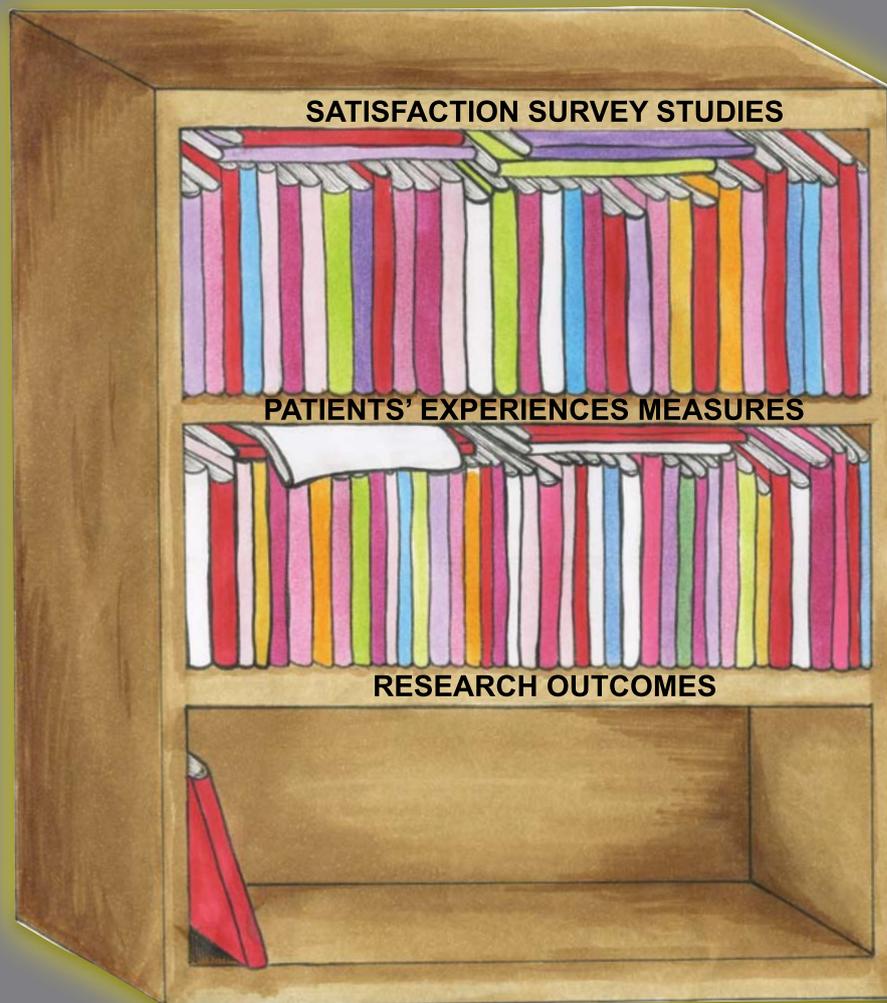


Patients' experiences

Top heavy
with research



Sarah Russell

Patients' experiences: Top heavy with research

Literature Review

2013

Correspondence

❖ Research Matters

Sarah Russell PhD, BA (Hons)

Principal Researcher

PO Box 1235

Fitzroy North VIC 3070

Email: sarahrussell@comcen.com.au

Website: www.research-matters.com.au

Design and desktop publishing: MacNificent

Cover illustration: 'Top heavy with research' by Erica Evans

© Bayside Medicare Local All rights reserved.

Russell S (2013) "Patients' Experiences: Top heavy with research" Research Matters: Melbourne

Acknowledgements

Our thanks to Jason Wasiak for his skills and expertise in searching academic databases, and Erica Evans for once again capturing a complex idea in a drawing.



Table of Contents

Summary	1
1 Introduction	2
1.1 Literature search.....	2
2 Patient feedback	3
2.1 Terminology.....	3
2.2 Types of patient feedback.....	3
Key messages from Section 2.....	5
3 Collecting patients' feedback	6
3.1 Sampling.....	6
3.2 Timing of data collection.....	6
3.3 Methods.....	7
Key messages from Section 3.....	11
4 Survey instruments	12
Key Messages from Section 4.....	13
5 Key variables that determine patients' experiences	14
5.1 Patient characteristics.....	14
5.2 Organisational characteristics.....	15
Key messages from Section 5.....	15

6 Purpose of patients' feedback.....	16
6.1 Provide information	16
6.2 Measure quality of health care services	16
6.3 Improve quality of health care	17
6.4 Change professional practice	17
6.5 Evaluate innovations	19
6.6 Improve the quality of specific interventions.....	19
6.7 Compare health services	19
6.8 Measure coordination of care	19
6.9 Rate health care services.....	19
6.10 Improve compliance	19
Key messages from Section 6	20
7 What we know about patients' experiences of primary care.....	21
7.1 What studies tell us	21
7.2 Disseminating results of studies	22
Key messages from Section 7	23
8 Future for patients' experiences.....	24
8.1 Patient Experience Framework.....	24
Key messages from Section 8	25
Conclusion	26
References.....	27

Summary

Consumer advocates have argued for many years about the need to improve the quality of health care from service users' perspectives. Prior to 1995, research on patients' experiences was small-scale and relied mostly on qualitative methods. However, once this type of research became mainstream, the sample sizes became large and the methods mostly quantitative. The UK's annual GP Patient Survey, for example, includes over 5.5 million people.

During the past three years alone, over 2,100 peer-reviewed articles were published on 'patient reported outcomes', mostly patients' satisfaction and experiences. These articles are remarkable for their repetitiveness. Although studies focus on different sites of health care or on a specific illness – and use different methods and various instruments – the existing studies draw similar conclusions. Most patients are satisfied with the health care they receive. Even those patients who have bad experiences are generally satisfied with their health care.

Health care organisations spend a considerable amount of time and resources on gathering data on patients' feedback. Most studies focus on a specific illness or sector in the health care system. This burgeoning interest in patient feedback reflects a shift towards patient-centred care. However, strategies for collection, collation, analysis and dissemination of patients' experiences remain ad hoc. In addition, a number of different instruments are used to describe and measure patients' experiences. Without standardised surveys, it is impossible to compare findings with other health services, or often even within the same service over time.

Patient satisfaction surveys remain the most common type of feedback though without a universal definition of satisfaction, measurements of patients' satisfaction are problematic. In addition, findings from satisfaction surveys are non-specific, making them useless for improving patients' experiences.

Patients' experiences provide a more discriminating measure of a health service's quality than questions about

satisfaction. However, relatively minor aspects of a health care consultation may have a significant impact on patients' experiences (but not on their clinical outcome). Evidence also indicates that patients' experiences are influenced by socio-demographic factors. This raises an interesting question: Does this reflect different expectations among different types of patients? Or do different types of patients within the same health service receive different types of care?

The focus to date has been on collecting data on patients' experiences rather than using the findings to improve service quality. In fact, little is known about how such feedback can be used to improve patient-centered care. There is some evidence that data collected at the level of individual teams, and close to the time when the care was experienced, may have the greatest impact on services.

A number of different methods have been used to measure patients' experiences, dividing broadly into qualitative and quantitative methodologies. Both methodologies are useful though for different purposes. The key to effective data collection is to use multiple methods and a range of data sources (including social media such as blogs, Twitter, Facebook, and rating websites). Multiple methods will enhance representation and therefore the validity of research findings.

The literature highlights individual, organisational and systemic barriers to using patients' feedback. One important barrier is professional scepticism about its value. Some practitioners argue that patients are not medical experts, and their perspective is therefore of no value. Health care practitioners may be experts about medical treatments, but patients are experts about their own lives. Patients clearly have the capacity to report on quality indicators that matter to them. This is the cornerstone of a patient-centred health care system, as opposed to a solely technically-centred system. ❖

1

Introduction

There is a substantial body of work exploring health care services from patients' perspectives. Although traditional measures continue to play an important role in evaluating health care quality, greater emphasis is now being placed on patient-reported outcome measures such as:

- Patients' satisfaction
- Patients' experiences
- Patients' perceptions
- Patients' attitudes

This literature review is not a systematic review of the literature on patients' experiences but rather a critical review of some recent studies – the methods used, assumptions made and conclusions drawn. The aim of this literature review is to:

- Clarify types of feedback and different constructs measured
- Investigate effective ways for collecting feedback
- Determine variables that determine patients' experiences
- Appraise the different ways patients' feedback is used

The objective of the literature review is to inform the design of a study to develop a more nuanced understanding of people's experiences of primary health care services in the Bayside Medicare Local area.

1.1 Literature search

A semi-structured search of academic databases was undertaken. The databases used were Medline and PsychInfo. The search was limited to articles published 2009 – 2013. The search used a series of recognised terms such as 'primary health care', 'patient and consumer satisfaction and experience'. The search terms were grouped to form a strategy designed for maximal retrieval of relevant studies in the database. All searches were limited to articles in English.

