



Patient Experience of health care performance

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Executive Summary

Patient-centred care, a fundamental tenet of quality healthcare, means delivering services which respond to and are sensitive to the needs and wishes of the consumers or patients. Without systematic ways of collecting information about patients' experience of the health care system, a vital perspective is missing from efforts to improve the quality of care. Submissions to the draft National Primary Health Care Strategy identified that consumer satisfaction, holistic care, equity of access, and obtaining feedback from users are some areas which are appropriate for performance management via indicators.

Mechanisms to measure performance of health care from a patient perspective

Measuring patient satisfaction is neither sensitive nor useful, as there is little evidence of reliability or validity of the tools that measure satisfaction, and almost all individuals are 'satisfied' with the care they received, regardless of its quality. Measuring expectations and experiences, the constructs underpinning satisfaction, is more fruitful to inform continuous improvement activities.

Expectations: The Picker Institute in Europe found patients distinguish between what they want as a citizen taxpayer, and what they want as healthcare users. Picker produces a series of survey tools that have become the foundation of many surveys of patient experience worldwide. The Picker tools measure eight dimensions of care that are important to patients: information and education, coordination of care, physical comfort, emotional support, respect for patients' preferences, involvement of family and friends, continuity and transition, and overall impression of care.

Experience: Patient experience is influenced by human and organisational factors at different levels of care. Information about patient experience can be collected by survey, by narrative methods or through patient feedback processes.

Surveys can be conducted at national, state, group or provider level. Examples include the Commonwealth Fund (international surveys); experiences with PHC in Canada (national level); Consumer Assessment of Healthcare Provider Surveys (CAHPS) in USA (standardised survey at health plan level) and National PCT Survey in UK (provider level). Appropriate sample sizes are needed if national surveys are to be useful for quality improvement at provider level. In Australia, most surveys at provider level take place for accreditation or audit purposes, for the sole use of the provider, and because of privacy cannot be aggregated up to provide information at regional or higher levels.

Narrative methods such as critical incidents, patient journey and tracer methodologies gather information by interviewing patients about a particular health incident in which they used a health service.

These patient experience measures are utilised to improve the quality of the care and services provided to consumers. This is achieved through a variety of drivers, from pay for performance, to accreditation, and clinical service redesign programs. Underpinning many of these drivers is the assumption that free market principles and transparent accountability processes will increase competitiveness amongst providers and organisations in the quality of care domain. The UK is the most advanced country in this respect, with their patient experience measures informing multiple

mechanisms, from annual public service agreements to patient choice websites, pay for performance schemes and provider and fundholder accountability.

Patient feedback systems and other mechanisms for community engagement and participation in planning and implementation at organisation or higher level are necessary, but do not replace systems to collect patient or client experience of the service being delivered on the ground.

How are the results of patient experience measures used?

Patient experience measures are intended to supplement rather than replace measures of clinical outcome and other measures of the process, outcomes and costs of safe quality care.

The reasons for studying patient experiences include:

- ⇒ external accountability of health care providers
- ⇒ enhancing patient choice
- ⇒ improving the quality of care and
- ⇒ measuring the performance of the health care system as a whole.

Patient experience information can be analysed in a variety of formats, for example auditing an organisation against its policies and procedures, auditing an organisation against external accreditation or best practice standards, or identifying incidents or points in the patient journey that have a significant impact on the patient.

When patient experience surveys are used as an auditing tool, ratings of performance are lower than in a traditional audit. The probable explanation is that patient journey methodologies assess if policies and procedures are enacted, as opposed to the traditional audit processes which test whether a policy or procedure exists in an organisation.

Standardised questions and comparison between health care facilities are required to provide information to enhance patient choice.

Patient experience is a component of the UK Quality and Outcomes Framework (QOF), a pay for performance scheme under which general practices receive a proportion of their income according to their score on indicators in the QOF. Patient experience points are calculated from the National Primary Care Trust Survey. The results of patient experience questions in the National GP Survey are made available to patients through NHS Choices to assist with choice of provider.

Providing patient feedback or experience information is not sufficient in itself to stimulate quality improvement, without being integrated into a system specifically designed to support the use of this information.

Information available to and used by patients

Australian users of primary health care services have little information to guide them in choosing a practice or practitioner. Resources include telephone directories, links through *Healthinsite* to the patient's jurisdiction, Divisions of General Practice, AGPAL to identify accredited practices, public libraries, and some specific consumer groups such as Cancer Voices NSW and *beyondblue*. In contrast, through NHS Choices UK patients have access to information about opening hours of practices, the services provided, names and qualifications of doctors, and clinical achievements of the practice on items of the Quality and Outcomes Framework including patient experience as measured by the GP Survey.

However, the use that patients make of such information is not clear. One UK study found the public do not like league tables comparing the performance of practices, being more interested in information about the context and availability of services. A US study found individuals seeking to change providers or waiting for elective treatments, rated patient experience information more highly than information on practice location and hours, physician characteristics and credentials, advice from other health professionals, and advice from friends. As more information becomes available on the internet, it is important to understand consumers' access to the internet and skills in using it as part of their help seeking behaviour. It is also necessary to consider consumers' health and functional literacy when providing health information to optimise its value.

Application in Australia

A review of patient experience measures concluded that European countries who wish to introduce similar programmes of measuring quality of care from the patient's perspective can learn at least three things:

- ⇒ measure detailed patient experiences instead of overall patient satisfaction
- ⇒ introduce an integrated system for:
 - internal quality measurement and improvement on the one hand
 - external reporting and accountability on the other hand
- ⇒ standardise questionnaires and methods.

Submissions to the NHHRC and the NPHCS indicate support for the measurement of patient experience from health consumer representative bodies, safety and quality organisations, multidisciplinary representative bodies, state government health departments and organisations such as the AGPN and Divisions of General Practice

Existing mechanisms which could be adapted include the 2010 Commonwealth Fund survey and the 2010 Australian Bureau of Statistics Survey. The Australian Commission in Quality and Safety in Health Care is considering including questions in each of these surveys to provide comparison on international and national level. The existing CATI surveys conducted regularly by State and territory jurisdictions could include appropriate questions about patient experience, standardised across the jurisdictions to collect information relevant to COAG agreements and National Partnerships. Existing instruments developed for accreditation of primary care providers at practice or provider level would be relevant for quality improvement at this level.

New options in a reformed health system include establishing patient experience systems to collect and use patient experience information from those high-need patients who voluntarily enrol in primary care entity. The advantage of this would be obtaining information about their experience across a number of providers.

The Australian Charter for Health Care Rights, recently endorsed by COAG, could provide useful standards against which to measure some aspects of patient experience at national level in each of the above options. The domains measured can include, though not be limited to the rights identified in the patient charter.

Experience elsewhere as well as local submissions suggests it is important for an independent organisation to develop and monitor this process.

Preface

Internationally, what mechanisms exist (eg. patient satisfaction surveys) to measure performance of primary health care from a patient/provider perspective? How is this patient/provider feedback used to inform policy/practice? How might this be applied in the Australian context?

This Policy Issue Review synthesised evidence from a variety of sources. The main aims were to: Examine national and international sources to identify what mechanisms exist to measure the performance of primary health care from a patient perspective, at national, regional and practice level. Identify what methods are used, what aspects of experience are measured, who is responsible.

Identify how the results of such assessments are used at different levels to inform policy and practice (ie. primary health care providers). Possible uses include public display, pay for performance, accreditation, quality improvement, benchmarking. (Note: measuring performance of primary health care from a provider perspective was out of scope of this review).

Identify what information about the primary health care system and its performance is available to and used by patients in Australia and overseas. (Note: information about health, disease, treatments, and prognosis was out of scope of this review)

This review was undertaken in the context of public consultations on the final report of the national Health and Hospital Reform Commission and the draft National Primary Health Care Strategy. Patient-centred care was a key guiding principle identified in the reform strategies.

A number of the key recommendations of the National Health and Hospital Reform Commission (NHHRC) Report¹ centred on the need to provide patient-centred care, to increase the role of the consumer-patient and the smart use of data and information to improve the health system. These specifically identified the need for:

- ⇒ a responsive and self improving health system
- ⇒ a 'patient-centred' health system
- ⇒ a strengthened consumer voice, including fostering community participation, and truly valuing consumer input at both a national and regional level
- ⇒ utilising information and data on performance to drive a continuous improvement cycle, including publicising the findings on health services so that consumers might make an informed choice
- ⇒ the use of evidence to improve the delivery of services at both a national and local level
- ⇒ devolution of responsibility to the Australian Commission for Safety and Quality in Health Care to moderate this process, and the necessary standards.

The draft National Primary Healthcare Strategy (NPHCS)² asserts similar points. It notes that a key method for monitoring quality of care provided (whether from a patient or provider perspective) is the accreditation process. Whilst a number of systems have been developed to report on the quality of primary care, the outcomes are often significantly removed from the organisation being evaluated, and the measurement process is prone to error and inaccuracies due to poor quality data, the need to manually extract the data (as opposed to having an automated system), and issues with privacy of patient information.

Submissions to the draft National Primary Health Care Strategy identified that consumer satisfaction, holistic care, equity of access, and obtaining feedback from users are some areas which are appropriate for performance management via indicators.²



1 Mechanisms to measure performance of health care from a patient perspective

Patient Satisfaction vs Patient Experience

Patient-centred care is fundamental tenet of quality healthcare³, which necessarily involves delivering services which respond to and are sensitive to the needs and wishes of the consumers or patients. Assessing whether health care is patient-centred will require the measurement of the quality of care from patients' perspectives, and service redesign in accordance with the results.

