour Force Survey. The coverage for the Labour Force Survey is based on a sample of private dwellings (about 26,000 residences) and a sample of non-private dwellings, such as hotels and motels. This sample covers approximately 0.32% of the civilian population of Australia aged 15 years and over.

Since 2009, three surveys have been undertaken. As this survey series is relatively new, various changes have occurred as part of the ongoing development process to maintain and improve data integrity. Consequently, some questions may not be directly comparable between surveys. The latest survey (2011–12 Patient Experience Survey) includes households in very remote areas of Australia.

The *Experience with health professionals module* focuses on visits to GPs, medical specialists and dental professionals. This module includes questions about what services were accessed, waiting times and financial barriers to accessing care. It also includes aspects of communication with GPs, specialists, and dental professionals. See Box 4.2 for details of patient experiences involving dental professionals from the most recent ABS Patient Experience Survey.

Box 4.2: Patient experiences with dental professionals

The 2011-12 Patient Experiences in Australia Survey found:

- nearly half (49%) of people aged 15 and over had visited a dental professional at least once in the previous 12 months
- for those people needing urgent dental care, 43% had waited two or more days between making an appointment and being seen by a dental professional
- one in five people (21%) delayed seeing a dental professional because of the cost, with a higher proportion of people living in disadvantages areas (27%) delaying seeing a dentist, compared to 15% of people living in the least disadvantaged areas (ABS 2012).

Health Care Pathways project

The ABS commenced work on the Health Care Pathways Project, funded by the National Health Performance Authority (NHPA), in 2013. This project involves developing and testing a survey topic to measure continuity of care amongst frequent users of primary health care services, in order to gather data to report the measure at the Medicare Local level.

Part of the NHPA's role is to report on the performance of primary health care organisations across Australia, consistent with the Performance and Accountability Framework. Three areas of performance are measured, including equity, effectiveness and efficiency; with 'continuity' being a measure of effectiveness.

The development of this new survey topic will provide the ABS with an opportunity to review current practices for collecting patient experience data, with a view to collecting future data in conjunction with the Health Care Pathways Survey.

The National Health Survey

The National Health Survey (NHS), conducted every 3–6 years by the ABS, is designed to obtain information on the health of Australians, their use of health services and facilities, and health-related aspects of their lifestyle. The survey aims to be nationally representative, with the most recent survey undertaken in 2011–13 as part of the Australian Health Survey. The NHS generally includes indicators on waiting times for services and financial barriers to accessing services. It is therefore only of peripheral interest to the subject of patient experience in non-GP primary health care, as it does not cover patient experience to any real extent or provide good coverage for non-GP primary health care services.

Council of Australian Governments' National Healthcare Agreement

In 2011, the Council of Australian Governments (COAG) signed the National Health Reform Agreement outlining plans for delivering major reforms to the organisation, funding and delivery of Australia's health system. These reforms aim to provide better access to services, improved local accountability and transparency, greater responsiveness to local communities and additional funding. Both the National Healthcare Agreements 2008 and 2011 require population reporting of indicators of patient experience annually, at jurisdictional level.

Initial indicators for Medicare Locals

The National Health Performance Authority (NHPA) is expected to monitor and report on access to services, quality of service delivery, financial responsibility, and patient experience at the Medicare Local level, as part of the *Healthy Communities Reports* (see Box 4.3).

Box 4.3: What are Medicare Locals?

'A national network of 61 Medicare Locals has been established as a key component of the Australian Government's National Health Reform agenda. Medicare Locals are independent primary health care organisations that work with local primary health care providers, Local Hospital Networks and communities to ensure that patients receive the right care in the right place at the right time.

Medicare Locals operate as health system planners at the regional level. They have primary responsibility for identifying and assessing the health care needs of their populations, improving the coordination and integration of primary health care in local communities, addressing service gaps, and making it easier for individuals, carers and service providers to navigate their local health care system.' (Page 4, Medicare Locals Operational Guidelines 2013).

The NHPA's Performance and Accountability Framework is designed to support improved local level performance assessment. The Framework underpins reporting across three domains; equity, effectiveness and efficiency of service delivery in health care.

As part of this process, it is envisaged that Medicare Locals will report on a series of indicators, including a measure of effectiveness (Indicator 6.3.2: Effectiveness – Patient experience) and measures of access (Indicator 6.3.3: Equity and effectiveness – Access). Over time, these initial indicators will be further developed once Medicare Locals become more established.