The search strategy identified a total of 2106 abstracts: 1908 from MEDLINE and 208 from PsychInfo. The abstracts were read by a single reviewer and coded thematically. A selection of articles from each theme was critically reviewed.

In addition to the automated search strategy, Google and Google Scholar were used to search for unpublished reports ('grey literature') and patient-centered experience websites. Finally, the reference lists of the included studies were checked to identify additional eligible references.

In total, 114 articles were included in the literature review. These articles include research studies, systematic reviews, expert opinion and government reports. ❖

Patient feedback

2

A key component of patients' willingness to provide feedback is a desire to improve things for other patients (Brown et al. 2009). Patients' feedback is mostly collected through surveys and questionnaires. However, exactly what is being measured in these surveys, or why it is being measured, is not always clear (Edwards et al. 2011).

2.1 Terminology

Cornwell and Goodrich (2011) claim that this area of research is "bedeviled by multiple terms with over-lapping but different meanings" (p1). They claim the efforts of researchers, bureaucrats and practitioners to understand and improve patients' experiences have been undermined by "muddled thinking" (p1). The most obvious example of this "muddled thinking" is the incorrect way in which the terms 'patients' satisfaction' and 'patients' experiences' are used. These two terms are often used interchangeably when in fact patients' satisfaction and experiences are two distinct constructs.

In the UK, the definition of 'patient experience' varies from trust to trust, and study to study (Robert et al. 2011). The Intelligent Board (2010) suggests that these constructs are confused because there is not a universal definition of "patients' experience" or "patients' satisfaction". Robert et al. (2011) claim that it is important to understand the definition of these two constructs.

2.1.1 Definition of patients' experience

The Intelligent Board (2010) offers the following definition of patient experience:

Patient experience is feedback from patients on 'what actually happened' in the course of receiving care or treatment, both the objective facts and their subjective views of it. The factual element is useful in comparing what people say they experienced against what an agreed care pathway or quality standard says should happen. The opinion element tells you how patients felt about their experience and helps to corroborate (or otherwise) other quality measures (p7).

2.1.2 Definition of patients' satisfaction

Satisfaction is a complex, multidimensional construct though it is often measured as if it were unidimensional (Malus et al. 2011; Kalucy et al. 2009). Some claim satisfaction indicates whether or not patients' expectations were met (The Intelligent Board 2010); others claim expectation may not be a predictor of satisfaction (Stenberg et al. 2012). A qualitative study found patients do not share a definition of satisfaction (Marcinowicz et al. 2010).

Interestingly, Hush et al. (2010) found patients could be satisfied with their health care without any improvement in their health status. This suggests that a patient's clinical outcome is not always a determinant of patients' satisfaction.

2.2 Types of patient feedback

There are many different types of patient feedback. This literature review focuses on two types of feedback: (1) patients' satisfaction surveys and (2) patients' experiences. Studies that track patients' visits with health care practitioners are also reviewed.

2.2.1 Patients' satisfaction surveys

Evidence suggests that most people are satisfied with their health care regardless of the quality of the care they receive – even those who have negative experiences are satisfied with the care they received (Worth 2013; Haggerty 2010; Kalucy et al. 2009). This is particularly the case for older people. A US study of older patients found that older patients' level of satisfaction with the quality of their primary care was not a good measure of the quality or effectiveness of the primary care service (Mold et al. 2012).

In the 1990s, it became evident that patient satisfaction data were problematic (Kalucy et al. 2009). A review of 195 studies on patient satisfaction found that the instruments/tools used to measure satisfaction lacked reliability and validity (Sitza 1999). In addition, dissatisfaction is non-

specific, making survey findings useless for improving patients' experiences (Kalucy et al. 2009; Reeves and Secombe 2008; Coulter 2006).

Kalucy et al. (2009) list the problems with patients' satisfaction surveys as:

- The lack of a universal definition of the term satisfaction
- A disinclination for patients to be critical because of not wanting to jeopardise their treatment
- Satisfaction being determined largely by factors other than the actual health care an individual receives
- Findings from satisfaction surveys being non-specific.

Despite these problems, measures of satisfaction continue to be collected.

2.2.2 Patients' experience surveys

Patients' experience surveys have begun to replace patient satisfaction surveys to measure the quality of health care services. Salisbury, Wallace, Montgomery (2010) claim that patients' experiences provide a more discriminating measure of a health service's quality and performance than questions about satisfaction.

Kalucy et al. (2009) list some reasons for studying patients' experiences. These reasons include:

- External accountability of health care providers
- Enhancing patient choice
- Improving the quality of care
- Measuring the performance of the health care system as a whole.

Patients' experiences surveys have been adapted from consumer surveys used in marketing (Edwards et al. 2011). They measure aspects of care that are important to patients. However, which aspects should be measured and in what ways is a recurring problem (Sliwa and Okane 2011). According to Roland (2012), it is important to determine what should be measured, how it should be measured and what difference the measurement might make (Roland 2012). Brown et al. (2009) agree, arguing that feedback should be used systematically and according to a clearly defined strategy.

Surveys measure two distinct aspects of care that determine patients' experiences.

1. Functional aspects of care (e.g. waiting times, access, cleanliness)
2. Relational aspects of care (e.g. dignity, compassion, emotional support)

Robert et al. (2011) argue that most surveys focus on functional aspects. They argue that more attention should be paid to relational aspects of patients' experiences. In the past, surveys focused on a specific health care service, not an individual practitioner. As such, they focused on functional aspects of health care services, not aspects of the practitioner-patient interpersonal relationship. Increasingly, studies focus on patients' experiences with a specific practitioner (Burford et al. 2012; Moore et al. 2011; Hueston and Carek 2011; Moore et al. 2011).

Kenten et al.'s (2010) findings highlight that relatively minor aspects of a medical consultation can have a significant impact on the patients' experiences. They found that the simple action of doctors greeting patients and introducing themselves could make the patient feel more comfortable. Other behaviours that have also been shown to affect patients' experiences include how doctors address them (Moore et al. 2011), the clothes that doctors wear (Hueston and Carek 2011) and how patients receive test results (Elder and Barney 2012). Although these behaviours may affect patients' experiences, it is unlikely these behaviours will affect patients' clinical outcomes.

2.2.3 Tracking patients' visits

Patients' self-reports of their number of contacts with health care services are not always accurate. In their study of patients who had experienced a stroke, Chishti et al. (2013) found patients under-reported the number of consultations they had with a GP. They argue that researchers should consider validating a sample against electronic records, particularly if patient self-reports of health care usage are to be used in economic evaluations in primary care. Chishti et al. (2013) acknowledge that obtaining patient records requires more effort than obtaining information from patient questionnaires.

Jackson et al. (2012) followed patients with chronic obstructive airways disease for a three-month period following hospital discharge. To assist with accuracy of patients' reports of their contact with health care services, Jackson et al. (2012) asked participants to complete a log. This log kept track of patients' contacts with health care services. The logs contained details of each visit with a health care practitioner such as the reason for the visit. This information may otherwise have been forgotten during an interview.

Key messages from Section 2

1. Without a universal definition of satisfaction, measurements of patients' satisfaction are problematic.
2. Patients' experiences provide a more discriminating measure of a health service's quality than questions about satisfaction.
3. Relatively minor aspects of a health care consultation may have a significant impact on patients' experiences though not on their clinical outcomes.
4. Patients' self-reports of their number of contacts with health care services are not always accurate. ❖

3

Collecting patients' feedback

There are many different ways health care organisations collect data on patients' experiences. According to the literature, the most effective ways to collect meaningful data on patients' experiences are:

- Mapping customer journeys and coordinating data collection across pathways of care.
- Collecting feedback from patients on core domains frequently
- Developing systems and processes to support collection using real time data
- Building flexibility for local organisations/ services/teams to capture locally relevant issues into data collection tools.

(Robert et al. 2011; Foot and Cornwell 2010; Brown et al. 2009)

The following section describes some technical issues in collecting data, including:

1. Sampling
2. Timing of data collection
3. Methods

3.1 Sampling

It is important to design an inclusive strategy that will ensure an adequate sample size and one that is representative of all those who use the health care service. Evidence indicates that response rates vary among different groups. Those who fail to respond to surveys tend to be young¹, poor, and uneducated (Kalucy et al. 2009). Other groups also under-represented include CALD communities and people with disabilities. To avoid sampling bias, it is necessary to design collection methods that encourage these under-represented groups to provide feedback.

It is important to ensure patient feedback is collected on an ongoing basis from a representative sample of patients, including disadvantaged groups (Brown et al.

2009). It is also important that a sample includes patients with sufficient experience with a health care service to be able to comment.

3.2 Timing of data collection

The timing of data collection is critical to ensure organisations use feedback effectively (Brown et al. 2009). Feedback collected at different times will potentially provide different responses.

3.2.1 Annual

In Australia and overseas, measurements of patients' experiences rely on national surveys. These national surveys often occur annually (e.g. ABS Patient Experience Survey; Victorian Patient Satisfaction Monitor) or biannually (The Menzies Now Australian Health Survey). Data are available infrequently.