Interest in gauging the patient's experience of health care originally took the form of patient satisfaction measurements, as healthcare in some countries moved towards free market consumerist principles around the 1970s.⁴ In the United Kingdom the development of the patient charter in 1991 further drew attention to the rights of the patient.⁵ Over time, these changes have led to the transformation of a patient's relationship with health care practitioners from one of a passive recipient and 'grateful supplicant'⁶ to that of a consumer with rights and expectations. The apparent commercialism in this transformation generated unrest with some physicians.⁴

In the 1990s it became clear that using patient satisfaction data was problematic, being neither sensitive nor useful. A review of 195 studies on patient satisfaction found little evidence of reliability or validity of the tools that measured the construct.⁷ Almost all individuals were 'satisfied' with the care they received, regardless of its quality.⁸ Issues with the measurement of patient satisfaction include:

- ⇒ the ambiguity of the concept of 'satisfaction' which is a multidimensional construct, though often measured as if it were unidimensional⁹
- ⇒ the lack of definition of the term satisfaction⁹
- ⇒ patient level biases, including a tendency for patients to treat medical professionals uncritically as experts, and a disinclination to be critical because of their gratitude or not wanting to jeopardise their treatment^{5,7,9}
- ⇒ satisfaction being determined largely by factors other than the care an individual receives, including age or educational attainment¹⁰
- ⇒ satisfaction being related only marginally to experience, and more to public events like media portrayals, the opinion of political leaders, and even national events that are not directly related to health¹¹
- ⇒ findings from satisfaction surveys being too non-specific to use to improve the quality of care delivered.^{9,12}

The more poorly designed the questionnaire, the more these issues are exacerbated.⁵

Dimensions of patients' health care experience

Measuring expectations and experiences, the constructs underpinning satisfaction, proved to be more fruitful and more adequate to inform continuous improvement activities.⁹ Early pioneers Angela Coulter and her team at the Kings Fund in the UK began by surveying expectations, and asking patients what they want from PHC.^{13,14,15} They found that patients distinguish between what they want as a citizen taxpayer, and what they want as healthcare users. As citizens, the public expects:

- ⇒ affordable treatment options, which are free at the point of care
- ⇒ safety and quality built into their health system

- ⇒ health promotion and preventative health built into standard service delivery
- ⇒ accessible local services, as well as access to national centres of excellence
- ⇒ universal health coverage, and equity in the structure of service delivery
- ⇒ participation in the development of services, and;
- ⇒ transparency accountability and the opportunity to input into policy decisions.¹⁴

When individuals are in the role of patients, their priorities are:

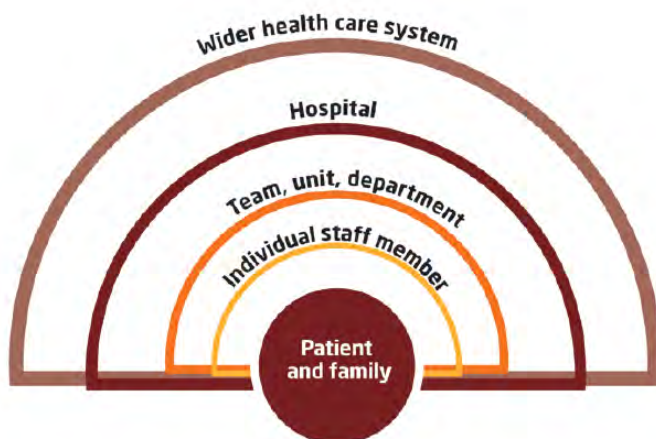
- ⇒ fast access to reliable health services, and longer opening hours
- ⇒ effective treatment options, by competent health professionals (including revising treatment to be delivered by a non-medical professionals)
- ⇒ participation and input into decisions
- ⇒ clear comprehensible information which enables self-care
- ⇒ attention to their physical and environmental needs
- ⇒ emotional support, empathy and respect
- ⇒ involvement of, and support for themselves, their families and carers, and;
- ⇒ continuity of care and smooth transitioning between services.¹⁴

Because patients are not generally in a position to comment on the technical quality of care^{16,17} patient experience measures are not intended to provide information from a clinical, gold standard. Measures of patient experience supplement rather than replace measures of clinical outcome and other measures of the process, outcomes and cost of safe quality care.

What influences patient experience?

Patients at the point of care are affected not only by their provider, but by broader, macro-level forces, as shown in Figure 1.

Figure 1 Dimensions of patient experience of the health system Source:³



Different instruments for measuring the patient experience relate to these different tiers within the health system. Table 1 lists the organisational and human factors at individual, clinical and organisational level which shape the patient experience at each of these levels of care. These factors help to interpret the meaning of patient experience, and also to identify where in the system action could be taken to address any concerns.

Table 1 Factors affecting patient experience³

	Organisational Factors	Human Factors	
Individual Level	Staff: <ul style="list-style-type: none"> • Education, training • Induction and preparation • Job description • Accountability • Permanent or temporary status • Support • Supervision and appraisal processes 	Staff: <ul style="list-style-type: none"> • Morale • Experience • Health status • Stress levels and wellbeing • Professional and personal attitudes and values • Support 	Patient: <ul style="list-style-type: none"> • Clinical need • Mental and physical capacity • Ability to assert needs • Age • Language/cultural background • Social status • Active family or other support • Depression, anxiety, and fear.
Clinical Level	<ul style="list-style-type: none"> • Performance Management and measures • Governance and accountability • Division of labour • Clarity or conflict over job boundaries • Policies and procedures • Record keeping • Skill mix • Deployment • Ability to meet demand • Stability of staffing 	<ul style="list-style-type: none"> • Leadership • Morale • Communication • Experience in team • Flexibility • Team ethos and values • Priorities 	
Institutional Level	Positive experiences and protected patients require: <ul style="list-style-type: none"> • Set organisational direction • Stable governance • Well developed data systems, and use of that data to improve quality • Ensuring delivery of services 	Positive experiences and protected patients require: <ul style="list-style-type: none"> • The creation of an open organisational culture where staff can raise their concerns • Creating a culture of effective teamwork • Enabling and supportive management styles • An expectation for staff to speak on behalf of the patient. 	

Methods of eliciting information about patient experience

As the 'patient experience' approach has gained prominence, a number of instruments and methods have been developed to measure the patient experience of health care events. Patient experience can be measured by survey, by narrative methods or through patient feedback processes.

Examples of these tools are available from PHC RIS. We have not included them as they extend to 98 pages.

Surveys and tools

The Picker Tools (Patient Level)

The Picker Institute Europe was one of the pioneers in developing surveys of patient experience. Picker produces a series of survey tools that have become the foundation of many surveys of patient experience worldwide. The Picker tools measure eight dimensions of care that are important to patients:

- ⇒ information and education
- ⇒ coordination of care
- ⇒ physical comfort
- ⇒ emotional support
- ⇒ respect for patients' preferences
- ⇒ involvement of family and friends
- ⇒ continuity and transition
- ⇒ overall impression of care.^{12,18}

Questions in the Picker tools do not assess whether patients are satisfied with this aspect of their care, but rather ask about the events surrounding that aspect.¹⁹ This avoids the shortcomings of measuring satisfaction, but still assesses quality in the domains that matter to patients. The tool uses forced choice, tick-box response categories. The results are in the form of a 'problem score': which indicates the presence or absence of a problem, and its extent.¹⁸

The long-form Picker instruments (56 questions) are specific enough to identify areas on which to focus Continuous Quality Improvement (CQI) activities. These questions have historically been used at a practice or ward rather than provider level. As the tools are standardised, they may also be used at higher levels, for example, at the Primary Care Trust level or at a state level in NSW.

The short form tool has only been used to assess patient experience for the purpose of public accountability and patient choice, as 15 questions is thought to be too short to assess the quality of the patient experience. The survey aligns well with the results of the longer version.^{18,20}

The Picker tools have been developed for a number of settings and demographic groups, including inpatient, outpatient, accident and emergency, PHC, ambulance, and for young and elderly people.²¹ The survey is currently used in:

- ⇒ the National Health Services' Primary Care Trust Patient Surveys (in England). The 15 item short form is included in the 30 item Health Commission survey²²
- ⇒ the NSW Health state-wide patient survey.¹⁹ The survey has undergone significant testing and has found to be reliable^{18; 20}
- ⇒ the Cancer Institute NSW Cancer Patient Satisfaction Survey.²³

Commonwealth Fund (International-Regional Comparison)

The Commonwealth Fund in the US developed a survey for a cross country analysis of health system performance in 2004²⁴, and 2007²⁵. The 2004 survey focused specifically on patient experiences within PHC, whereas the 2007 survey measured experiences across the entire health system^a. As the 2004 survey was conducted in five (English speaking) countries, small variations in terminology exist between the surveys.

1 ^a The Australian Commission in Quality and Safety in Health Care is considering adding questions to the 2010 Commonwealth Fund survey of patient experience of health care in these countries (Prof Chris Baggoley, personal communication 10 November 2009).