Healthy Communities reporting to date by the NHPA has used the ABS Patient Experience Survey to examine broad aspects of patient experience at the Medicare Local level, specifically access to services (NHPA 2013). However, as noted previously, the ABS Patient Experience Survey has limited coverage of non-GP primary health care services.

Patient experience measures in Australian hospitals

Substantial progress has been made by the Patient Experience Information Development Working Group (PEIDWG) in developing a core, common set of patient experience questions for hospital surveys of admitted patients. Pilot testing of the questions has taken place in South Australia and New South Wales. Results from the pilot studies in November 2012 were released in a report entitled *Report on the Pilot Study of National Core Common Hospital Patient Experience questions* in December the same year.

PEIDWG members noted a range of issues which may affect the comparability of jurisdictional patient experience information resulting from implementation of the core common questions, including different approaches to: sampling, inclusion and exclusion criteria, time from discharge to survey, and the effects of different administration methods (survey modes).

Project 1: Hospital patient experience information is one of the agreed AHMAC funded patient experience projects being managed by the AIHW. The project focuses on standardising the information collected using the core, common patient experience questions, through the development of a data set specification which conforms to national standards and includes information on the modes of data collection.

General Practitioners' patient experience surveying

The RACGP as part of their their quality improvement and accreditation process (with respect to the National Safety and Quality Health Service Standards and RACGP's Standards for General Practice) requires practices to collect information about patients' experiences as part of their quality improvement processes. The two options available for GPs to systematically collect feedback about patient experience are:

- using a RACGP approved validated patient experience questionnaire (currently two validated patient feedback questionnaires have been approved – see below)
- developing an individual practice-specific method (questionnaire, focus groups or patient interviews) that conforms with RACGP requirements

Practices are required to collect information about patient experience and demonstrate this information has been used to drive quality improvement activities. The broad categories required for inclusion in patient experience data collections of primary health care are:

- patient demographics
- access and availability of care
- information provision to patients

- privacy and confidentiality of care
- continuity of care
- communication skills of clinical staff
- interpersonal skills of clinical staff.

Two validated patient feedback questionnaires have been approved by the RACGP for use in Australian general practices – the UltraFeedback's Patient Satisfaction Instrument and the Practice Accreditation and Improvement Survey. GPs are able to select the patient feedback process that best fits their practice and then engage the commercial company responsible for the accredited survey to undertake the survey on their behalf. These companies collate and analyse the patient experience data and provide feedback to the specific practice.

While information collected by GPs on patient experience helps inform quality improvement within individual practices, there is no requirement for the data to be collated centrally or regionally.

Aboriginal Patient Journey Mapping Tools Project: Communicating complexity

The measurement of patient experience among Aboriginal and Torres Strait Islander Australians may best be done through specific research into this area. The relationship between patients and health care providers is the foundation of care and requires communication across cultures, geography and life experiences (Flinders University School of Medicine 2013).

The Managing Two Worlds Together project focuses on better understanding the barriers and enablers to access, quality and continuity of care for country Aboriginal people travelling to and from city hospitals. A set of Aboriginal patient journey mapping tools were developed by the research team working with health care providers in country Aboriginal primary health care services and city hospitals (Dwyer et al. 2011).

Initially paper-based tools were used for analysis to better understand and record experiences of patients and their families, the perceptions of health care staff, and the gaps and health care responses occurring on each journey. As the project continued, the potential and scope of the tools to be used by health care providers, case managers and educators in a range of different settings emerged.

The project will further develop, refine and potentially transform the tools from a paper-based to a computer-based form, so they can be used in training and education and in quality improvement of health care and systems.

This project, due for completion in December 2013, will produce tools suitable for use in two main ways: as an educational aid in the training of health care staff, and to assist health care staff engaged in work to improve the quality of patient journeys (i.e. in audit, review and care system planning). Health care providers, coordinators, managers and educators can then apply the tools to their specific purposes and situations.

Aboriginal and Torres Strait Islander Health Performance Framework

The Aboriginal and Torres Strait Islander Health Performance Framework monitors progress of the health system and broader determinants of health in improving health outcomes for

Aboriginal and Torres Strait Islander people. This framework consists of the three National Health Performance Framework tiers:

1. *Health status and outcomes* – providing an overall indication of current health status and recent trends on a range of issues, including child and maternal health, chronic diseases, injury, communicable diseases, and social and emotional wellbeing.
2. *Determinants of health* – focusing on factors outside the health system that affect the health of Aboriginal and Torres Strait Islander people, such as income, education, environmental factors, community capacity and health behaviours (factors strongly associated with disease and ill health).
3. *Health system performance* – covering the performance of the health system including population health, primary health care and secondary/tertiary care services

The third tier covers a range of programs and service types, including child and maternal health, early detection and chronic disease management, continuous care, access to secondary/tertiary care, the health workforce and expenditure. This tier measures health system performance including effectiveness, responsiveness, accessibility, continuity, capability and sustainability. It contains indicators relevant to patient experience, such as waiting times for services and financial barriers to accessing services. There is currently no specific reporting of patient experience information, however.