3.2.2 Real-time

Real time feedback refers to collecting data from patients soon after they used a health care services. Increasingly, organisations are designing real-time patient feedback systems. Brown et al. (2009) claim that real-time patient feedback provides organisations with an opportunity to increase their responsiveness to service users. According to Brown et al. (2009), the 'fresher' the information, the more effective it can be.

Foot and Cornwell (2010) argue that managers and clinical teams should monitor quality of care as often as they monitor budgets. They need relevant, accurate, timely, frequent information from patients to make improvements and compare their own services with others. This requires access to real time or 'near real time' feedback, based on standard questions, with demographic information to allow for assessment of population mix, and subsequent case mix adjustment (Foot and Cornwell 2010).

Real time data may cultivate a greater sense of staff ownership; a greater sense of dialogue between staff and

¹ People under 18 are often not included in sample.

patients; and foster a greater interest in the consistency of the quality of services across an organisation (Robert et al. 2011). However, Robert et al. (2011) argue that real time data typically focus on 'snapshots' of individual experiences of care and do not reflect the wider context around such episodes.

There are a range of products, such as hand-held devices and touch screen kiosks that collect real-time feedback. Patients' feedback using these products has limitations, not least because they can only gather responses to 'what' questions. The 'why' and 'how' questions require face-to-face methods to better understand the experience of the person. In addition, real time data collection often does not consider sampling and can be unrepresentative (e.g. likely to exclude older people).

3.3 Methods

A number of different methods have been used to measure patients' experiences, dividing broadly into qualitative and quantitative methodologies. Both methodologies are useful but for different purposes. Surveys may provide information about what is important to patients (Malus et al. 2011) but they do not indicate why it is important. Surveys do not provide nuanced understandings of people's experiences of health care services.

Increasingly, mixed methods are being used, such as using both postal, phone and online surveys. The key to effective data collection is to use multiple methods and data sources, to enhance representation and therefore the validity of research findings.

3.3.1 Quantitative methods

This section discusses a range of different quantitative methods including:

- Self-administered postal surveys
- Telephone surveys
- Online ratings and surveys
- Real time surveys (e.g. hand held devices, touch screen kiosks)

3.3.1.1. Self-administered postal surveys

Postal surveys are convenient and generally user-friendly, depending on the survey's length and complexity. Postal surveys are favoured by certain groups of the population, such as older people and those with lower educational standards. Anonymous self-administered postal surveys can result in higher reporting of a practitioner's undesirable behaviour than face-to-face methods.

It is possible to obtain large volumes of quantitative data through the use of postal surveys. The average response rate of postal surveys (with multiple reminders)

is 38%. This response rate is below the minimum that is recommended for epidemiological studies (Hush et al. 2010).

3.3.1.2 Telephone surveys

Both interviewer-assisted and computer-assisted telephone surveys are used to administer surveys that collect patients' feedback. Computer-assisted telephone interviewing (CATI) is a technique in which the interviewer follows a script provided by a software application. This method is used for large research studies. The ABS Patient Experience Survey and the Australian Health Survey, for example, both used CATI. Telephone surveys with CATI are usually shorter than traditional telephone interviews. Unlike interviewer-assisted telephone interviews, CATI do not give participants an opportunity to provide detailed responses, nor often enough time to provide well considered answers.

3.3.1.3 Online ratings

Increasingly, Internet sites provide opportunities for patients to rate their practitioners. Greaves et al. (2012) claim that patients now rate their family doctors on the Internet in the same way as they might rate a hotel on TripAdvisor or a seller on eBay. There are also web-based assessment tools such as Global Rating Scale (GRS) that makes a series of statements requiring users to answer 'yes' or 'no'. From the answers, a health care service's GRS score is automatically calculated. The GRS is used by health services to assess how well they provide patient-centred services (Sint Nicolaas et al. 2012).

Both Greaves et al. (2012) and Lopez (2012) claim that findings from Internet and traditional paper based survey measures of patients' experiences are similar. However, Greaves et al. (2012) note that unsolicited web based ratings (and comments) are often anonymous, making it impossible for case mix adjustments.

Rozenblum and Bates (2013) argue that people using website ratings may be more extreme (positive or negative) in their views, and be younger than the general population. Also, they argue 'gaming' may occur in which providers or their representatives give favourable ratings to boost the ratings of the health care service.

3.3.1.4 Online surveys

Online surveys are increasingly being used to assess the quality of health care from patients' perspective. Zuidgeest et al. (2011) argue that the potential benefits of online surveys (e.g. reduced effort, quick and lower costs) should be balanced against potential weaknesses (e.g. low response rates and lack of accessibility for those without the Internet). People who use the Internet are

more affluent, better educated, more often male, and younger than people who do not use Internet (Zuidgeest et al. 2011).

Self-administered online surveys have the same advantage as paper surveys in that they avoid the moderating effects of an interviewer's presence, and may therefore result in more truthful responses to sensitive questions than personal interviews. In their study, Martino et al. (2012) found that a one-page letter, signed by the chief medical officer, emphasising the importance of the online survey, and a brief phone call reminder improved the response rate to an online survey.

In populations that already use the Internet, online surveys have been found to be a useful means of conducting research. They have shorter response times than postal surveys and some online surveys have shown much higher response rates than postal surveys (Zuidgeest et al. 2011).

3.3.1.5 Real time surveys

Surveys on handheld devices

Personal hand held devices are being used to collect real time data from patients about their experiences, mostly in hospital. Eastern Health, for example, has implemented a new device that provides instant feedback from patients during their hospital stay (Hendry and Gatehouse 2013; Gatehouse 2011). The Patient Experience Tracker System (PETS) records responses from patients about their experience, including treatment from staff, involvement in their own care and communication. PETS is part of Eastern Health's 'In the Patient's Shoes' strategy, which promotes the need for staff to use patient feedback to inform and improve the way they provide care.

Robert et al. (2011) questioned the accessibility and utility of the hand-held devices. Older patients and those for whom English is not their first language found these devices difficult to use. They also expressed some concerns that these devices were given mostly to friendlier and more cooperative patients. Some health care services had tested hand-held devices, abandoned them and moved on to other methods. Others continued to find them useful (Robert et al. 2011).

Touch-screen kiosks

Dirocco and Day (2011) examined the feasibility of collecting feedback from patients at the point of care using touch screen kiosk technology. They argue that kiosks are an important advance, however participants self-select which causes a sample bias.

3.3.1.6 Mixed quantitative methods

Combining an online survey with a traditional paper follow-up survey is being used as an alternative to a postal survey (Zuidgeest et al. 2011). Patients then have a choice of completing the survey online or as a paper survey (e.g. Victorian Patient Satisfaction Monitor 2012). To encourage patients to complete the Victorian Patient Satisfaction Monitor, patients who had not returned the paper survey or completed the survey online within two weeks were forwarded a reminder letter. The most recent Victorian Patient Satisfaction Monitor had a response rate of 38%, with 8% completing the survey online (2012).

Zuidgeest et al. (2011) argue that a mixed-mode survey (both paper and online survey) should be used rather than just an Internet survey or just a postal survey. They found that combining an Internet survey with a paper follow-up survey was less expensive than a postal survey. This mixed method also overcame the problems associated with online surveys such as the possible exclusion of the elderly and less educated.

3.3.2 Qualitative methods

There are a wide variety of qualitative methods used to explore patients' experiences. The most common qualitative methods cited in the literature are:

- Complaints and compliments
- Open-ended questionnaires
- Face-to-face interviews
- Telephone interviews
- Focus groups
- Web based comments
- Narrative methods
- Patient journeys
- Patient co-design

3.3.2.1 Letters, compliments and complaints

Patients generally write letters, comments and feedback cards when they receive exceptionally good or bad care. Complaints and compliments represent both ends of the spectrum. They are not a proactive method of learning systematically about patients' experiences to improve service delivery – they rely on patients making the effort to make the complaint/compliment (Kalucy et al. 2009). Nonetheless, complaints and compliments can play an important role in evaluating the quality in a health care setting.

Robert et al. (2011) argue that more meaningful analysis of complaints is needed. They argue that complaints are typically not collated or analysed at local or national levels in a way that is useful for quality improvement.

3.3.2.2 Open-ended questionnaires

Coulter (2006) argues that well designed questionnaires for patients could contribute usefully to an assessment of both the technical competence and interpersonal skills of practitioners. Rather than asking patients to rate their care using general evaluation categories (e.g. excellent, very good, good, fair, poor), Coulter suggests asking them to report in detail on their experiences of clinical care during a particular consultation. These types of open-ended questions are designed to elicit reports on what actually occurred, and how patients felt about what happened (Coulter 2006).