The specific areas of focus were:

- ⇒ overall views of the health system
- ⇒ access to healthcare
- ⇒ patient/physician relationship
- ⇒ coordination of care
- ⇒ hospitalisations, emergency room experiences
- ⇒ preventative care
- ⇒ out of pocket expenses
- ⇒ prescription and medication errors
- ⇒ use of information technology
- ⇒ health status and chronic conditions.²⁴

The 2007 survey covered seven countries and reviewed the following areas of patient experience:

- ⇒ overall views about the healthcare system
- ⇒ health status
- ⇒ choice and quality
- ⇒ access to care and coordination problems
- ⇒ experiences with primary care doctors and use of teams/non-physician clinicians
- ⇒ use of specialists and specialist/GP coordination
- ⇒ elective surgery, hospitalisation and ER use
- ⇒ health care coverage and administrative hassles
- ⇒ financial out of pocket and financial burdens
- ⇒ prescription use and medical errors
- ⇒ access to medical records
- ⇒ chronic conditions.²⁵

Development of this survey was informed by the experts who worked on the Picker Patient Experience Survey, and closely aligns with their domains.²⁶ The general nature of these questions makes them inappropriate for use at the provider or practice level, as they do not specify aspects of service delivery but rather more global reflections on experiences with the health system. The survey is therefore more appropriate for national comparisons.

Clinician & Group Consumer Assessment of Health Plan Survey (Health Plan Level, USA)

The Clinician and Group Consumer Assessment of Health Plan Survey (C&G CAHPS), under the banner of the larger *Consumer Assessment of Healthcare Providers and Systems*²⁷ is endorsed by the Agency for Healthcare Research and Quality (AHRQ), the national government body responsible for healthcare quality and research in the US. The CAHPS was originally designed to evaluate health insurance plans in the US,²⁷ though a variant was developed to measure experiences with primary care clinicians and their practices. The core scales measure:

- ⇒ access
- ⇒ communication with the health provider and other workers at the clinic
- ⇒ use of recall systems
- ⇒ efficacy of screening people with chronic conditions.

Supplementary items can be added to measure considerations for the cost of care, thoroughness of consultations, health promotion activities, provider communication and shared decision making.²⁸

The development of the survey differed from other measures of patient experience. The C&G CAHPS was developed in consultation with a number of stakeholder groups: physicians, health

plans, health quality assurance groups and experts on survey content and administration.²⁸ However, the assessment of patient experience is based on domains determined to be of importance by 'experts' rather than patients, calling into question the 'patient-centred-ness' of these instruments. There is no mention of considering the patient/consumer as a stakeholder group for consultation when developing the domains which are of importance to patients.

The original health plan version of this survey represents the largest and most appropriate questionnaire to measure commercial health plans. As such, it has been adopted as one of a number of endorsed measures to be used in the Netherlands.⁹

Ambulatory Care Experiences Survey²⁹ (Provider Level)

Used predominantly in Massachusetts in the US, this survey was borne out of the lack of instruments that could provide meaningful information at the provider level. First developed in a state wide demonstration, it represents the most extensive effort to date to gather patient experience information at a provider level in Massachusetts.

Two broad domains are covered, with a number of sub-measures.

- ⇒ The 'quality of physician-patient interaction' domain measures communication quality, interpersonal treatment, whole-person orientation, health promotion, patient trust, relationship duration.
- ⇒ The second domain, 'organisational features of care' assesses organisational access, visit based continuity, integration of care, clinical team, and office staff.

Responses are measured on a scale of 0-100, the higher the score, the more favourable the rating.

To obtain reliable results from this survey, over 100 patients must be surveyed per provider. Whilst the information covered in this survey can be aggregated to higher levels (eg. regional or state level) this survey measures a limited perspective of what is important to the patient: only the quality of interactions, and organisational dimensions. As such, it should not be considered a comprehensive measure of patient experience.

Australian surveys which include the patient perspective

Few sources provide information on the value, quality or outcomes of care in general practice, and there is little information on patient satisfaction or experience with service, according to a 2008 report by the AIHW³⁰ giving a critical evaluation of Australian data collections relating to general practice.

Most of the comprehensive, systematic surveys on the quality of care from the patient perspective in Australia have been conducted by state health departments, but their focus is on acute care. All of these surveys use satisfaction measures which are prone to error, and participants tend to rate practitioners and services overly highly for reasons mentioned above. Both the South Australian and Victorian surveys focus on the hospital/acute care sector, using computer-assisted technologies to conduct the interview. Aspects of these surveys are summarised in Appendix 1.

NSW Health

NSW Health began surveying patient experience two years ago on a three year contract as part of Clinical Service Redesign. The process includes two streams of survey: the Picker tools, and the patient journey methodology. The survey obtains responses from approximately 15 000 patients.³¹

Anecdotal evidence suggests that full use is not currently being made of this survey, judging from the response to a question from Libby Kalucy to Richard Matthews, the Acting Director General of

NSW Health at the Sax Institute HARC Forum on 4 November: “we struggle to make good use of the information we collect”. With this survey, there is no commitment to improve on quality that was found in the previous year’s surveys. There are currently no leveraging tools at the disposal of NSW Health, partially because they are unsure of appropriate benchmarks and expectations (Gray, 2009).

Patient journey (or ‘discovery’) interviews are conducted with patients from five specific groups, eg. older persons with chronic care needs. Patients are asked about their recent experiences with the system, and then asked to categorise their experience according to the Picker dimensions of care important to patients, which they are shown. Information is gathered on an annual basis. The patient journey interviews are managed by the organisations themselves, which provide summaries to NSW Health.

Other Australian Studies

- ⇒ SA Health has conducted the *South Australian Patient Evaluation of Hospital Services* since 2001.³² This survey measures the degree of satisfaction (but not experience) in the areas of: coordination of care; provider communication; meeting personal need; responsiveness to needs; access; physical layout of the hospital; involvement in care.
- ⇒ Victoria’s Department of Human Services conducts a similar survey which measures degree of satisfaction, (but not experience) in: access and admission; treatment information; physical environment; discharge and follow up processes; overall satisfaction.³³
- ⇒ The *Australian Longitudinal Study on Women’s Health*³⁴ measures satisfaction with a aspects of GP service delivery in their sample of three cohorts of 40 000 women, who were aged 18-23, 45-50, and 70-75 when the study began in 1996.
- ⇒ The Cancer Institute NSW conducts a *Cancer Patient Satisfaction Survey*²³ with a random sample of patients and outpatients using public and private hospitals. The survey uses 96 questions on patient experience from the Picker tool. This survey informs the advocacy work of the Cancer Voices³⁵ consumer group.
- ⇒ The Commonwealth Fund includes Australia in its International survey on the patient experience (described in the previous section) though these data can only be used for international comparison.

The UK NHS Patient Choices

The UK has been attempting to move towards a more patient-centred model of healthcare for a number of decades, though these efforts, have failed to change the experience of persons on the ground.³⁶ The British government announced in 2000 its intentions to move patient experience to the centre of health policy. The Quality and Outcomes Framework (QOF) was developed as a driver to achieve this, as well improved quality and safety in general.

The first QOF was initiated in 2004. It consisted of a number of domains, both clinical and organisational, which specify areas for quality improvement via a payment system (entitled the General Medical Services). Patient experience was a key domain within the QOF. In the second iteration of the QOF, there was a marginal reduction in the number of points allocated for patient experience, though it still accounts for approximately 15% of the total points determining the payment ratio. The QOF covers both the primary care sector as well as hospitals.

The NHS has a number of surveys which measure the patient experience.

Many initiatives measure, and use aspects of patient experience within the UK, the most notable being GP patient surveys and PCT National surveys. The GP Patient Survey is conducted by Ipsos

Mori and is displayed on the NHS choices website. The PCT National survey (Picker survey) is distributed by Primary Care Trusts together with the Healthcare Commission. This survey is linked to the pay for performance scheme, as well as the public service agreements. Others are:

- ⇒ *The PCT Vital Signs*: these indicators are developed from conglomerations of other information, including the GP patient survey and the PCT National survey. PCT Vital Signs are a set of national priority areas, determined by the central government/department of health and disseminated for public accountability.³⁷
- ⇒ *NHS National Staff Survey*: some items in this questionnaire assess safety factors which influence the patient experience^{38,39}
- ⇒ *National Inpatient Survey*: This survey is the same as the PCT survey, though amended for an inpatient population.⁴⁰
- ⇒ *The Patient Environment Action Team Survey*: This survey is developed by the government, though the NHS Trusts assess the setting. It assesses the built environment, food quality and privacy and dignity.⁴¹

The NHS is also currently trialling patient journey methodology as a tool to improve the design of service delivery.⁴²

Patient experience now informs strategy and practice at multiple levels within the NHS:

- ⇒ Practices, who use it to manage their own performance
- ⇒ Information goes directly to the Primary Care Trusts, who use it to manage performance of the practices, as well as their own performance
- ⇒ NHS Choices dissemination website
- ⇒ Public service agreements
- ⇒ Pay for performance incentive payments
- ⇒ Whole of government accountability.

The NHS GP Survey of patients is part of a regular data collection to meet the NHS commitment to patient-centredness and patient choice. The results of the survey are intended as a guide to choosing services and are publicly available on a website, though the site assumes a high educational level and would not be easily usable by somebody unfamiliar with the language of data analysis.⁴³ Results are also available in a more accessible form through the NHS Choices website where citizens can choose a GP based on their score and other characteristics.⁴⁴

Each quarter a survey is sent by mail to patients registered with each GP surgery (total of 5.7 million respondents annually). In subsequent quarters different patients are sampled. The questionnaire may also be completed online and is available in 13 languages.⁴³ The survey uses the Local Health Services Questionnaire, based on the Picker tools but with many refinements undertaken in consultation with PCTs and consumers.⁴⁵ The survey gathers practice level data in five categories:

- ⇒ Access and waiting
- ⇒ Information and choice
- ⇒ Clean comfortable, friendly, private
- ⇒ Safe, high quality joined up care, and
- ⇒ Building closer relationships.⁴⁶

Information resources need to be designed with input from potential users, with consumers choosing topics, and testing draft resources to ensure they are understandable and meet their needs.⁴⁷ A group from the University of Manchester used an action research process to inquire about the needs and preferences of patients for information to guide choice in primary health care.