Commonwealth Fund

The Commonwealth Fund, a not-for-profit organisation based in the United States, aims to promote high quality health care, particularly for society's most vulnerable. Australia's participation in the Commonwealth Fund surveys provides opportunities for comparison of health system performance at an international level.

As part of its international program in health policy, the Fund undertakes population-based patient experience surveys in 11 countries, including Australia, in three year cycles. In 2010, the Commonwealth Fund examined healthcare experiences in the general population. The ACSQHC and the NSW Bureau of Health Information worked with the Commonwealth Fund to report on access to and use of primary care services, use of specialists, out-of-pocket costs, prescriptions, and hospital and emergency department experiences in Australia.

As part of this work, the Commonwealth Fund financed an increase in the sample size from 1,000 to 3,000 participants, and the NSW Bureau of Health Information financed an additional 500 participants. The survey was conducted using a web-based computer-assisted interviewing (CATI) system, with participants selected from the electronic White Pages. The total sample size was 3,552, with a response rate of 26%. The survey was weighted according to age, sex, education, urban/rural location, and state or territory.

The Commonwealth Fund survey drew on the 8 dimensions of the patient-centred care identified by the Picker Institute, including: patient's overall view of the health system; access; respect for patient values; coordination and integration of care; information, communication and education; transition and continuity; and experiences of harm or potential harm.

These surveys were conducted with patients who had received services as inpatients, through to those who received services in primary health care settings, including information on experiences at the interface between these setups. While potentially of use in

patient experience across the Australian health system, there is no information in these surveys specifically on non-GP primary health care services.

4.3 Developing surveying instruments to measure patient experience

In developing future survey instruments to measure patient experience in the non-GP primary health care sector (among people who have recently used services), the following need to be considered:

1. The purpose of the survey instrument needs to be determined (for quality improvement and/or performance monitoring). This has implications for whether population or patient samples are suitable and also implications for how comparable the resulting information needs to be.
2. Where possible, patient survey tools for performance monitoring should include a core set of items standardised at a national level to enable the collation and comparison of patient care experience by other jurisdictions and in other contexts. For non-GP primary health care settings a sensible starting point may be the current RACGP-accredited questions which map to the Picker domains of patient-centred care.
3. Patient surveys should include questions specifically addressing recognised patient-centred care domains and assess more than just patient 'satisfaction'.
4. A flexible approach should be available to enable patient survey instruments to be tailored to the specific needs of different services provided in the non-GP primary health care sector; instruments such as interviews, focus groups and case studies.
5. Guidelines need to be developed to advise on relevant survey instruments, sampling protocols, frequency of surveying, reporting requirements, feedback mechanisms and evidence of practice improvements in response to patient feedback.

Future options

The Australian Government and state/territory governments are currently in the process of implementing uniform patient experience measurement standards across Australia in hospitals and in GP settings.

If there is interest in measuring patient experience in non-GP primary health care settings, a number of options could be considered:

1. Undertaking further work to define primary health care and non-GP primary health care and what this consists of in a practical sense in jurisdictions or at the regional level (Medicare Locals/Local Health Networks for example), that is, undertaking definitional, classification and counting work. This definitional work could sensibly guide a range of other activities including comparable service directories at the Medicare Local level and potentially support Activity Based Funding development.
2. Improve fundamental data capture of non-GP primary health care information as a basis for collecting a range of information including patient experience data. This could potentially commence with state/territory-funded community health information and build on the Victorian Government's model whereby primary health care providers could be surveyed regardless of whether they have a GP component. Pending further development, validation, piloting and implementation of the Victorian patient

experience tools these could potentially be adopted more broadly. This is also broadly consistent with the present ACT approach (currently under review).