3.3.2.3 Face-to-face interviews

Face-to-face methods are perhaps the most inclusive method, though do not generate large numbers. They are effective for gathering feedback and for following up on any issues, either clinical or social. However, face-to-face methods are time consuming and can cost a considerable amount to administer.

Patients are known to like being followed up – they appreciate having someone check up on them (Cochran et al. 2012). However, follow up interviews can alter the results by enhancing patient satisfaction and feelings about continuity of care (Cochran et al. 2012).

Face-to-face surveys can be an extremely rich source of data; however the moderating effect an interviewer's presence can have on responses needs to be taken into account. Studies have shown that some people are reluctant to express concerns openly in face-to-face interviews because they anticipate defensive or hostile reactions from staff or fear an adverse impact on their future care (Entwistle et al. 2003).

3.3.2.4 Telephone interviews

There is a distinction between (1) telephone interviews in which respondents are picked randomly; (2) telephone interviews that are pre-arranged with the respondent; or (3) telephone interviews that the respondent expects a follow-up call at some point after an episode of care. Response rates are likely to be higher when patients expect to receive a call. When people are contacted opportunistically, telephone interviewing may be viewed as intrusive.

Similar to face-to-face interviews, the presence of an interviewer may produce 'moderating results' in people's responses. They can also enhance patient satisfaction and feelings about continuity of care.

3.3.2.5 Focus groups

Focus groups are used as a stand-alone method to explore patients' experiences or as a precursor to a questionnaire or survey. Mavaddat (2009) used focus groups as the initial information-gathering phase. These focus groups assisted in the development of a questionnaire that assessed patients' views of the quality of primary care mental health care services (Mavaddat 2009). Malterud and Ulriksen (2010), on the other hand, used a focus group to explore obese patients' experiences with GPs. They purposefully selected patients to participate in these focus groups.

3.3.2.6 Web based comments

Internet sites provide opportunities for patients to document their experiences. Some examples of websites include 'NHS choices', 'I want Great Care' and 'Patient Opinion'. Patient Opinion began in UK in 2005 and is funded by hospitals that subscribe to access the data. The site allows people to give anonymous online comments about their experiences of hospital services. Other consumers can then read these comments. The NHS also collects and shares case studies on the Patient Experience Network website. The aim of the Patient Experience Network is to share ideas to drive improvement in patients' experiences.

Rozenblum and Bates (2013) describe patient-centred healthcare, social media² and the Internet coming together as the 'perfect storm'. They argue that the Internet and social media have the potential to create a major shift in how patients and healthcare organisations connect.

Greaves et al. (2013) suggest descriptions of patients' experiences on social networks, blogs, Twitter and hospital review sites should be collected and analysed as a tool for continuous service monitoring. They argue that this data could detect institutional poor performance immediately, and in a valid and consistent way – in fact, social media could detect poor performance before conventional measures of healthcare quality (e.g. annual surveys). They claim that social media could capture information on a daily basis and at low cost.

Greaves et al. (2013) claim that anywhere people talk about their experience of health care online is a potential source of information (e.g. social networks, Twitter, Facebook, discussion fora and rating websites). However, to use data from the Internet and social media is a complex task. It requires harvesting free text and then processing this data into useful information (Greaves et al. 2013). The process involves identification of appropriate websites, and then 'scraping' – that is, pulling relevant information

² A search on Facebook found pages for Primary Health Care in both Qatar and Nigeria in which service users made comments about their health care experiences.

off websites on a regular, automated basis using specialised software and then using algorithmic processes such as natural language processing (Greaves et al. 2013).

Lyles and Sarkar (2013) agree that social media provides a new way to engage in a dialogue with patients. However, they recommend traditional qualitative analysis rather than 'big data' analytical techniques such as natural language processing. They argue that natural language processing may miss the nuances in patients' experiences (Lyle et al. 2013).

Rozenblum and Bates (2013) claim that using the Internet and social media to share health care experiences is valuable for those patients who use these platforms, but question the value of this data for health care organisations. Rozenblum and Bates (2013) argue that approaches that use social media have many potential biases because they do not come from representative segments of the population. They also warn that social media can be gamed.

3.3.2.7 Narrative methods?

Narrative methods involve interviewing patients about a particular encounter with a health service. This method allows patients to identify incidents or points in the patient journey that have had a significant impact on the patient. With narrative methods, the researcher can explore personal experiences beyond the boundaries of a questionnaire. Narrative methods have the potential to provide insights into various health practices that can help guide the provision of effective healthcare services (Hsu and McCormack 2010).

Narrative methods can elicit detailed information that can be used for quality improvement for specific aspects of service provision. They give an actual representation of whether best practice standards are met, or organisational policies and procedures followed, without being constrained by a survey. However, the number of patients interviewed is small, as the one-on-one interview method is a time consuming process for gathering information. Also, researcher characteristics, including respect, understanding, and acceptance, are key attributes of success in conducting narrative work, particularly with older people (Hsu and McCormack 2010).

According to Robert et al. (2011) patients' stories create a sense of ownership and motivate staff to find solutions to problems (Robert et al. 2011). However, a small sample size has the potential for organisations to contest the results in the event of poor findings as the findings could be argued to be unrepresentative.

Both Tsianakas et al. (2012) and Petroz et al. (2011) compared surveys and patient narratives. In Petroz et al.'s (2011) study, participants noted that the Likert-scale

approach required them to aggregate their feedback rather than share their individual stories and perceptions when evaluating care. Tsianakas et al. (2012) found survey data helpful as a screening tool to identify potential problems within the breast cancer service, but did not provide sufficient detail of how to improve the service. Tsianakas et al. (2012) recommend future studies use survey and open-ended questions.

Narrative methods are different from traditional audit processes. Traditional audits test whether a policy or procedure exists in an organisation. Narrative methods describe how policy or procedure is actually enacted.

3.3.2.8 Patients' Journeys

Jackson et al. (2012) argue that it is important to document patients' journeys across program and organisational boundaries. Patient stories can inform strategies to improve and integrate health care services. Integration has been identified as having potential to address many current issues in health care such as access, continuity of care and quality (Jackson et al. 2012). Their study, for example found patients had concerns about health care system integration such as: (1) system navigation, (2) access and (3) social support.

Sample sizes for patients' journeys are often extremely small. Jackson et al.'s (2012) study followed only four (4) patients with chronic obstructive pulmonary disease. These four patients were followed for three months following discharge from hospital. During this period, three (3) interviews were conducted with each participant. In addition, participants were invited to document their contacts with health care services in a log. The logs provided information such as date, type of contact (phone or visit), practitioner contacted, reason for contact, contact outcome, and other comments deemed relevant by each participant. Jackson et al. (2012) found these logs an important addition to the interview process because they "enabled participants to tell their stories effortlessly" (p230).

Jackson et al. (2012) also used the logs to develop maps that visually depicted each participant's journey. These visual representations highlighted how many appointments and how many different providers each participant encountered as well as the timing of each.

The patient journey methodology has been considered for accreditation and auditing processes. The Australian Commission on Safety and Quality in Health Care, for example, has recently suggested using patient journey interviews to complement traditional auditing processes for health care organisations³. The Australian Council of Healthcare Standards are currently using face-to-face surveys in the Patient journey surveys⁴.

According to Greenfield et al. (2012), there is little empirical evidence to support using patient journey methodology for accreditation. Their study compared patient journey surveys with the current accreditation survey. They concluded the patient journey surveys complement traditional methods of accreditation. They suggest further research is required to calculate the costs and benefits of including patient journey surveys within accreditation programs.

3.3.2.9 Patient co-design

Drawing on concepts from the design sciences, experience-based co-design (EBCD) focuses on how staff and patients move through and interact with different parts of a service. EBCD is a form of participatory action research that seeks to capture and understand how people experience a process or service. Patients and staff share their respective experiences, identify and agree on improvement priorities and work together to achieve them. In Tsianakas et al.'s (2012) study, fieldwork involved 36 filmed narrative patient interviews, 219 hours of ethnographic observation, 63 staff interviews (receptionists, nurses, doctors) and a facilitated co-design change process involving patient and staff interviewees over a 12-month period.

3.3.3 Mixed methods

Qualitative data (from complaints, patient stories, focus groups, social media and observations) can be used with quantitative data on clinical quality, activity, costs and staff experience. This data can be presented in a way that tells a story: about whether and how the quality of experience is changing over time; whether it is reliable across the organisation; and how it compares with the quality of services in other organisations (Robert et al. 2011).

Key messages from Section 3

1. There are important technical issues involved in collecting data, including the numbers needed to obtain reliable results, the timing of the data collection and the way in which responses vary within different population groups.
2. Qualitative and quantitative methodologies are used for different purposes.
3. No single method of collecting feedback will reach every group within the community.
4. An inclusive strategy will involve a number of different methods. ❖

3 Interestingly, the RACGP has endorsed The Practice Accreditation and Improvement Survey (PAIS) to obtain patient satisfaction data (not patient experience) for accreditation purposes. PAIS is an exit-survey that is administered by the receptionist to a number of consecutive patients. The questionnaire contains 27 items that are rated by patients. It takes about 3-5 minutes to complete. Results from patient responses are aggregated and presented in graphic format to the practice according to various patient characteristics such as gender and number of previous visits. The survey has been designed by CFEP, and the literature to support the survey (cited on the webpage) was published 12 years ago.