An information source about general practice services was developed, called *Your GP Guide*⁴⁸ and was designed to be usable by and useful to patients.⁴⁹ *Your GP Guide* was an independent, not for profit organisation within the National Primary Care Research and Development Centre at the University of Manchester. The guide was endorsed by the Royal College of General Practitioners and marketed to GPs, who paid a subscription fee and uploaded their own information, as a way of promoting their practices. The guide has now been incorporated into the NHS Choices website.⁴⁴

USA

In the USA, consumers have been increasingly shouldering the burden of the cost of their care⁵⁰ Consumers are therefore increasingly interested in quality and value for money. In the USA organisations which are independent of both government and health services are charged with gathering and providing information on patient experience and related matters.

The National Committee for Quality Assurance (NCQA)⁵¹ is a private, not-for-profit organisation dedicated to improving health care quality. NCQA accredits health maintenance organisations using information from the *Healthcare Effectiveness Data and Information Set (HEDIS)*. Within this data set are the results of the *Consumer Assessment of Healthcare Providers and Systems Survey (CAHPS)*. CAHPS is developed and endorsed by the US Government Agency for Healthcare Research and Quality. Aside from accreditation, the information enables consumer choice of plan.

The federal government has recently instituted a nation wide survey using a variant of the CAHPS, the Hospital CAHPS, to measure performance of every hospital in the country.⁵⁰ In a staggered fashion, the scores on indicators derived from the HCAHPS will be linked to financial incentives provided by the Centre for Medicare and Medicaid (a federal government body akin to the Department of Health and Ageing).

In addition to these movements at a national level, individual states have organised separate reporting systems. The California Cooperative Healthcare Reporting Initiative⁵² (CCHRI) is a statewide collaborative of health plans, provider organisations, and purchasers, jointly funded by these groups, which provides standardised and comparable information on the performance of health care plans and on the performance of health maintenance organisations and healthcare groups. CCHRI provide on number of data sets on to the public:

- ⇒ Clinical Quality Indicators: The California Physician Performance Initiative (CPPI), which is endorsed by the American Medical Association.
- ⇒ Patient Experience of health plans:
 - The *Patient Assessment Survey (PAS)*
 - Provider After-Hours Access Survey (PAHAS), which measures aspects of patient experience such as access.

Results are provided to the group practices to inform quality improvement, and summary information is also reported publicly through the California Office of the Patient Advocate.⁵³

Other National Surveys

New Zealand

In New Zealand, some measures of patient access to services are included in the national health survey⁵⁴ which includes reasons for choosing a primary health care provider and reasons for not accessing a GP when needed. Another source of national level data is the Survey of Family, Income and Employment (SoFIE) study by Statistics New Zealand⁵⁵ which has a health component and Primary Care sub study. The University of Otago –Wellington Health Inequalities Research Program

uses these data to study the contribution of access and continuity of primary health care to health status. Both these data sources are based on national samples and data are not available at a service provider level.

Canada

Similarly, in Canada, patient experience has been assessed by Statistics Canada⁵⁶ in a survey designed to provide data at a national level and estimates for the provinces, but not at a level which would enable patient choice between health services.

The Canadian Community Health Survey (CCHS)⁵⁷ which is undertaken yearly includes a number of questions on health service performance and utilisation. Some components of the survey each year are available at health region level.

Europe

In several European countries, surveys are taking place assess patient experience. According to a review by the Norwegian Knowledge Centre for the Health Services⁵⁸ commissioned by the Organization for Economic Cooperation and Development (OECD), this is the case in Denmark, Norway and The Netherlands as well as England. The report⁵⁵ provides a comprehensive review of national and cross national surveys of patient experience. However, apart from work in the UK and the USA it did not find examples of this information being collated at provider level. For further information about European surveys see Table A1 in Appendix.

Considerations in developing or choosing patient experience survey methodologies

A variety of methodologies can be used to conduct patient surveys:

- ⇒ postal Surveys (used by the NHS GP Patient survey)
- ⇒ face-to-face survey (used in the Patient journey surveys by Australian Council of Healthcare Standards (ACHS))
- ⇒ computer assisted telephone interviewing (larger research studies such as the Commonwealth fund, NHS GP patient survey, State government surveys)
- ⇒ internet based surveys (NHS GP Patient survey, RACGP/Ultrafeedback Patient information survey).

Different methodologies have the potential to include or exclude particular population groups. In the UK multiple methodologies were used to overcome this, and those using the [alternative] telephone based methods tended to be from ethnic minority groups.⁵⁹ However, mail methods are the most cost effective, and together with web based surveys tend to yield the highest response rates.⁶⁰

Gathering meaningful patient information requires careful consideration when sampling to:

- ⇒ obtain a sample of patients with sufficient experience with a provider to be able to comment
- ⇒ ensure representation from disadvantaged groups
- ⇒ ensure adequate sample size if the results are to be used to assess or accredit a practice or provider.

In the Australian health care system, the absence of a patient enrolment system presents additional challenges in determining a patient's usual practitioner. At the local level, it is necessary to determine the number of times a patient visits a practice or practitioner before they are able to assess their experiences with them. On the other hand, individuals from disadvantaged groups are more likely to be missed if only those with a regular medical home are surveyed, as those from lower socioeconomic status groups are more likely to attend GPs irregularly.⁶¹

Similar issues may be encountered with survey response. Those who fail to respond to surveys tend to be young, poorer, and less educated than the dominant white majority.²⁹

At a practitioner-level, small sample sizes can create issues with perceived reliability of the data gathered. This has been a key point for UK general practitioners contesting the results of data⁶² although their concerns have since been shown to be unfounded.⁶³

Measurement needs to be clearly related to a specific aspect of care or health system performance to be useful for quality improvement processes. Part of the problem with previous surveys reliant on measures of satisfaction with services was that a dissatisfaction result was non-specific, and so service improvements could not follow.^{9,12}

Narrative methods: Critical Incidents, patient journey, tracer methodologies

Critical incidents, patient journey and tracer methodologies are narrative methods of gathering patient experience information. Though there are various names for this method, each has a simple basic premise: patients are interviewed about a particular health incident in which they used a health service. The process noted on the patient's health record can be used to guide the interview. Interviewers try to elicit information on how the process occurred, and how well this worked from the patient perspective.

All health care organisations and their personnel operate under policies and procedures, accreditation, best practice standards, and their own aspirations as a professional health organisation. Patient journey narratives give an actual representation of whether these standards are met or followed, without being constrained by the structure of a survey. This also allows patients to identify areas of concern that may not be asked about in structured surveys.

Patient experience information can be analysed in a variety of formats, for example:

- ⇒ auditing the organisation against its policies and procedures
- ⇒ auditing the organisation against external accreditation or best practice standards⁶⁴
- ⇒ identifying incidents or points in the patient journey that have a significant impact on the patient.^{42,65,66}

Considerations in using narrative methods

When patient experience surveys are used as an auditing tool, the results differ from those in traditional auditing processes.⁶⁴ In a study conducted across multiple hospitals and community health organisations, almost 90% of the ratings of performance were lower using the patient experience method than traditional audit. As a result, many organisations that have met standards using the traditional audit method would not meet them using patient journey methodology.⁶⁴ The probably explanation is that patient journey methodologies assess if the policies and procedures are enacted, as opposed to the traditional audit processes which test whether a policy or procedure exists in an organisation.

The patient journey method can elicit detailed information which is easy to use within a 'plan-do-study-act' cycle of quality improvement for specific aspects of care. If auditing the organisation against its standards, quantitative information (of meeting or not meeting standards) may also be obtained, allowing for comparison over time. The number of patients interviewed is small, as the one-on-one interview method is a time consuming process for gathering information. This small sample size has the potential for organisations to contest the results in the event of a poor finding as the findings could be argued to be unrepresentative. Anecdotal evidence suggests that over time

resistance to this information declines, and is replaced with the need to increase their skills to facilitate acting on the results.⁶⁷

Routine patient feedback mechanisms

Complaints systems remain an important part of ensuring safety and quality in the healthcare setting, though they are not a proactive method of learning systematically about patient experiences to improve service delivery. Many accreditation models relevant to PHC involve continuous improvement cycles as a core competency for the practice or clinician.^{68,69,70,71} This improvement cycle is often informed by patient complaints, or feedback mechanisms, which some organisations consider is the standard method for gaining information about patients' experience with a healthcare provider or service.⁷² However, patients will generally complain or give feedback on their care only when the situation is perceived to be severe, so complaints represent the end of the spectrum when a perceived wrongdoing has already occurred, and rely on the patient making a complaint.

Patient representation and community engagement in developing strategic directions can be seen as another form of patient experience feedback to improve the quality of service provision. While such systems and mechanisms for community engagement and participation in planning and implementation at organisation or higher level are necessary, and endorsed by the draft NPHCS, they do not replace systems to collect patient or client experience of the service being delivered on the ground.

Critical Friends is a concept from education, where a Critical Friend is defined as an experienced individual who works in an advisory capacity offering support and guidance to a project or working group^b. The concept, about which Professor David Colin-Thomé from UK Department of Health spoke at the AGPN Forum in Sydney on 6 November 2009, is being increasingly used in the UK and in Australia in general practice to provide useful input into practice improvement.