3. Build on the work of the RACGP accreditation process (whereby standard accredited patient experience surveys are made available for GP use, which can be tailored for use in specific settings and as mail out or focus group modes) and/or the common hospital patient experience questions to develop standard agreed questions for adoption across primary health care settings. These questions could usefully guide quantitative or more qualitative approaches at the jurisdiction or Medicare Local level, which could build on foundations laid by the former Divisions of General Practice in this area. Further work would be needed to consider the feasibility of coordinating any collection and collation of data, not a feature of the RACGP accreditation process.
4. For a more population-based approach (as opposed to surveys of recent service recipients), priority non-GP primary health care services could be identified and the ABS Patient Experience Survey expanded to capture patient's experiences with a selection of these services. For example, population health surveys may provide the most realistic option for measuring patient experience of privately-funded and delivered services (such as privately purchased physiotherapy and pharmacy services) and for patient experience across multiple service providers (as being considered in the Health Care Pathways Project). If pursuing this option, it would still be important to develop a consistent definition and understanding of what constitutes the specific aspect of primary health care so that information provided by respondents was meaningful. There are several issues with a population survey approach (sample size, timeliness) that limit its usefulness in quickly responding or identifying early service quality issues.

A number of the above options could be pursued to help build a more complete picture of patient experience in non-GP primary health care settings. To maximise the benefits and minimise costs of pursuing any of the above options, it would be important to seek alignment with or 'piggy back' on patient experience developments already in place.

5 Conclusions

Information about patient experiences is important to guide health care quality improvement and also enhances a culture of patient engagement. Under certain circumstances information about patient experiences can also inform health performance reporting. Patient experience information provides a window into the extent to which health care is patient-centred and is in increasing demand by consumers, consumer advocates and for national and regional performance reporting and quality improvement processes.

While there have been selected activities to describe, validate and standardise patient experience information in the hospital and GP setting, there has been limited understanding to date of the types of patient experience information currently available within the non-GP primary health care sector.

Definition of 'non-GP' primary health care

One of the difficulties in documenting existing approaches for measuring patient experience within the non-GP primary health care sector is accurately defining 'What is 'non-GP' primary health care?'

Primary health care is configured and administered differently across Australia, spanning a range of activities, settings, professional groups and funding streams. There is no consensus definition about what constitutes primary health care in Australia, making it difficult to define what constitutes 'non-GP' primary health care.

There is no coordinated data capture about relevant primary health care (non-GP or other) available in a given region or jurisdiction, nor information available to count or describe services or their patients. In this context it is not surprising that there is little coordinated information available to measure patient experiences in this environment.

One respondent noted that health departments currently do not have reliable inventories of all non-GP primary health care providers, thereby making it difficult for this sector to accurately measure their activity. They noted that this gap could be filled but not without initial ground work to better define the non-GP primary health care sector.

While it is possible that more patient experience data is collected in non-GP primary health care settings 'on the ground', this information is not collected or collated in a standardised or comparable way. This also reflects a broader lack of data relating to primary health care facilities, the services they provide and those accessing the services.

Current collection of patient experience in primary health care

Specific components of patient experience are currently measured nationally by the ABS patient experience survey and as a by-product of routine accreditation for GPs. Beyond these activities, there is no routine, ongoing or standardised collection of patient experience information in non-GP primary health care settings.

While focussing predominantly on experiences with General Practice, within the non-GP primary health care sector, the ABS patient experience survey also covers dental professionals (covering waiting times, financial barriers to access and aspects of communication with the patient).

Within the GP component of the primary health care sector, patient experience data are collected for practice accreditation purposes but the data are not publicly available. The primary purpose of the collections is to comply with accreditation standards and inform GPs of how they can improve patient experiences as part of their quality improvement processes.

In developing patient experience measurements in the non-GP primary health care sector, consideration could be given to ensure consistency with the RACGP broad categories and principles required for inclusion in GP patient experience data collections. These broad categories encompass many of the Picker survey domains (see Section 2.4 for details).

Priorities for collecting patient experience data

Many jurisdictions reported that collecting non-GP primary health care patient experience data is currently not a priority, as they are first rolling out patient experience measurement in hospitals. They noted that many non-GP primary health care providers have limited resources and capacity and many do not receive Commonwealth funding. Any request for non-GP service providers to collect additional data may increase the reporting burden and take away funding from current service provision.

Results

Overall, our study confirms that while there have been selected activities to validate and standardise patient experiences in the hospital and GP setting, there has been limited documentation of patient experiences within the non-GP primary health care sector.