4 <http://www.safetyandquality.gov.au/our-work/clinical-communications/patient-clinician-communication/>

4

Survey instruments

In recent years, there has been a proliferation of different instruments/tools that describe, measure or compare patients' experiences. These tools use different approaches, formats and questions to measure similar attributes. Robert et al.'s (2011) report did not include a list of the different tools that have been used because the list was too long – the list extended to 98 pages. Although many tools ask similar questions, the wording of the questions are different (Robert et al. 2011).

Systematic reviews highlight the large number of different tools used to measure patients' satisfaction and experiences. For example, Adler et al.'s (2010) systematic review included 12 studies with 9 different satisfaction measures. The large number of different tools makes it difficult to compare findings. This explains, in part, why so few studies are eligible for inclusion in systematic reviews. In Hush et al.'s (2011) systematic review of patients' satisfaction with muscular skeletal therapy, their search located 3,790 citations. However, only 15 studies met the inclusion criteria (0.4%). Similarly, Hudon et al.'s (2011) systematic review of patients' perceptions of patient-centred care located 3,045 articles with 26 meeting the inclusion criteria (0.8%) and Ridd et al.'s (2009) systematic review of doctor-patient relationship found 1985 abstracts of which 11 studies were included (0.5%).

Although there is a plethora of data, it is often difficult to make sense of this data because different surveys ask different questions. Without standardised surveys, it is impossible to compare findings with other health services, or often even within the same service over time.

Picker Institute Europe pioneered measuring patients' experiences of health care. Picker produces a series of survey tools that have become the foundation of many surveys 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

In USA, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) provides a nationally standardised, validated tool to measure patients' experiences in primary health care practices. The CAHPS surveys have been validated and are readily available at no charge in the public domain. Additional question can be added to the core survey (Browne et al. 2010). Patients are asked to assess their experiences in areas that research has shown patients value such as:

- Ease of scheduling appointments
- Availability of information
- Communication with clinicians
- Responsiveness of clinic staff
- Coordination between health care providers.

According to Kalucy et al. (2009), surveys of patients' experiences in Australia should cover the dimensions of care included in the Australian Charter of Healthcare Rights. These seven rights are:

- Access
- Safety
- Respect
- Communication
- Participation
- Privacy
- Ability to comment.

In addition, Kalucy et al. (2009) argue surveys of patients' experiences should cover coordinated/integrated care provision, managing transition and accountability.

Brown et al. (2009) claim that organisations choose to use different questions in different settings and for different purposes. They also claim that the questions

asked in surveys are often the wrong ones. They argue this is due to survey design which is determined by managers and/or researchers, rather than by patients. With the wrong questions, these surveys do not collect the data that is required (Brown et al. 2009).

The Doctors' Interpersonal Skills Questionnaire (DISQ)⁵ is frequently used to assess the practitioner-patient relationship. It has been used in a variety of professional contexts – hospitals, general practices and community health (Burford et al. 2012). Surveys like DISQ focus on communication, a key element of the clinical consultation (Burford et al. 2011). DISQ contains 12 items with each item answered on a five point scale - 'Poor', 'Fair', 'Good', 'Very good' and 'Excellent'. The items included are:

- Satisfaction with visit
- Warmth of greeting
- Listening skills
- Explanation skills
- Reassurance
- Confidence in ability
- Able to express concerns and fears
- Time in consultation
- Respect shown
- Patient's personal context
- Patient as a person
- Recommend doctor to a friend.

Key Messages from Section 4

1. A large number of different instruments have been used to describe, measure and compare patients' experiences.
2. Without standardised surveys, it impossible to compare findings from different studies. ❖

⁵ The DISQ is owned and operated by CFEP Surveys. It is currently being used by RACGP.

5

Key variables that determine patients' experiences

A complex mix of organisational and human factors affect patients' experiences. For example, Burford et al. (2011) suggest different patients may value different behaviours and qualities in practitioners. They also argue that communication between practitioners and patients varies with clinical contexts, and may be influenced by age and gender differences between patient and practitioner.

There is evidence that patients' experiences are influenced by their age, gender, ethnicity, educational levels, health status, expectations, disposition, social status, time since care, and previous experience (Robert et al. 2011; Haggerty 2010; The Intelligent Board 2010; Kalucy et al. 2009). However, the reasons for this are not well understood.

The finding that patients' characteristics influence their experiences raises an interesting question. Does this reflect different expectations among different types of patients? Or do different types of patients within the same health service receive different types of care? This question is particularly relevant when payments are linked to surveys findings, as in the UK. Health services located in low socioeconomic areas, for example, could be disadvantaged by loss of income (Salisbury, Wallace, Montgomery 2010).

Damman et al. (2011) argue that it is not possible to make fair comparisons of health services that use data from patients' experiences surveys without adjustments for case-mix (Damman et al. 2011). It is important to note that anonymous data, such as when people describe their experiences on websites, cannot be adjusted for case-mix.

5.1 Patient characteristics

5.1.1 Age

Numerous studies confirm that older patients provide more favourable perceptions of care than younger patients (e.g. Lyratzopoulos et al. 2012; Addink et al. 2011; Kontopantelis et al. 2010; Mead and Roland 2009). Addink et al. (2011), for

example, found young people reported the lowest levels of satisfaction and experience of access to GPs.

5.1.2 Gender

Stenberg et al. (2012) concluded that gender affected both expectations and experiences, however their analysis however did not involve gender per se. Their assumption that "confident" type is more often male and "ambiguous" type more often female is arguable.

Hush et al. (2010) found female patients reported slightly higher satisfaction than male patients. They suggest that this difference may be due to different determinants of satisfaction – for example, female patients focus on communication while male patients focus on treatment outcomes (Hush et al. 2010).

The important finding from studies that analysed gender is that the differences in patients' experiences associated with gender are small (Lyratzopoulos et al. 2012; Stenberg et al. 2012; Hush et al. 2010).

5.1.3 Ethnicity

Lyratzopoulos et al. (2012) found Asian patients reported a less positive primary care experience than white patients. The large number of Asians who live in low socioeconomic areas and attend services that receive low scores on patients' experiences surveys can, in part, explain this finding. However, Lyratzopoulos et al. (2012) also found that Asians reported less positive experiences of doctor-patient communication than white patients in the same practices.

5.1.4 Education

Rademakers et al. (2012) found that patients' educational levels impacted on their experiences of patient-centred care, though the impact was only small. Less educated patients regarded patient-centred care as less important than educated patients. Less educated patients reported

receiving 'too much', and more highly educated patients 'too little', in the domains of communication, information and shared decision making (Rademakers et al. 2012). It has also been observed that some patients prefer to be more involved in consultations than others (Burford et al. 2011).

5.1.5 Health status

Lyratzopoulos et al. (2012) found those in poor health reported a less positive primary care experience than those in better health. This finding is consistent with an earlier systematic review (Crow et al. 2002). This difference may be accounted for by those in poor health having a higher exposure to health care services, increasing chances of having a negative experience (Lyratzopoulos et al. 2012).

5.1.6 Work status

Addink et al. (2011) found that people working full time, or those with long commuting times to work, reported the lowest levels of satisfaction, particularly with access to GPs.

5.2 Organisational characteristics

There are also organisational characteristics that affect patients' experiences. Boyd et al. (2013) found that patients' experiences were affected by the size of health services, with larger health services scoring less than smaller ones. They found that patients' experiences of access are better in smaller health services. Boyd et al. (2013) found that patients in smaller practices were much more positive about their experiences of being able to get through on the phone, make appointments and see their preferred doctor. Other studies also show smaller practices are associated with higher satisfaction of continuity of care (Kontopantelis et al. 2010).

In addition to size of health service, research has found a relationship between staff wellbeing and patient experiences, though this relationship is complex (Maben et al. 2012; Szecsenyi 2011). Szecsenyi (2011) found a correlation between doctor's job satisfaction and patients' satisfaction. Not surprisingly, people who enjoy their jobs provide a better quality of care.

Kalucy et al. (2009) also notes the importance of staff morale and professional attitudes as factors that affect patients' experiences. Other organisational factors that impact on patients' experiences include division of labour, clarity over job boundaries, policies and procedures and stability of staffing (Kalucy et al. 2009).

Key messages from Section 5

1. There is evidence that patients' experiences are influenced by sociodemographic factors (e.g. age, education, ethnicity)
2. To make comparisons of health services, data from patients' experiences surveys need to be adjusted for case-mix.
3. Organisational factors may also affect patients' experiences. ❖

6

Purpose of patients' feedback

Draper and Hill (2005) argue that articulating the purpose of patients' feedback is a critical first step. However, Edwards et al. (2011) suggest that the purpose of patients' experiences surveys remains unclear. It is not clear whether surveys are intended to evaluate the individual practitioner, organisation or the entire health care system (Edwards et al. 2011).