Systems and processes to drive the measurement of patient experience

Independent commissions charged with review of health system performance

In the UK and USA, organisations with independence from government and from health services are charged with gathering and providing information on patient experience and related matters.

The Care Quality Commission (CQC)⁷³ is the independent regulator of all health and adult social care in England. It became operational in March 2009 when the Healthcare Commission ceased to exist. The Care Quality Commission has a number of roles in registering health and social care providers, monitoring and inspecting services, enforcing standards and improving services by undertaking regular performance reviews and special reviews on particular services, pathways of care or themes where there are particular concerns about quality. All findings are publicly reported and board meetings are open to the public.

In the USA, the National Committee for Quality Assurance (NCQA)⁵¹ is a private, not-for-profit organisation dedicated to improving health care quality. NCQA accredits health maintenance

^b elearning.heacademy.ac.uk/wiki/index.php/Critical_Friend

organisations using the *Consumer Assessment of Healthcare Providers and Systems Survey (CAHPS)* (see p 9, 10, 13).

In addition to this national body, individual states have organised impartial reporting systems. The California Cooperative Healthcare Reporting Initiative (CCHRI)⁵² works closely with California Office of the Patient Advocate⁵³ which provides public access to CCHRI data (see more detail on page 13).

Accreditation & Quality Improvement

Some accreditation bodies such as The Quality Improvement Council, the Australian General Practices Accreditation Limited and Quality in Practice, and the Australian Physiotherapy Association currently operate voluntary accreditation processes for primary care organisations in Australia. Each has mechanisms to gather information on patient experience in a traditional sense. For example:

- ⇒ All these organisations mandate a patient complaints and/or feedback system through their accreditation process.
- ⇒ QIC mandates consumer representation in developing directives for their organisations.
- ⇒ AGPAL mandates that accredited practices must adapt their service delivery to the needs of their customers.

While these mechanisms involve potential patients, they are proxy measures for gathering and responding to patient experience information to improve service delivery. For example, QIC assumes that consumer engagement by a small number of representatives can be extended to represent the wider population, and that this is a valid representation of patient experience information.⁷²

A more promising method for using patient experience information within an accreditation context is to use the traditional audit to obtain evidence on the existence of adequate policies and procedures, and patient experience information to test whether the policies and procedures are followed. The Australian Commission on Safety and Quality in Health Care has suggested that patient journey interviews might be used to complement traditional auditing processes for health care organisations, though without replacing them entirely.⁷⁴ The RACGP has endorsed a Patient Information Survey⁷⁵ for use by general practices as an online tool to obtain patient satisfaction data (not patient experience) for accreditation purposes.

Pay for performance (P4P)

The NHS in the UK employs a pay-for-performance system to drive quality improvement – the Quality Outcomes Framework (QOF) (see p 12). As well as clinical measures, patient experience is included in the QOF despite some reservations from providers about why patients should have any role in determining GP payment⁶. Patient experience is measured through the PCT Patient Survey, part of a package which determines the payments. Information is gathered from approximately 1.4 million patients per survey round by Ipsos MORI. As the survey is conducted annually, this results in a total of 5.7 million respondents per year⁷⁶. The QOF is linked to £67 million in payments annually, with patient experience items being 15% of payments to practices.

Similarly, in the US, the Consumer Assessment of Healthcare Provider Surveys (HCAHPS) has developed a hospital-oriented survey to be used for pay for performance.⁷⁷ This was linked to hospital payments beginning in 2007, when 2% of their annual budget for inpatient services was withheld until they reported⁵⁰. From October 2008, under the value based purchasing plan,

hospitals will receive additional funding and incentives to meet targets on indicators, including those that measure patient experience.

Public & Funder Accountability

The GP Patient survey in the UK and HCAHPS systems make organisations accountable to the public and central governments. This is achieved via the requirement that a threshold of performance on patient experience measures must be met in order to receive their maximum funding. The same information is translated into a format comprehensible to the public and published online,^{44,78} as well as being available via the telephone⁷⁹ allowing for public accountability of the organisations' performance. This is expected to encourage the organisations to improve the quality of their care care.⁸⁰

At present, a report on the NSW Health patient experience survey is available to the public via their website¹⁹ though the report is promoted neither as a tool for public accountability, nor for patient choice. It is not linked to any incentive programs or targets, though the potential for this to occur in the future has not been ruled out^{c, 67}

2 How the results of patient experience measures are used

The reasons for studying patient experiences can differ between countries. The motives vary between:

- *external accountability of health care providers*
- *enhancing patient choice*
- *improving the quality of care and*
- *measuring the performance of the health care system as a whole.*⁹

Often, patient experience surveys serve multiple purposes. For example, the work of the Picker Institute in the English NHS aims at providing comparative information for the Care Quality Commission (previously the Healthcare Commission) and the public. Therefore, they serve external accountability and consumer choice. At the same time, providers use the results for internal quality improvement. To that end, the Picker Institute offers a toolkit and a good practice database to assist practitioners to use patient experience information to improve service delivery.⁸¹

If the goal is consumer choice, a comparison of patient experiences across health care facilities is required, which in turn requires for the standardisation of questionnaires and methods. The development of the American CAHPS surveys was an explicit attempt to standardize patient surveys in order to produce consumer report cards, thereby facilitating consumer choice. However, recently the CAHPS consortium too has put considerable effort into the development of the so-called 'CAHPS Improvement Guide'; a guide for health plans and health care providers seeking to improve their performance in the domains of quality measured by CAHPS surveys.

Authors of a review of patient experience measures concluded:

From the work conducted in the USA and England, European countries who wish to introduce similar programmes of measuring quality of care from the patient's perspective can learn at least three things:

- *measure detailed patient experiences instead of overall patient satisfaction;*

3 ^c Dr Richard Matthews, Acting Director General of NSW Health, commented at a SAX Institute Seminar in Sydney on 4 November 2009 that NSW health is struggling to make good use of the information.

- *introduce an integrated system for:*
 - *internal quality measurement and improvement on the one hand, and*
 - *external reporting and accountability on the other hand; and*
- *standardize questionnaires and methods.*⁹

What is the likely response to information on patient experience?

Reaction of GPs

Initially, there was unrest in the UK and resistance to the idea of patients evaluating doctors. This was partly general resistance to performance measurement and the pay for performance system, but doctors also mistook surveys of patient experience to be a judgement of the technical quality of care which was provided.¹⁶

The NHS GP Survey of Patients has been criticised by the British Medical Association for having low response rates and thus small sample sizes which has seen general practices penalised on the basis of the responses of very small numbers of patients and many practices have appealed the funding decisions.⁸² This fear has not been corroborated in an analysis of the representativeness of the respondents compared with the general population which found little evidence to support their concerns about low response rates and selective non-response bias.⁶³

Patients as experts on their care

Overseas, there was some unrest at the proposition of patients rating the quality of care. A study in the UK concluded that patient experience is not a useful measure of the quality of care, as patient experience is only weakly related to technical and clinical indicators of good care.⁸³ However, this misinterprets the concept of patient experience, as experts have noted.¹⁶ Patients are not medical experts although they are still able to report on non-technical quality indicators that matter to them. This is a critical aspect of having a patient-centred health system, as opposed to a solely technically-centred system where patients' experience of care is of no value.

One way of understanding this is to consider the dimensions of quality service: completeness, accuracy, timeliness, style and equity^d. Completeness and accuracy encompass the professional clinical aspects of service, best judged by methods such as clinical audit and health outcomes rather than consumer survey or narrative. However consumers are in a good position to comment from their experience on their perceptions of the timeliness, style and equity of service, matters about which professions may feel less defensive.

Reaction of health care organisations

Support for the NSW survey of patient experience has grown, from an initially shaky ground.⁶⁷ Organisations were originally critical of the survey process, though now are more supportive despite uncertainty as to how to act on the findings of the surveys.

NSW Organisations were originally critical of the survey process used to ascertain patient experience, though now are more supportive despite

Does patient experience information lead to changes in practice?

The two routes by which indicators are likely to produce change are via selection or change.⁸⁴ Selection describes the process by which consumers will choose one provider over another on the

4 ^d From presentation by Bill Cossey, head of the SA Office of the Government Management Board in about 1990 in Adelaide, attended by Libby Kalucy.

basis of their performance on an indicator. Change takes place if a provider is stimulated (on the basis of their indicator score via funders and regulators) to improve their performance in a particular area. Therefore, one can expect that the areas that are targeted in an indicator are the ones that are specifically going to improve. This process will not necessarily stimulate general improvements across the board. Incentives must specify that people at higher levels than the providers respond to the patient experience information.⁸⁵

A 2008 systematic review⁸⁶ found scant evidence that publishing patient care performance data improves quality of care. The evidence is especially unclear when examining improvements at the level of individual providers and practices. Rigorous evaluation of many major public reporting systems is lacking. However evidence suggests that publicly releasing performance data stimulates quality improvement activity at the hospital level. The effect of public reporting on effectiveness, safety, and patient-centeredness remains uncertain.

What works to improve quality generally?

The provision of patient feedback or experience information is not sufficient in itself to stimulate quality improvement, without a system that is specifically designed to support the use of this information. Large scale trials found no improvement in care from simply delivering this information to practitioners.⁸⁷ Most practitioners were positive about the importance of patient feedback and ready to act on their results before patient experience trials.⁸⁸ However after receiving the results GPs perceived patient information was less relevant, time consuming and a waste of time. There are many other barriers to practitioners implementing evidence, as listed in Table 2.

Table 2 Barriers to practitioners implementing evidence in quality improvement.