Appendix A: Stakeholder contact list

Listed below are the key stakeholders contacted by AIHW requesting information on existing approaches for measuring patient experience in the non-GP primary health care sector:

- New South Wales Health
- Department of Health, Victoria
- Queensland Health
- Western Australia Health
- South Australia Health
- Department of Health and Human Services, Tasmania
- Australian Capital Territory Health Department
- Department of Health and Families, Northern Territory
- Office for Aboriginal and Torres Strait Islander Health
- Australian Bureau of Statistics
- Australian Medicare Local Alliance
- Consumers' Health Forum
- Child Welfare and Prisoner Health Unit, AIHW
- Dental Statistics and Research Unit, AIHW
- Winnunga Nimmityjah Aboriginal Health Service.

Appendix B: Questionnaire template

Please complete the following templates for each separate in-scope patient experience information source. Attach a copy of the each survey instrument if possible.

Data source name	
Data source description	
Purpose	
In scope non-GP primary health care services/ settings	
Coverage of in-scope non-GP primary health care services/ settings	
In scope/target population	
Response rate for in scope/target population	
Collection methodology	
Time period covered	
Data source questions	
Domains of patient experience	
<ul style="list-style-type: none"> • Access to care 	
<ul style="list-style-type: none"> • Respect for patients' values, preferences and expressed needs 	
<ul style="list-style-type: none"> • Coordination and integration of care 	
<ul style="list-style-type: none"> • Information, communication and education 	
<ul style="list-style-type: none"> • Physical comfort 	
<ul style="list-style-type: none"> • Emotional support, alleviation of fear and anxiety 	
<ul style="list-style-type: none"> • Involvement of family and friends 	
<ul style="list-style-type: none"> • Transition and continuity 	
How are data used?	
Publications and other outputs	
Access to data	
Further information	

Appendix C: Completed questionnaires

Below are all completed questionnaires received from stakeholders.

1. ABS Patient Experience Survey

Data source name	ABS Patient Experience Survey 2011-12
Data source description	The ABS Patient Experience Survey is conducted annually and collects national data on access and barriers to a range of health care services, including general practitioners, medical specialists, dental professionals, imaging and pathology tests. Data are also collected on aspects of communication between patients and health professionals. This is a population survey not a survey of providers.
Purpose	To collect summary data on access and barriers to a range of health care services including general practitioners, medical specialists, dental professionals, imaging and pathology tests, hospital admissions and emergency department visits. The survey includes data from people that did not access health services as well as from those who did and thus enables data collection on barriers to accessing health services. It also enables analysis of health service information in relation to particular population groups.
In scope non-GP primary health care services/ settings	Medical Specialists, Dental Professionals, Pathology, Imaging, Hospital Emergency Department, Hospital Admissions.
Coverage of in-scope non-GP primary health care services/ settings	N/A
In scope/target population	The scope of the ABS Patient Experience Survey was restricted to people aged 15 years and over. It also excluded the following: <ul style="list-style-type: none"> • Australian permanent defence force members • diplomatic personnel of overseas governments, customarily excluded from Census and estimated population counts • overseas residents in Australia • members of non-Australian defence forces (and their dependents) • persons living in non-private dwellings such as hotels, university residences, boarding schools, hospitals, retirement homes, homes for people with disabilities, and prisons • persons living in discrete Indigenous communities (excluded for operational reasons). • 2011-12 is the first time this survey has included households residing in very remote parts of Australia.

Data source name	ABS Patient Experience Survey 2011-12
Response rate for in scope/target population	After taking into account sample loss, the response rate for the ABS Patient Experience Survey (2011-12) was 79.6%. In total, information was collected from 26,437 fully responding households. One person aged 15 years or over from each household was asked questions in relation to their own health. This includes 334 proxy interviews for people aged 15 to 17 years, where permission was not given by a parent or guardian for a personal interview.
Collection methodology	Please see explanatory notes: http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4839.0Explanatory%20Notes12011-12?OpenDocument
Time period covered	Survey undertaken annually; 2009, 2010-11, 2011-12 and collects information from individuals on the 12 months prior to interview.
Data source questions	Questionnaire (PDF) available from the ABS website: http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/5D47372155379374CA257ABE0012F4A7/\$File/questionnaire%20for%20pub.pdf
Domains of patient experience	
• Access to care	Yes, see questionnaire.
• Respect for patients' values, preferences and expressed needs	Yes, see questionnaire.
• Coordination and integration of care	N/A (although will be included for 2012-13 cycle)
• Information, communication and education	Yes, see questionnaire.
• Physical comfort	N/A
• Emotional support and alleviation of fear and anxiety	N/A