Kalucy et al. (2009) suggest that information about patients' experiences can be used in many different ways – 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. They recognise that patients' experiences often involve more than one health care service (Kalucy et al. 2009).

The next section describes the different reasons for collecting patient feedback that are cited in the literature. These reasons are:

1. Provide information
2. Measure the quality of a health service
3. Improve quality of health care
4. Change professional practice
5. Evaluate innovations
6. Improve quality of specific interventions
7. Compare health services
8. Measure coordination of care
9. Rate GP practices
10. To improve patients' compliance

6.1 Provide information

Kalucy et al. (2009) claim information about patients' experiences can highlight aspects of a particular health care service that are important to those who use it. They also claim that patients' experiences can inform governments about how adequately the health care system is meeting the needs of the population.

This raises the question about how health care services, and indeed governments, respond when patients' experiences data informs them that the health care service (or system) is not meeting the needs of its population.

Brown et al. (2009) argue that the exercise of collecting feedback, and discussing the findings at meetings is only as good as the action that comes out of it. However, when tabling findings of patients' experiences surveys at meetings, the minuted action is often to make a record of the report but to take no further action (Robert et al. 2011). The numerous reports on patients' experiences provide information, but not action. Robert et al. (2011) claim that examples in which patient experience data is used to spark debate and action in meetings are rare.

6.2 Measure quality of health care services

What constitutes quality of a health care service, and how to measure it, is the subject of ongoing debate (Gardner and Mazza 2012). Although there are varying definitions of quality in health care, most definitions now include patients' experiences. According to Kalucy et al. (2009 p1), without systematic ways of collecting information about patients' experiences of the health care system, a "vital perspective" is missing from efforts to improve the quality of care.

It is arguable whether patients' experiences are a reliable indicator of quality. Salisbury, Wallace and Montgomery (2010), for example, suggest that it is difficult to know whether patients' experiences reflect differences between quality of practices, performance of practitioners, or variations between patients themselves. In addition, Rao et al. (2006) concluded that patients' experiences are not a useful measure of the quality of care, as patients' experiences are only weakly related to technical and clinical indicators of good care.

Despite these reservations, patients' satisfaction and experiences are increasingly being used as an indicator of the quality of a health care service. Other indicators

include clinical effectiveness and safety. Raleigh and Frosini (2012) argue these three indicators – clinical effectiveness, safety and patients' experiences – are closely related and should be examined together. However, patient experience data are typically collected and reported on separately from data on clinical effectiveness and patient safety⁶. As a result, patient experience indicators are sometimes considered as remote adjuncts to clinical work. Both Raleigh and Frosini (2012) and The Intelligent Board (2010) recommend that patients' experiences become an integral component of quality assessments, "not an additional silo" (The Intelligent Board 2010, p11).

Robert et al. (2011) argue that improving patients' experiences does not have the same status or value as improving clinical effectiveness and patient safety. They argue that health care organisations require the same level of skill in data collation, analysis and interpretation to monitor patients' experiences as they do to monitor clinical quality, service activity and financial budgets. Health care organisations need to ensure that (1) sufficient resources are allocated to collate and analyse patient feedback; (2) the data are robust; and (3) organisations have the necessary skills in data analysis, including qualitative analysis (Shared Intelligence, 2010).

Interestingly, Raleigh and Frosini (2012) found that health care services that delivered better experiences for patients generally also performed better on clinical quality in terms of both process and outcome measures. Although their analysis did not demonstrate a causal link, they found higher standards of clinical quality were more strongly associated with functional, rather than relational domains of patients' experiences (Raleigh and Frosini 2012).

6.3 Improve quality of health care

Health care organisations focus on collecting data rather than using data to improve service quality (Robert et al. 2011). Kalucy et al. (2009) suggest that measuring patients' experiences should inform continuous improvement activities. UK's recent GP Patient Survey suggests that this is not the case. The GP Patient Survey added five dimensions of access: (1) getting through on the phone to a practice; (2) getting an early appointment; (3) getting an advance appointment; (4) making an appointment with a particular doctor; and (5) practice's opening hours. Despite all the additional data on access, Addink et al. (2011) found this data did not improve access.

⁶ There are some exceptions. Kings College Hospital in UK, for example, triangulate data from different sources to help them make sense of the quality of patient experience. Patients' experience data is shown alongside clinical and financial and activity data in an integrated performance report for all clinical directorates. The experience data is based on patient exit survey at discharge, comments cards, complaints data and national survey results.

There is an implicit assumption that the results of patient surveys will lead to an improvement in the quality of health care. However, the mechanism for how information about patients' experiences will improve quality remains unspecified (Edwards et al. 2011). According to Davies (2011) little is known about how such feedback can be used to improve patient-centered care.

Clearly, measuring patients' experiences does not in itself improve the quality of care, but it is a critical step. The information can reveal system problems – such as gaps in coordination and communication problems. Although collecting the information is essential, using the information for improvement is the goal (Browne et al. 2010).

In some countries, the results of patients' experiences are beginning to be used to inform quality improvement processes (Edwards et al. 2011). The UK is the most advanced country in this respect, with data on patients' experiences informing multiple mechanisms. These mechanisms include: annual public service agreements, pay for performance schemes and provider accountability. In the UK, for example, patient feedback has become a significant policy driver, particularly for public hospitals and general practices. In 2000, The British government announced its intentions to move patient experience to the centre of health policy. In response to this announcement, The Quality and Outcomes Framework (QOF) was developed. Patient experience is a key domain within the QOF (together with clinical measures).

6.4 Change professional practice

Despite the prevalence of feedback as a quality improvement strategy, there is little evidence that healthcare professionals modify their practice when given performance feedback. A systematic review concluded that the effectiveness of feedback depends, in part, on how the feedback is provided (Ivers et al. 2012). Simply giving practitioners the results of patients' feedback has not been effective for instigating change (Coulter 2006).

A systematic review of multi-source feedback, which includes patient feedback, concluded that the evidence that patient feedback has a positive effect on practice change is inconclusive (Miller and Archer 2010). Another systematic review concluded that feedback generally leads to small but potentially important changes in professional practice (Ivers et al. 2012). The effectiveness of feedback depends to some extent on who is surveyed and how the results are disseminated. Ivers et al. (2012) recommend future studies should compare different ways of providing feedback.

Clearly, simply carrying out a survey will not change practice. It is also clear that feedback on its own does not improve professional practice (Roland 2012). It is important that staff receive the results of surveys and opportunities to use this information. In addition, feedback that lacks credibility, contradicts prior knowledge, or is experienced as a threat at the individual level, is unlikely to be effective (Asprey et al. 2013).

Several barriers to using patient survey results to improve practice have been identified in the literature. These barriers are individual, organisational and systemic.

6.4.1 Individual barriers

Some practitioners question the validity of patient surveys. A systematic review noted practitioners were concerned about surveys' low response rates and questioned the representativeness of the sample (Asprey et al. 2013). Practitioners also felt that surveys failed to address some salient issues, and the results provided insufficient detail to facilitate change. There was also some unease about the influence of political influences underpinning the introduction and use of patient surveys (Asprey et al. 2013).

Some practitioners question patients' ability to accurately measure quality of care (Manary et al. 2013; Mold et al. 2012). Mold et al. (2012) suggest that clinical quality and patients' experiences are distinct but related domains that require separate evaluation measures. Roland (2012) agrees that patients are not able to judge technical aspects of care. They suggest using medical records, not patients' experiences, to evaluate technical aspects of care. They argue that patients' judgments of practitioners' technical competence are heavily influenced by the quality of communication during the consultation.

Edwards et al. (2011) noted a tension between GPs satisfying patients and providing good health care. Worth (2013) argues that patients tend to focus on issues such as personality, communication, waiting times, whether the practice offers sufficient parking and quality of magazines in the waiting room (Worth 2013). Worth (2013) argues that correcting minor problems such as the provision of parking spaces and up-to-date magazines can improve patients' satisfaction, but it does not impact on the quality of health care that is delivered, or indeed patients' health outcomes.

Heje et al. (2011) argues that any changes in professional practice based on patients' feedback requires the practitioner to be sensitive to patients' opinions and motivated to change. A follow-up survey of practitioners working in paediatric departments, for example, found practitioners were positive about a parent experience survey (Iversen et al. 2010). Based on this study, Iversen et

al. (2010) claim that patient surveys have a potential to be actively used in quality improvement actions, though it is noteworthy that the survey used in their study involved parents, not patients.

Finally, practitioners without training in statistical methods may have difficulty interpreting survey results. In addition, the numeric scores given to complex interactions between patients and practitioners are often considered to be simplistic. Roland et al. (2009) questioned the validity of using simplistic scores from patients' experiences surveys to determine payments to GPs⁷.