Barriers to the implementation of evidence		
Organisational environment	Social environment	Professional environment
Financial disincentives (eg. a lack of reimbursement)	Standards of practice (eg. usual routines)	Clinical uncertainty (eg. an unnecessary test for vague symptoms)
Organisational Constraints (eg. a lack of time)	Opinion leaders (other stakeholders' disagreement with evidence)	Sense of competence (eg. self confidence in skills)
Perception of liability (eg. risk of complaints)	Medical training (eg. obsolete knowledge)	Compulsion to act (eg. the need to do something)
Patient expectations (eg. a desire for a known treatment)	Advocacy by interest groups (eg. pharmaceutical companies)	Information overload (eg. inability to appraise large amounts of evidence)

Practices require appropriate support to improve the gap between the ideal and their own performance. Providing such support is the approach taken by the Australian Primary Care Collaboratives, which have led to significant improvements in participating practices.⁸⁹ The concept of practical support fits with anecdotal evidence from the NSW health survey, where structured support was needed to ensure organisations could translate the evidence into practice.⁶⁷ Another example of structured support for quality improvement is shown in the following case study.

Client Focused Evaluations Program

The Client Focused Evaluations Program (CFEP)⁹⁰ is a Brisbane based private organisation run by Michael Greco, a former Director of Patient Experience for the National Primary Care Development Team in the UK. CFEP has a number of survey tools which can be used to elicit patient feedback in general practices. The service provided by CFEP is confidential and results are not publicly available. Greco identified two ways in which this work could lead to improvement, especially if the practices discussed the results with patients:

- ⇒ Doing things better – improvement: eg. patient on recruitment panel for new staff, patient input on plans for extended premises, more thoughtful organisation of waiting room.
- ⇒ Doing better things – innovation: eg. patient led workshop on specific conditions, patient present in health centre for dealing with queries, patient led design of new surgery website^e.

CFEP is currently working with Brisbane South Division of General Practice which is actively promoting that GPs use patient feedback on their interaction skills to drive learning and improve performance.^{46,91}

Along with a program of GP education in enhanced interaction skills, 25 patients from each practice are asked about the interaction skills of their GPs. The results are de-identified and fed back to individual GPs. Even though the information remains confidential to that GP and is not used in any other way, it can be confronting. In a presentation at the 2009 Integrated PHC Conference⁹¹ Vicki Poxon from Brisbane South Division of General Practice told of one GP who initially thought it was “the work of the Devil” but later came to be the greatest advocate for the project. An evaluation of the program by the UNSW Centre for Primary Care and Equity is in progress.

The method of support is not ‘one size fits all’, but needs to be adapted to suit context and the area of improvement.^{92,93} However, a number of basic and general guidelines have been derived from systematic reviews (Table 3).

Table 3 Effectiveness of methods of information transfer for quality improvement.

Source: Adapted from ^{94,93,95}

Method	Effectiveness
Educational materials	Mixed effects, not generally effective.
Conferences and courses	Mixed effects.
Audit	Mixed effects.
Interactive, small group meetings	Mostly effective.
Educational outreach by experts in a field	Effective, moderate degree of change. Especially effective for preventative health strategies.
Feedback	Mixed results. May depend of simplicity of implementing information.
Reminders	Effective, especially for preventative health activities.
Clinical information systems – decisional support	Effective if via a computer at the point of the decision.
Introduction of computers for QI	Generally effective.
Multi-professional collaboration	Effective for a number of different chronic diseases.
Financial incentives and interventions	Effective.
Combined approaches.	Almost always more advantageous than a single approach.

5 ^e Notes made by Libby Kalucy from workshop with Michael Greco at GP&PHC Research Conference 2007.

3 Information available to and used by patients

Patients make choices about health care when they need to choose a general practitioner or other provider, or to decide about their options for elective care. In the latter case, the concept of 'informed choice' rather than 'informed consent' is emerging as a legal standard in some States of the USA, in recognition of the complexity of choice about 'preference sensitive care'^f, to be consistent with patient values, situations and availability of options.

To make an informed choice of general practice or general practitioner a person needs to know whether that practice provides the services that they need. The person may have a specific language requirement, desire to have a female GP, seek a GP is skilled, experienced and accredited in a field which concerns them, or seek a GP with good communication skills and able to provide a high standard of care.

Finding a primary care provider in Australia

Australian users of primary health care services have little information which is specifically designed to guide them in choosing a practice or practitioner³⁰ although quality assured information on health conditions is available to Australians through the *HealthInsite* website⁹⁶. Consumer Health Forum, RACGP and other organisations provide good information about what to look for when choosing a provider. However many existing resources are not written for consumers and do not provide information at a service level which would assist patients to choose between services.

Australians have the following options, none of which provide information which is linked to patient experience of care.

Telephone directories

Telephone directories are the most readily available source of information for patients or potential patients about primary care providers as they are widely known, and available in print or electronic form. However, they provide no details of access, hours, billing practices, special interests or accreditation status, partly because of the constraints on advertising by medical practitioners.

HealthInsite

The Australian Government website *HealthInsite*^g supports the use of telephone directories for patients choosing providers. It also provides easy links to each state via a map, where searchers can find programs like Human Services Finder in SA⁹⁷ with a quick search option that delivers contact information for practices in a postcode, some details on hours and billing systems. This system includes providers other than GPs. *HealthInsite* obviously requires people to have access to the internet, and the skills to use it. People also need to be aware of the existence of the site.

Divisions of General Practice

Locally some Divisions of General Practice, such as Northern Division of General Practice Melbourne⁹⁸, provide Google maps to choose a GP, practice, GPs speaking community languages, Aged Care Homes and HMR Accredited Pharmacists.

6 ^f Professor Elliott Fisher, presentation 4 November 2009 at Sax Institute, Sydney
<http://www.saxinstitute.org.au/researchassetsprograms/BetterHealthServicesThroughResearch/HARCpas/EventsPresentationsDownloads.cfm?objid=771>

7 ^g http://www.healthinsite.gov.au/topics/Health_Services

Public Libraries

Some variable information is available through public libraries or municipal councils as part of their provision of community information. A good example was Mitcham council⁹⁹ in South Australia which provides information on the services provided at the surgery, the GPs' qualifications, languages spoken, admitting rights as well as opening hours and service charges.

General Practice Accreditation

The most reliable source of information on the quality of a general practice in Australia is its accreditation status, which would be evident to a consumer who knows to look for a window sticker at the practice and knows what accreditation entails.

The Royal Australian College of General Practitioners provides accreditation standards for general practice which have been developed in consultation with general practitioners Australia wide⁷⁰. All practices accredited with AGPAL (Australian General Practices Accreditation Limited) are assessed against these standards.

AGPAL¹⁰⁰ is a not for profit organisation which accredits general practices in Australia. It has membership from nine general practice stakeholder organisations. The Quality in Practice (QIP) organisation, which is a subsidiary of AGPAL, accredits Physiotherapy, optometry and medical imaging practices, using standards developed by these professions.

To obtain accreditation, a general practice is obliged to provide public information only about the name of the general practitioners, the first names of clinical staff and billing details. The qualifications of GPs and the achievement of any clinical or quality and safety standards are not included. One of the standards relates to providing opportunities for, and responding to, patient feedback, but there is no requirement to make this public.

The public are able to search a list of accredited practices on the AGPAL website¹⁰⁰ by postcode to reveal a list of accredited practices in their area. The Top 20 accredited practices in Australia are also listed on the website. AGPAL provides marketing resources, including window stickers, for accredited practices to promote their accreditation. However, we do not know the extent of consumer knowledge about accreditation and the benefits that flow from it such as access to PIP and SIP payments.

Consumer groups

Many consumer groups such as the Health Issues Centre facilitate consumer input into health service design and management rather than focusing on documenting patient experience and enabling choice. However some consumer groups provide information on patient experience with the aim of prompting health system reform.

The Cancer Voices NSW group³⁵ uses the results from a *Cancer Patient Satisfaction Survey*²³ conducted by the Cancer Institute NSW to inform their advocacy work.

Other groups conduct their own research on patient experience. One example is the 2005 Not for Service Report¹⁰¹ by the Mental Health Council of Australia and the Brain and Mind Research Institute in association with the Human Rights and Equal Opportunity Commission, which collated the experience of consumers through community consultation, submissions and two community surveys.

Another is the 2004 Dare to Care report¹⁰² by SANE, which is based on analysis of information supplied and issues raised in 9 630 calls to the SANE Helpline; interviews with consumers, carers, mental health professionals and community support workers and a national survey on stigma.

beyondblue has taken the initiative to provide information on individual GPs. On its website *beyondblue* maintains a list of general practitioners who have completed either Level 1 or 2 of the Better Outcomes in Mental Health Care Program or have post graduate qualifications in mental health. Inclusion of their details on the *beyondblue* website directory^h is voluntary for GPs. It is not a complete list, nor does it imply any endorsement by *beyondblue* about the competence of the practitioner.

Provision of information to aid choice has been actively resisted by some GPs and anecdotal evidence suggests some have been reluctant to disclose accreditation for the Better Outcomes in Mental Health Care Initiative or Veterans' Affairs, or being listed as 'youth friendly', due to fear of being overwhelmed with demand.

Websites

A new development is the growth of websites where people publicly share their experience of businesses, including health practitioners. Two Australian sites are Womow (Word of Mouth on the Web) and Rave About It^{103,104}. The information on these sites is provided by individuals who wish to contribute and is not systematically collected or necessarily fair to the practitioner under scrutiny.