Data source name	ABS Patient Experience Survey 2011-12
<ul style="list-style-type: none"> • Involvement of family and friends 	No but is being considered for future cycles.
<ul style="list-style-type: none"> • Transition and continuity 	N/A
How are data used?	Data is used for the COAG and Performance and Accountability Framework.
Publications and other outputs	http://www.abs.gov.au/ausstats/abs@.nsf/mf/4839.0
Access to data	<p>Customised data requests</p> <p>Special tabulations of the data are available on request. Subject to confidentiality and sampling variability constraints, tabulations can be produced from the survey incorporating data items, populations and geographic areas (including state and territory level data), tailored to individual requirements. These are provided in electronic form. All inquiries should be made to the National Information and Referral Service on 1300 135 070.</p>
Further information	ABS website catalogue no. 4839.0

2. Dental Satisfaction Survey

Data source name	Dental Satisfaction Survey
Data source description	The Dental Satisfaction Survey was conducted by the AIHW jointly with the 2002 National Dental Telephone Interview Survey (NDTIS)
Purpose	Examine differences in the levels of satisfaction with dental care in a cross-sectional survey and to extend the available data for examining changes over time in the dental satisfaction levels of health cardholders, particularly those receiving public-funded dental care.
In scope non-GP primary health care services/ settings	Public dental health services
Coverage	The 2002 NDTIS interviewed individuals from households randomly selected from five metropolitan sites (NSW, Vic, QLD, SA and WA) and eight non-metropolitan sites which included the rest of each State (NSW, Vic, QLD, SA and WA), or the entire State/Territory (Tas, ACT and NT); thirteen sites overall, with sample sizes determined to yield at least 600 participants per site in the metropolitan sites, and 400 participants per site in non-metropolitan sites. The individual selected from households with more than one occupant was chosen by random allocation of the persons aged 5 years and over to have the last birthday or the next birthday.
In scope/target population	The sampling frame used in the Dental Satisfaction Survey was participants in the 2002 National Dental Telephone Interview Survey who were 18 years of age and over and had visited a dental professional within the previous 12 months. Where the participants did not hold a health card, a random sample of one in four was used, while all holders of health cards were included in the sample. This sampling methodology was used to balance the number of persons with and without health cards.
Response rate for in scope/target population	Participation per site in the NDTIS varied from 56.2 per cent to 74.4 per cent, with an overall response rate of 64.8 per cent. The rate of refusals was 35.2 per cent. 3073 persons aged 18 years or over were available for selection for inclusion in the Dental Satisfaction Survey.
Collection methodology	Potential respondents in this study were the 1543 participants in the 2002 NDTIS, eligible for selection because they were 18 years of age or more and had made a dental visit within the last 12 months.

Data source name	Dental Satisfaction Survey
<p>Collection methodology (Cont.)</p>	<p>The participants were informed at the time of their telephone interview that they had been chosen for a further questionnaire, and their address was checked with the details already held in the database. A questionnaire was mailed to the address, usually within a week of the telephone interview. After two weeks, a reminder card was sent to those persons from whom a completed response had not been received. A second and third approach, consisting of a letter and a replacement questionnaire, were subsequently made at two-weekly intervals.</p> <p>Data were weighted by household size (the number of persons aged 5 years or more) and by geographic sampling region to account for differing sampling probabilities due to the sampling design. The data were also post-stratified and weighted by age and sex to ensure that the weighted data more accurately represents the Australian population for each region as estimated by the Australian Bureau of Statistics. All results presented are weighted unless specified otherwise.</p> <p>Missing data items in the 2002 Dental Satisfaction Survey occurred with similar frequency and were treated in the same way as in the 1995, 1996 and 1999 surveys. Over 17% of respondents had one or more items with no response recorded. Within sub-scales between 4% and 12.8% of respondents had missing values, which represented up to 31% of groups such as those persons aged 65+ years or who speak a language other than English at home.</p>
<p>Time period covered</p>	<p>July to mid-December 2002</p>
<p>Domains of patient experience</p>	<p>Factor analysis of the 2002 Dental Satisfaction Survey (31 items) resulted in very similar factors to the 1995 factor analysis, when the extra 7 items relating to cost and facilities were introduced. Seven factors emerged from the factor analysis, compared to seven in 1995, and eight in 1999. The factors corresponded to:</p> <ul style="list-style-type: none"> Factor 1 dental professional and services received Factor 2 communication Factor 3 facilities/clinic staff Factor 4 affordability Factor 5 clinic location/appointments Factor 6 service results Factor 7 unnecessary costs plus conceptually unrelated items