6.4.2 Organisational barriers

Organisational barriers that prevent patients' feedback from being used to improve practice include insufficient time for clinical teams to discuss survey results, lack of resources for educational programs and delays in disseminating these results (Brown et al. 2009; Reeves and Secombe 2008). Brown et al. (2009) claim that feedback is more effective when the findings are disseminated together with educational programs.

Another organisational barrier concerns the way data is presented to services – results are often aggregated and therefore lack relevance to specific services within the organisation. Although most findings are given anonymously, Edwards et al. (2011) note the potentially destructive effects of feedback if an individual practitioner feels it is directed at her/him. Burford et al. (2011) also notes the inappropriate use of feedback, both inadvertent and deliberate.

6.4.3 Systemic barriers

Systemic issues include the low priority given to using survey results within the health care system as evidenced by the lack of resources to facilitate changes (Reeves and Secombe 2008). Suggested ways of improving the use of survey findings include a systematic approach to quality improvement; giving survey results higher weightings in the performance management system; leadership by senior members of the organisation; organisational support for leaders in quality improvement; and training staff in quality improvement methods (Reeves and Secombe 2008).

Disseminating detailed information about survey results to health care services – as opposed to aggregated 'report cards' – is an important factor in the success of patient survey programs (Reeves and Secombe 2008). In addition, staff appreciate receiving feedback in the patients' own words as this makes the comments seem more 'real' to them (Brown et al. 2009).

⁷ The UK payment link was removed in 2011.

6.5 Evaluate innovations

Surveys of patients' satisfaction and experiences have been used to evaluate innovations within a health care service. De Leon et al. (2012), for example, assessed patients' satisfaction and experiences before and after electronic health records were implemented in primary health care practices. Not surprisingly (given that patients are generally satisfied with the health care they receive), they found that patients were satisfied both before and after the innovation. De Leon et al. (2012) found that electronic health records improved communication between patients and the health service, but only for those with email access. Those who did not use the Internet did not benefit from the innovation – but they remained satisfied with their health care.

6.6 Improve the quality of specific interventions

The most commonly researched intervention is communication during the patient-practitioner consultation. Patients are frequently asked to describe, measure, evaluate their experience of consultations, mostly with GPs though occasionally with other practitioners. Hancock et al. (2012), for example, explored patients' experiences of dietetic consultations. Their aim was to improve consultations by understanding patients' experiences of consultations. Patients were invited to discuss their experience of the consultation with a research dietitian who was not involved in their care. Like most qualitative studies the sample was small (17 participants). They found that certain factors, such as good communication and rapport, receiving effective and reliable information and resources, and nonjudgmental, regular support, were important factors in creating a positive experience of their consultation. The interesting finding is that participants had different opinions about what constituted these factors. The latter finding would have been missed on a survey.

6.7 Compare health services

In addition to the research literature, there are also numerous public reports of patients' experiences. For example, the results of the USA's 'Hospital Consumer Assessment of Healthcare Providers and Systems' (HCAHPS) are used to compare hospitals. Similarly, the English National GP Patient Survey compares general practices.

The results of both surveys are available to the general public though practitioners are more likely than patients to access surveys results (Fung et al. 2008). Browne et al. (2010) and Fung et al. (2008) found that

making the results available to the public resulted in small improvements in doctors' performance. It has been suggested that practitioners take notice when they are publicly compared with their peers (Fung et al. 2008).

6.8 Measure coordination of care

Rather than only measuring patients' experiences of individual health services, Robert and Cornwell (2011) suggest also measuring patients' experiences during transitions between services. According to Burges et al. (2010) measurements of coordination of care rely on feedback from patients. Robert and Cornwell (2011) suggest that the long-term aim is to develop 'Patient Experience Indicators' focused on individual journeys rather than measurements in organisational silos.

A number of standardised surveys have begun to include items on care coordination. Not surprisingly, findings from these surveys show that individuals with multiple chronic conditions are more likely than others to experience problems with coordination of care and lower quality of care. Burges et al. (2010) argue that this finding has implications for incentive programs, such as those in UK. It may inadvertently discourage physicians from providing care to patients with multiple conditions (Burges et al. 2010).

6.9 Rate health care services

Patients' responses to the UK's GP Patient Survey are used to give GP practices a score. The rating amalgamates findings on areas such as convenience in securing an appointment; length of time patients have to spend waiting in reception; opening hours; and skill of doctors and nurses at explaining things and listening to patients (O'Dowd 2012).

Doctor rating websites are a burgeoning trend. Lopez (2012) found the majority of Internet reviews of primary care physicians are positive in nature. Their findings reaffirm that the health care encounter extends beyond the doctor-patient dyad – several other factors, all of which have been previously noted in earlier studies (e.g. access, and convenience), affect patients' reviews of practitioners.

6.10 Improve compliance

A correlation between patients' experiences and treatment compliance has been identified. For example, Alami et al. (2011) found that a negative experience with an orthopedic surgeon led to decreased compliance with medical treatment and an increased likelihood of seeking alternative therapies. Similarly, Saatci et al. (2010) found patients' satisfaction was significantly associated to their glycemic control and compliance to diet and physical

exercise in patients with diabetes. These studies, and others, show that patients' experiences have a strong relationship to patients' compliance (Browne et al. 2010). The better patients' experiences, the more likely patients will comply.

Key messages from Section 6

1. The purpose of patient experience surveys is rarely clearly articulated.
2. Most definitions of health care quality now including patients' experiences.
3. Clinical effectiveness, safety and patients' experiences are measurements of quality and should be examined together.
4. The barriers to using patient survey results to improve practice are individual, organisational and systemic.
5. There is a correlation between patients' experiences and treatment compliance.
6. Rather than only measuring patients' experiences of individual health services, patients' experiences during transitions between services should also be measured. ❖

What we know about patients' experiences of primary care

7

Most studies measure inpatients' satisfaction of hospitals. However, Robert et al. (2011) claim that some findings from these studies are relevant to other areas of health care such as primary care. They claim that we know what matters to patients. For example, what matters to patients in primary care settings is:

- An efficient appointment system
- Friendly and supportive staff (particularly receptionists)
- Feeling 'listened to'/included in care

Robert et al. (2011) claim that there is evidence about the generic themes that matters to patients in both acute and non-acute settings. These generic themes are:

- Good information provision
- Having confidence in health professionals
- Awareness and understanding of specific health condition
- The right treatment from the right staff at the right time
- Continuity of care
- Being treated as a person
- Partnership with professionals

7.1 What studies tell us

The UK and USA are at the forefront of the research on patient reported outcomes, including patients' experiences. The UK, for example, introduced a national patient survey over 10 years ago. Since then, all NHS trusts have been required to survey a sample of their patients on an annual basis and report the results to the Healthcare Commission.

Studies undertaken to measure patients' perspective can be classified as:

1. International
2. National
3. Local

In addition, many local studies focus on a specific health care sector (hospital, GP clinic, primary health care site) or a specific illness.

7.1.1 International studies

The Commonwealth Fund surveys people in countries such as Australia, Canada, New Zealand, the United Kingdom, and the United States about their experiences of primary health care services (Schoen et al. 2011; 2009; 2004). The data can only be used for international comparison not individual health care services. The Commonwealth Fund survey closely aligns with Picker Patient Experience Survey. It measures:

- 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.

7.1.2 National and regional studies

For over a decade, both the UK and USA have collected national data on patients' experiences. The annual GP Patient Survey compares GP practices in UK; the 'Hospital Consumer Assessment of Healthcare Providers and Systems' (HCAHPS) in USA provides comparisons of hospitals locally, regionally and nationally. However, until recently, Australia did not have systematic arrangements for measuring and monitoring patients' experiences at the national level.

In 2009, the Australian Bureau of Statistics (ABS) added the Patient Experience Survey to the Multipurpose Household Survey (MPHS). The Patient Experience Survey collects national data on access and barriers to a range of health care services, including general practitioners. Prior to the ABS survey, Australia relied mostly on regional and State-based surveys that focused primarily on acute care. Some examples include:

- NSW Health's survey used the Picker tools, and the patient journey methodology⁸.
- Victoria's Department of Human Services' survey measures degree of satisfaction (but not experience) in: access and admission; treatment information; physical environment; discharge and follow up processes; overall satisfaction.
- NSW Cancer Institute's Cancer Patient Satisfaction Survey used questions from the Picker tool. This survey informs the advocacy work of the Cancer Voices consumer group.

Lyratzopoulos et al. (2011) claim that the administrative costs of large national surveys are substantial. They argue that the number of patients sampled should be the minimum necessary to provide statistically robust estimates of performance.

7.1.3 Local studies

In addition to the large national and regional studies, many health care services collect and analyse data on patients' experiences, from the perspective of a service or a single team within a service. There is evidence that data collected at the level of individual teams, and close to the time when the care was experienced, has the greatest impact on services (Marshall et al. 2012).