Information on health care and health care performance internationally

NHS Choices (UK)

The worldwide trend towards patients sharing their experience online is starting to become mainstream, with Gordon Brown in the UK calling for "*an "information revolution" enabling the public to give eBay-style feedback on public services - including the NHS.*"¹⁰⁵

The results of the GP patient survey are intended as a guide to choosing services and are publicly available on a website. However the site assumes a high educational level and would not be easily usable by somebody unfamiliar with the language of data analysis.⁴³

8 ^h http://www.beyondblue.org.au/index.aspx?link_id=3.455

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Brownlow Group Practice(training practice)

Old Royal Infirmary
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We are currently accepting new patients
[How to register](#)

Getting started

- Welcome
- Need to see a doctor?
- Need a prescription?
- Need to register?

More about us

- Meet the staff
- Services & clinics
- Facilities
- Explanations

Performance & feedback

- How we perform
- What patients say
- Add your views
- National patient survey**
- Local surveys

Where we are and the area

- Map & travel info

What patients think

What is national patient survey information?

The information below is taken from the 2009 GP Patient Surveys. People registered at general practices across England were asked how easy or difficult it is for patients to see or speak to a doctor at their practice. The graphs for each question show the results for this practice together with a comparison figure for other local surgeries and for England as a whole. More detailed results from the GP Patient Survey 2008/09 are available from the GP Patient Survey website at: www.gp-patient.co.uk.

In general, are you satisfied with how easy it is to get through to someone on the phone at your doctor's surgery?

Entity	Satisfaction Level (%)
Brownlow Group Practice	~75%
Liverpool PCT	~70%
England	~68%

Practice Info

Brownlow Group Practice
 Old Royal Infirmary
 70 Pembroke Place
 Liverpool
 Merseyside
 L69 3GF
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NHS Choices⁴⁴ (see web page screen dump above) supports patients to choose a GP by providing information on the opening hours of practices, the services provided and the names and qualifications of the doctors. There is also information on the clinical achievements of the practice on items of the Quality and Outcomes Framework, including patient experience as measured by the GP Survey. Some practices also provide patient experience results from surveys carried out by the practice using the GPAQ (General Practice Assessment Questionnaire) or IPQ (Improving Practice Questionnaire) compared with the national average. NHS Choices has a facility where patients can provide feedback on their primary health care experiences. The information submitted is moderated according to a set of rules and made public.

Information on the performance of Primary Care Trusts is publicly available on the website of the Care Quality Commission.⁷³ Trusts are graded as weak, fair, good or excellent and on 13 different categories with information available on several indicators in each category. The information is presented clearly using menus and rather than presenting data tables, large coloured dots indicate whether the PCT scored better, worse or the same as other PCTs on an indicator.

USA

In the USA, where there is no national health system, health care is provided as a market commodity and the consumer has free choice in paying for the health care they can afford. The US Case study (page 13) describes a number of national and state level initiatives which provide data that is publicly available from health plans to facilitate informed choice.

In California, information is available to facilitate choice between health plans, health services and medical groups through the California Cooperative Healthcare Reporting Initiative (CCHRI). The California Office of the Public Advocate provides public access to this information.⁵³ Comparative ratings are provided in the form of one to four stars for meeting standards of care and for patient experience. Numeric scores are also provided to enable detailed comparison between medical groups (not individual physicians). The information is simply presented and easy to find. Medical groups can refuse to have their results made public.⁵³

Healthgrades¹⁰⁶ is an independent organisation in the USA which compiles information on medical practitioners and healthcare organisations. Information includes: their education, registrations and accreditations, any disciplinary actions and includes patient experience data, although this appears to be contributed by visitors to the site. People seeking information on a doctor must register and pay a fee for a report.



The screenshot shows the HealthGrades website interface. At the top, there is a navigation bar with links for Home, Physicians, Dentists, Hospitals, Nursing Homes, Health Manager, Drug Ratings, and Take Our Survey. The main content area is divided into several sections. On the left, a 'Welcome to HealthGrades' banner features a photo of a doctor and a nurse, along with text describing the organization as the leading independent healthcare ratings organization. In the center, a section titled 'How do your local healthcare providers rate?' lists features such as five-star ratings, instant reports, and disciplinary actions, with buttons for Doctor, Hospital, and Nursing Home Ratings. On the right, a large blue badge proclaims '#1 HealthGrades ranked the #1 doctor-ratings site by Compete'. Below this, there is a testimonial from Alan, Dulles, VA, and a 'Today's Health Headlines' section with a link to 'Cooling May Reduce Brain Lesions in Mice'.

Evidence on how consumers use information

There is surprisingly little evidence about how health consumers use publicly provided information. One English study¹⁰⁷ used focus groups to examine the attitudes of consumers and GPs to the public dissemination of comparative reports on the quality of care in general practice. Patients identified concerns about the trustworthiness of the data and the perceived political motivation driving the initiative. They were uneasy about encouraging practices to compete and wished to protect their practice from managerial interference. However, there was general support for the principal.

In a later study⁴⁹, the same research group confirmed that the public do not like league tables comparing the performance of practices and were more interested in information about the context and availability of services. If it were to be provided, the public wished to know more about the source of comparative information so they could make judgements about its veracity. A NHS review of ways to support informed decision making in primary care⁴⁷ found health service users did not use information about the quality of health care because of difficulty in understanding the information, disinterest, lack of trust, lack of timely access to the information, lack of choice and a preference for trusting anecdotal evidence from family and friends.

A 2004 national survey to assess Americans' perceptions about the quality of health care, their awareness and reported usage of information in making their health care choices¹⁰⁸ found a similar preference for asking friends and family or a health professional. Only 37% of respondents indicated that they would go to a website containing quality information, although this 2004 figure rose from 28% in a previous survey in 2000.

Similarly, other US studies^{86,109} have found that patients did not often use performance information to select better performing providers as it is often difficult to understand and patients are more interested in physician level data than data at the level of health services or plans. This is because at the point of decision making, patients are often unaware of information that could inform their decision making.

Conversely, a US trial of a web based physician level information resource for patients choosing a primary care physician found that patients valued information about other patients' experiences.¹⁰⁹ When individuals are seeking to change providers or are waiting for elective treatments, they tend to rate patient experience information more highly than information on office location and hours, physician characteristics and credentials, advice from other health professionals, and advice from friends. The team recommended that such a resource is targeted at patients known to be making a health care choice.

With health information increasingly being web-based, it is important to understand consumers' access to the internet and skills in using it as part of their help-seeking behaviour. A population survey conducted in the UK¹¹⁰ found that use of the internet for health related information was most prevalent among middle aged people and those in higher SES thresholds. There is a curvilinear relationship between age and use of internet-based patient experience information, with young people using it slightly less than those in the 35-59 year age bracket, though this drops off significantly for those from 60-96, probably because of their degree of computer literacy. However, a 2008 South Australian survey showed that online health information seeking has rapidly increased amongst older age groups (65+ years) since 2001. As the internet has matured its audience has become more diverse, although disadvantaged groups (including the elderly) may have been 'late adopters' of online health informationⁱ. People from lower socioeconomic groups make higher use of telephone based health information¹⁴.

Health Literacy

In 2006 a Adult Literacy and Life Skills Survey was conducted in Australia.¹¹¹ Health literacy is defined as:

*the knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy.*¹¹¹

The study assessed the ability to understand and use information from various kinds of narrative texts, skills required to locate and use information contained in various formats including forms, tables and charts, numeracy and problem solving. It found that 47% of adult Australians had less than the minimum level of skill needed to locate, use and understand health care information.

Health literacy is now recognised internationally as a problem. A national telephone survey on self management of chronic disease by the Picker Institute¹¹⁰ found that most people seek information

9 ⁱ Reinfeld-Kirkman, Kalucy and Roeger 2009: paper under review.

about primary health care from their GP or from leaflets in the GP surgery. The authors of the survey report recommended more intensive support for certain groups if they are to become active participants in their healthcare, creative and well targeted strategies to deliver health information to patients and the public, and encouraging doctors to act as a conduit to supplementary sources of information and support as well as providing information directly to their patients.

The need for Information Intermediaries was also raised by 'The Informed Patient' project¹¹² undertaken by Cambridge University Health. This research initiative provides recommendations to guide policy making on the provision of information to patients in Europe, supported by a report which explores what information patients need in order to be fully engaged in the management of their healthcare. The report recommends that

- ⇒ patient information needs should be addressed using a variety of traditional media and that emerging technologies should be explored
- ⇒ low literacy levels require attention to the design of materials and addressing issues such as trust, reliability of information, distinguishing between information and advertising, and appropriate standards.

The NHHRC highlighted reform as a key strategy which will underpin consumer engagement in the healthcare system. The NHHRC Final Report¹ recommends incorporating health literacy into school curriculum, however this will not assist individuals who go on to develop chronic illnesses later to understand and manage their health. Don Nutbeam¹¹³ identified three additional strategies to enable consumers to use the health system more effectively:

- 1 Providers need to become more responsive to patient needs and situation, including low health literacy levels.
- 2 Greater attention to provider's communication with patients, ensuring they are appropriate to the patients' literacy levels.
- 3 The development of adult education programs in health, such as those currently being undertaken in the UK.

4 How might this be applied in the Australian context?

Who is likely to support surveying patient experience?