Data source name	Dental Satisfaction Survey
<ul style="list-style-type: none"> • Access to care 	
<ul style="list-style-type: none"> • Respect for patients' values, preferences and expressed needs 	
<ul style="list-style-type: none"> • Coordination and integration of care 	
<ul style="list-style-type: none"> • Information, communication and education 	
<ul style="list-style-type: none"> • Physical comfort 	
<ul style="list-style-type: none"> • Emotional support and alleviation of fear and anxiety 	
<ul style="list-style-type: none"> • Involvement of family and friends 	
<ul style="list-style-type: none"> • Transition and continuity 	
How are data used?	
Publications and other outputs	Stewart JF & Spencer AJ 2005. Dental Satisfaction Survey 2002. AIHW cat. no. DEN 141. Adelaide: AIHW Dental Statistics and Research Unit.
Access to data	
Further information	info@aihw.gov.au

3. National Prisoner Health Data Collection

Data source name	National Prisoner Health Data Collection (NPHDC)
Data source description	The NPHDC is the only national source of information on the health of prisoners in Australia, covering a broad range of health issues and social determinants of health. Paper-based data collection forms are completed in the context of routine health assessments and service provision, by prison health services.
Purpose	The NPHDC was designed to monitor a set of agreed indicators – aligned to the National Health Performance Framework – to help ensure appropriate health services are in place to meet the needs of the prisoner population.
In scope non-GP primary health care services/ settings	Clinical services provided to prisoners while in custody.
Coverage of in-scope non-GP primary health care services/ settings	All visits to the clinic over the specified 2-week collection period are recorded.
In scope/target population	All prisoners who visited the prison clinic over the specified 2-week collection period.
Response rate for in scope/target population	Not available
Collection methodology	<p>While a range of information is collected as part of the NPHDC, from a primary care perspective there are 3 specific relevant forms:</p> <ul style="list-style-type: none"> • clinic form – completed for all prisoners in custody who used the prison clinic during the data collection period. Included questions about demographics of the prisoner, who initiated the visit, problem managed at the clinic and who saw the prisoner. • medications form – completed for all prisoners in custody who were administered medications on 1 day of the data collection period. Included questions about prisoner demographics and medications administered (but excludes routine medication, e.g. paracetamol). • prison discharge form – completed for prisoners who were scheduled to be released from prison within 4 weeks from the data collection period. Questions 21; 23–32; and 45–47 are relevant to primary health care received in prison.

Data source name	National Prisoner Health Data Collection (NPHDC)
Time period covered	Data for the most recent NPHDC were collected over a 2-week period in May 2012 (14-27 May), and provided to the AIHW. The NPHDC has been conducted 3 times: 2009, 2010 and 2012. The exact timing of the data collection and how often it will be conducted in the future is not yet confirmed.
Data source questions	
Domains of patient experience	
<ul style="list-style-type: none"> • Access to care 	<p>YES: see discharge forms Q25a & b - while in prison this time could you easily see a medical practitioner (Doctor/GP) (25a) or nurse (25b) if you had a health problem?</p> <p>Q26b - If you did not visit the prison clinic, why not?</p>
<ul style="list-style-type: none"> • Respect for patients' values, preferences and expressed needs 	<p>YES: discharge form Q45 - while in prison this time, do you think you received culturally appropriate health care? (Indigenous prisoners only)</p>
<ul style="list-style-type: none"> • Coordination and integration of care 	
<ul style="list-style-type: none"> • Information, communication and education 	<p>YES: Q28a - When you visited the prison clinic, did you get as much information about your condition and treatment as you wanted from the healthcare professional?</p> <p>YES: Qu28b - When you asked questions at the prison clinic, did you get answers you could understand?</p>
<ul style="list-style-type: none"> • Physical comfort 	
<ul style="list-style-type: none"> • Emotional support and alleviation of fear and anxiety 	
<ul style="list-style-type: none"> • Involvement of family and friends 	
<ul style="list-style-type: none"> • Transition and continuity 	<p>YES see discharge form Q40 - Are you currently on any prescribed medication that will continue after your release from prison?</p> <p>YES: Q41 - Do you have a referral or appointment to see any of the following health professionals after your release from custody?</p>
How are data used?	State/territory departments responsible for prisoner health use the information for planning and policy information.