Submissions to the NHHRC and the NPHCS indicate that support and suggestions for measuring patient experience are generated primarily from:

- ⇒ Health consumer representative bodies¹¹⁴
- ⇒ Safety and quality organisations^{115,116,117,118}
- ⇒ Multidisciplinary representative bodies¹¹⁹
- ⇒ State government health departments¹²⁰
- ⇒ Other organisations such as the AGPN¹²¹ and Divisions of General Practice.¹²²

There is wide ranging, in principle support for improving the patient experience of the health care system, though without specification what mechanisms might be undertaken to achieve this. The Australian Medical Association¹²³, Dieticians Association of Australia¹²⁴, and the National Prescribing Service¹²⁵ argue against any standardised measurement of PHC (which by default would eliminate the ability to measure patient experience in any macro sense).

Patients themselves could support the use of their experiences to drive change and reform. Anecdotal accounts from Dr Tony Hobbs of his 12 month's experience with a group of 'Critical Friends' in his own practice at Cootamundra suggest this is an important mechanism to harness patient support and engagement in change, which is gaining ground in the UK, associated with the work of Michael Greco.

What existing mechanisms could be adapted to collect information?

Surveys could be conducted at national, state, regional, practice or provider level.

- ⇒ For international comparison, the Australian Commission in Quality and Safety in Health Care is considering adding questions to the 2010 Commonwealth Fund survey of patient experience of health care in these countries, which would provide national level data to compare with other countries (Prof Chris Baggoley, personal communication 10 November 2009).
- ⇒ The Australian Commission on QSHC is also considering options for including questions about patient experience in the national health survey which the Australian Bureau of Statistics will conduct in 2010. This survey could provide data at national, state and possibly regional level depending on the sample size.
- ⇒ The existing regular CATI surveys conducted by State and territory jurisdiction could include appropriate questions about patient experience, which could be standardised across the jurisdictions to collect information relevant to COAG agreements and National Partnerships.
- ⇒ At the provider level there is potential to build on current accreditation initiatives (such as the RACGP endorsement of the patient satisfaction survey) to include meaningful patient experience measures, together with information about the providers' response to the feedback. This information is of most value when there is continuity of patient care with a single provider or practice.

However patient experience often involves more than one provider and setting. Voluntary enrolment of high needs patients is a suggested avenue for reform, and this presents the opportunity for developing processes to survey patient experience. It is likely that surveying experiences in this group of patients is likely to take into account more than one provider.

Who or what organisations could undertake patient experience measures

In the UK, it was acknowledged that the development and use of any survey was going to come under a significant amount of pressure from external stakeholders⁸⁵. A buffer was created by placing the development, implementation and regulation of the survey under a non-government, independent third party (the equivalent of which would be the Australian Commission for Safety and Quality in Healthcare in Australia). Indeed, the ACSQHC has expressed an interest in developing and managing such measures.¹¹⁶ An ACSQHC-managed process is supported by a number of other key stakeholders in the primary healthcare sector.¹¹⁴

What dimensions of care should be included in surveys?

Surveys of patient experience should cover the dimensions of care included in the Australian Charter of Healthcare Rights¹²⁶ developed in 2008, to which a number of the submissions to both reform strategies^j referred. This Charter, which is intended to provide a platform for discussions

^j NHHRC: Australian Council on Healthcare Standards sub no 30; Consumers Health Forum Sub no 509; Health Consumers Alliance SA Sub No 090; National Breast and Ovarian Cancer centre Sub no 122; Australian Commission for Quality and Safety in Health Care Sub no 428; Queensland Office of the Patient Advocate Sub No 489; Australasian Health Complaints Commissioners Sub No 518; including NHHRC First Round).

about health rights between patients, consumers, families, carers and healthcare providers, covers the seven rights of a patient within the Australian healthcare system: access, safety, respect, communication, participation, privacy and the ability to comment.

In addition, surveys of patients experience should cover coordinated/integrated care provision, managing transition and accountability. These are included in the Picker Patient Experience dimensions of care - information and education, coordination of care, physical comfort, emotional support, respect for patients' preference, involvement of family and friends, continuity and transition, and overall impression of care.^{12,18}

Collecting information about patient experience is necessary but not sufficient to bring about change

Problems in other countries⁸⁵ suggest surveys of patient experience would need to be a phased implementation as part of a system for change and redesign, rather than the rapid introduction in isolation by government. Collecting information about patient experience and feeding it back to providers does not lead to change and improvement without considerable practical support to use the information. Thus in the USA the Consumer Assessment of Health Plans Survey CAHPS consortium is developing 'CAHPS Improvement Guide'; a guide for health plans and health care providers seeking to improve their performance in the domains of quality measured by CAHPS surveys (see page 10); Picker Europe offers a toolkit and a good practice database to assist practitioners to use patient experience information to improve service delivery (see page 11); and the APCC, NSW Health and CFEP present Australian examples of the need for practical assistance to improve quality (see page 21).

Other barriers to the introduction of patient experience measurement

The benefits of measuring patient experience need to be considered in the context of the system they are to support. In a system such as the US where the health system is driven by free market consumerist principles, publicly available measures of patient experience enable the patient choice which drives improved healthcare standards. The UK, which has introduced a 'quasi-market',¹²⁷ also encourages competition between services, enabled by public release of patient experience ratings in order to improve service quality. In Australia, workforce deficits in some areas don't support competition for patients so other system drivers need to be considered.

This review found conflicting evidence regarding the reaction of consumers to public reporting, with some suspicion about the validity of the information and a preference for obtaining information from friends and family. Part of the reticence may be due to inadequate health literacy levels, which is certainly the case in Australia¹¹¹, underlining the importance of well designed information sources and the availability of information intermediaries.

There is likely to be resistance from the medical profession towards the public reporting of patient experience at practice or practitioner level. As detailed above there has been (unfounded) concern in the UK by doctors about the validity of patient experience surveys as a basis for a pay for performance payment. There are also concerns that the quality of medical care cannot be assessed by consumers.¹⁶

Benefits of measuring patient experience

In Australia, publicly available information about patient experience at a provider level would assist other potential patients to choose a provider. Information about patient experience can support

11 NPHCS: National Breast and Ovarian Cancer Centre Sub no 085; Consumers Health Forum Sub no 169; Health Consumers Alliance Sa Sub No 218; Queensland Health Sub no 264.

system and/or service improvement in the right circumstances, even if the information is not available publicly. It can make the system visible from the patient perspective, and may reveal gaps and deficiencies in coordination and integration which are not apparent to providers. Information about patient experience can highlight aspects of the health system that are important to those who use it, and indicate to the government how adequately the health system is meeting the needs of the population.



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Appendix 1 Australian and International surveys which include patient experience



Country	Process	Number of Respondents	Breadth of PE measurement*	Freq.	Level information is surveyed/used					Survey						Driver			Public Provision of Information			
					Provider	Practice/Dept.	Region	National	International	Picker	ACES	CAHPS	Patient Journ.	PEQ	Other	Accreditation	P4P	Accountability		Research	Gen. QI/ Policy	
Australia	NSW Health Patient Experience Survey	73 446	Comprehensive	Annual	x	x	x			x				x					x		x	Yes, but not for patient choice.
Canada	Experiences with PHC in Canada ¹²⁸	11 582	Moderate	Occasional				x							x					x		Yes, but not for patient choice.
Denmark	National Survey of Patient Experiences	26 313	Moderate																			
	National Survey of Psychiatry Inpatients ⁵⁸	25 696	Comprehensive (only surveyed psychiatric)	Once-off	x	x	x	x							x				x	x	x	No.
Netherlands		8644										x										Yes, patient-centred website, reports.
New Zealand	National Health Survey ⁵⁴	17 000	Limited	Annual			x	x							x						x	Yes, but not for patient choice.
	Survey of Family, Income and Employment	18 320	Limited	Bi-annual				x							x					x	x	Yes, but not for patient choice.
Norway	General outpatient	19 266	Comprehensive	Once-off		x	x	x						x					x	x	x	
	General inpatient	13 700	Comprehensive	Once-off		x	x	x						x					x	x	x	
	Paediatric inpatient	3 308	Comprehensive	Once-off		x	x	x						x					x	x	x	
	Psychiatric inpatient/ outpatient	2 676/ 6 677	Comprehensive (only surveyed psychiatric)	Once-off		x	x	x						x					x	x	x	



Country	Process	Number of Respondents	Breadth of PE measurement*	Freq.	Level information is surveyed/used					Survey						Driver					Public Provision of Information	
					Provider	Practice/Dept.	Region	National	International	Picker	ACES	CAHPS	Patient Journ.	PEQ	Other	Accreditation	P4P	Accountability	Research	Gen. QI/ Policy		
USA	Consumer Assessment of Healthcare Providers and Systems.	NA	Comprehensive if supplementary items are used.	Annual		x						x				x	x	x		x	Yes, patient-centred website, reports.	
	Ambulatory Care Experiences Survey	NA	Comprehensive	NA	x						x							x		x	No.	
UK	GP Patient Survey	2 163 456	Comprehensive	Quarterly		x	x	x		x								x		x	Yes, patient-centred website, reports.	
	Primary Care Trust/Healthcare Commission Patient Experiences Survey		Comprehensive	Annual		x	x	X		x						x	x			x	Yes, patient-centred website, reports.	
	Patient Environment Action Team	1265 sites	Limited – Environment only	Annual		x	x	x							x			x		X	Yes, patient-centred website, reports.	
	Primary Care Trust Vital Signs	Derived from PCT & Patient Survey	Limited – snapshot of overall results	Annual			x	x		x								x			x	Yes, patient-centred website, reports.
	Public Service Agreements	Derived from PCT & Patient Survey	Limited – snapshot of overall results	Annual				x		x											x	
	NHS National Staff Survey	110 staff		Occasional		x	x								x						x	