Data source name	National Prisoner Health Data Collection (NPHDC)
How are data used? (Cont.)	Comparison of data from previous years is difficult because the participating jurisdictions have changed, and therefore comparisons at the national level should be used with caution. Comparisons between years at the jurisdictional level may be more appropriate. Trend data for those states and territories which have participated in all three data collections would also be possible
Publications and other outputs	The AIHW website provides prisoner health data which can be downloaded free of charge. Reports including The health of Australia's prisoners, and thematic bulletins, are published and are available on the AIHW website where they can be downloaded without charge.
Access to data	Users can request data not available online or in reports via the Child Welfare and Prisoner Health Unit, Australian Institute of Health and Welfare on (02) 6244 1000 or via email to prisoner.health@aihw.gov.au. A fee may be charged for substantial requests on a cost-recovery basis.
Further information	prisoner.health@aihw.gov.au

References

- ABS (Australian Bureau of Statistics) 2012. Patient experiences in Australia: Summary of findings. ABS cat.no. 4839.0. Canberra: ABS.
- AIHW (Australian Institute of Health and Welfare) 2008. Review and evaluation of Australian information about primary health care: a focus on general practice. Cat. no. HWI 103. Canberra: AIHW.
- AIHW 2009. Towards national indicators of safety and quality in health care support project: a focus on primary health care. Canberra: AIHW.
- AIHW 2010. Australia's health 2010. Australia's health series no. 12. Cat. no. AUS 122. Canberra: AIHW.
- AIHW 2012. Australia's health 2012. Australia's health series no. 13. Cat. no. AUS 156. Canberra: AIHW.
- ACSQHC (Australian Commission on Safety and Quality in Health Care) 2011a. Patient-centred care: improving quality and safety through partnerships with patients and consumers. Sydney: ACSQHC.
- ACSQHC 2011b. Practice-level indicators of safety and quality for primary health care: Consultation Paper. Sydney: ACSQHC.
- ACSQHC 2013. Patient and Consumer Centred Care. Viewed 7 November 2013, <<http://www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care>>.
- APHCRI (Australian Primary Health Care Research Institute) 2005. Primary Health Care Position Statement, Australian Divisions of General Practice. Canberra.
- APHCRI 2013. What is primary health care? Viewed 7 November 2013, <<http://aphcri.anu.edu.au/about-us/what-primary-health-care>>.
- CHF (Consumers Health Forum of Australia) 2012. Submission to the International Alliance of Patients' Organizations Patient-Centred Healthcare Indicators Review May 2012. Viewed 01/11/2013, <<https://www.chf.org.au/pdfs/sub/sub-876-IAPO-patient-centred-care.pdf>>.
- DoHA (Department of Health and Ageing) 2009. Primary Health Care Reform in Australia – Report to Support Australia's First National Primary Health Care Strategy. Canberra: The Department of Health and Ageing.
- DoHA 2011. Primary care. Canberra. Viewed 05/11/2012, <<http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/theme-primarycare>>.
- DoHA 2013. Primary health care reform in Australia – report to support Australia's first national primary health care strategy. Viewed 04 June 2013, <www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/nphc-draftreportsupp-toc~nphc-draftreportsupp-ch2>.
- Dwyer J, Kelly J, Willis E, Glover J, Mackean T, Pekarsky B & Battersby M 2011. Managing Two Worlds Together: City Hospital Care for Country Aboriginal People – Project Report. The Lowitja Institute, Melbourne.

Flinders University School of Medicine 2013. Managing Two Worlds Together. Viewed 7 November 2013, <<http://www.flinders.edu.au/medicine/sites/health-care-management/research/mtwt>>.

NHPA (National Health Performance Authority) 2013. Healthy Communities: Australians' experiences with access to health care in 2011-12. Viewed 11 November 2013. Released 20 June 2013, <[http://www.nhpa.gov.au/internet/nhpa/publishing.nsf/Content/Report-Download-Healthy-Communities-Australians-experiences-with-access-to-health-care-in-2011-12/\\$FILE/NHPA_HC_Report_Patient_Exp_June_2013.pdf](http://www.nhpa.gov.au/internet/nhpa/publishing.nsf/Content/Report-Download-Healthy-Communities-Australians-experiences-with-access-to-health-care-in-2011-12/$FILE/NHPA_HC_Report_Patient_Exp_June_2013.pdf)>.

Picker Institute Europe 2013. Patient & service user experience surveys. Viewed 7 November 2013, <<http://www.pickereurope.org/adult-and-patient-service-user-surveys>>.

Starfield B 2008. The Future of primary care refocusing the System. *New England Journal of Medicine* 359:2087-2091.

SCRGSP (Steering Committee for the Review of Government Service Provision) 2013. Report on Government Services 2013. Productivity Commission, Canberra.

Wong T 2013. Measuring patient experiences in primary health care: a review and classification of items and scales used in publicly available questionnaires. Centre for Health Services and Policy Research University of British Columbia, Vancouver.