Robert et al. (2011) and Marshall et al. (2012) claim that collecting local data enhances a greater sense of staff ownership of the results, helps motivate staff to act on the results ("these are our patients, talking about our service") and encourages a better dialogue between staff and patients. It does not however reflect the experiences of patients as they progress through a service or along a pathway of care. Waibel et al. (2012) notes that patients may see many different types of practitioners in a variety of health services, particularly patients with chronic illnesses.

Examples of local studies include Consumer Assessment of Healthcare Provider Surveys (CAHPS) in USA and National Primary Care Trust (PCT) Survey in UK. In Australia, surveys are often undertaken at the provider

level for accreditation or audit purposes. The results from these surveys are for the sole use of the provider. Privacy laws prevent aggregating survey results to provide information at regional or higher levels (Kalucy et al. 2009).

7.1.4 Studies that focus on specific illnesses

Many surveys on patients' experiences focus on patients with a specific illness such as diabetes, back pain, multiple sclerosis, heart disease, asthma, spinal chord injuries, head injuries, infertility etc. There are also studies that focus on mental illnesses and a range of different types of cancer. The implicit assumption is that a patient's experience of a health care service depends, in part, on the nature of their illness.

7.1.5 Generic framework

Robert et al. (2011) disagree that studies should focus on specific illnesses or sectors in the health care system. They support a generic framework of 'what matters' to patients, applied across illnesses and sectors. Robert et al. (2011) argue that a generic framework can be applied to a wide range of illnesses and treatments. They suggest the Institute of Medicine and Picker frameworks are broadly appropriate for 'what matters most' to patients in both acute and non-acute sectors. They acknowledge that further work is required to confirm that this framework is also appropriate for acute mental illnesses (Robert et al. 2011).

Robert et al. (2011) argue that the most common generic themes are:

- Feeling informed and being given options
- Staff who listen and spend time with patient
- Being treated as a person, not a number
- Patient involvement in care and being able to ask questions
- The value of support services
- Efficient processes

7.2 Disseminating results of studies

Results of surveys measuring patients' experiences and satisfaction are increasingly being shared with the public via the Internet. In UK, the results of GP patient surveys are documented on numerous websites, including the NHS choices website. These websites provide people with items of the Quality and Outcomes Framework that includes patients' experiences. Despite making survey findings accessible for those who use the Internet, what patients make of such information has not yet been well researched.

⁸ In the NSW study, patient journey (or 'discovery') interviews were conducted with patients. Patients were asked about their recent experiences with the system, and then asked to categorise their experience according to the Picker dimensions.

The websites also provide information about opening hours of practices, the services provided, names and qualifications of doctors. In contrast, Australian users of primary health care services have little information to guide them in choosing a health service or practitioner.

Key messages from Section 7

1. The UK and USA are at the forefront of the research on patients' experiences.
2. Until recently, Australia did not have systematic arrangements for measuring and monitoring patients' experiences at the national level.
3. Data collected at the level of individual teams and close to the time when the care was experienced has the greatest impact on health care services. ❖

8

Future for patients' experiences

Robert et al. (2011) argue that further research is not required to find out 'what matters most' to patients. They argue that we know what matters most to patients. Instead, attention should shift to a quality improvement mode in which solutions are developed to meet patients' needs – based on what we know matters most.

Rather than publish further research, health care organisations should use this information to improve their services (Robert et al. 2011; Brown et al. 2009). Roland (2012) agrees, arguing that research is needed on how survey results can be used to improve patients' experiences in primary care. Roland (2012) also argues that feedback should only be sought directly from patients on 'what matters most' to them if this information is (1) not already available and (2) uniquely available from patients.

Robert et al.'s (2011) report 'What matters to patients?' Developing the evidence base for measuring and improving patient experience led to some policy recommendations. Their recommendations include:

- Recognise and maximise the value of patient stories
- Use measures that allow comparison over time and between organisations:
- Collect and use real time data (or near real time data)
- Triangulate quantitative and qualitative data to create a narrative
- Make better use of investment in data collection by making sure it is analysed and reported and integrated into routine governance and management process
- Demonstrate leadership and organisational commitment
- Integrate patient experience into clinical and financial strategies and establish service level reporting on all the dimensions of quality

- Receive regular reports at the board to create momentum
- Link patient experience to training and education
- Dedicate resources to the tasks of capturing, understanding and improving patients' experiences.

8.1 Patient Experience Framework

In February 2012, the UK's NHS National Quality Board (NQB) published the 'Patient Experience Framework'. This framework outlines those elements that are critical to patients' experiences of health care services. The objective of this national policy is to develop a quality measurement system by 2015. This quality measurement system will provide national and local health organisations, practitioners, patients and the general public with reliable, valid data on the clinical quality and safety of health services including how patients' experience these health services. However, Robert et al. (2011) and Roland (2012) are concerned that measurements alone may not result in improvements in quality of health care.

GPs in England have recently received an incentive to carry out surveys in their own practices. This incentive requires GPs to plan and discuss the results of the GP survey with a Patient Experience Group⁹. These groups offer a new way of increasing patient involvement (Roland 2012). The Lancashire Care Foundation Trust in UK, for example, proposes to establish Patient Experience Groups (Marshall et al. 2012). They will oversee the delivery of the patient experience 'agenda'. The main responsibilities of the Patient Experience Groups will be:

- Setting standards for the patient experience at team, service and network level
- Combining information on patient experience from various sources, including: reports from Patient Opinion; complaints and compliments; local and national surveys

⁹ Also known as Patient Reference Group and Patient Participation Groups

- Commissioning, directing and disseminating surveys of patient experience
- Providing integrated patient experience ratings for a clinical team as part of the Quality Map, and identifying 'hot spots' where patient experience may be unacceptable
- Identifying trends and themes in patient experience to inform strategic-level planning and decision making, community engagement and improvement
- Ensuring that timely and appropriate action is taken as a result of insights from service users and that service users are kept informed about what has been done
- Overseeing the implementation of the detailed delivery plan for improving patient experience
- Commissioning and overseeing the delivery of staff training that relates to improving the patient experience
- Providing the Board with quarterly reports on the implementation of the detailed delivery plan and the state of patient experience across the organisation.

(Marshall et al. 2012 p7-8)

Key messages from Section 8

1. Further research on patients' experiences is not required.
2. Patients' experiences should inform continuous quality improvements in health care services. ❖

Conclusion

Health care organisations clearly spend a considerable amount of time and resources on gathering data on patients' feedback. The cover of this report visually depicts the large number of patient satisfaction surveys and patients' experience measures that has been reported in the literature.

In addition to providing material for research publications, patients' experience surveys are increasingly being used as an indicator of the quality of health care services. Measures of patients' experiences complement rather than replace other indicators of quality. Patients' experiences need to be integrated with these other indicators of quality, including clinical outcomes.

Patients' experiences often involve more than one health care service. So, rather than only measuring patients' experiences of individual health services, patients' experiences during transitions between services should also be investigated. The aim is to focus on individual 'journeys' rather than in organisational silos.

Patients' experiences should be routinely collected and analysed as a tool for continuous service monitoring and quality improvements. Rather than publish further research on patients' experiences, health care organisations should focus on using information about patients' experiences to improve their services. ❖

References

- Addink R, Bankart M, Murtagh G, Baker R. (2011) Limited impact on patient experience of access of a pay for performance scheme in England in the first year *European Journal of General Practice* 17 (2): 81-86
- Adler R, Vasiliadis A, Bickell N. (2010) The relationship between continuity and patient satisfaction: a systematic review *Family Practice* 27 (2): 171-178
- Alami S, Boutron I, Desjeux D, Hirschhorn M, Meric G, Rannou F, Poiraudau S. (2011) Patients' and practitioners' views of knee osteoarthritis and its management: a qualitative interview study *PLoS ONE* 6 (5): e19634
- Arora N, Reeve B, Hays R, Clauser S, Oakley-Girvan I. (2011) Assessment of quality of cancer-related follow-up care from the cancer survivor's perspective. *Journal of Clinical Oncology* 29 (10): 1280-1289
- Asprey A, Campbell J, Newbould J, Cohn S, Carter M, Davey A, Roland M. (2013) Challenges to the credibility of patient feedback in primary healthcare settings: a qualitative study *British Journal of General Practice* 63 (608): e200
- Boyd G, David S, Hodgkiss F. (2013) *Scottish Patient Experience Survey of GP and Local NHS Services 2011/12 Volume 3: Variations in the Experiences of Primary Care Patients* Scottish Government
- Brown H, Davidson D, Ellins J. (2009) *Real-time Patient Feedback Project Final Report* Health Services Management Centre and NHS West Midlands
- Browne K, Roseman D, Shaller D, Edgman-Levitan S. (2010) Analysis and commentary. Measuring patient experience as a strategy for improving primary care *Health Affairs* 29 (5): 921-925
- Brennan M, Butow P, Marven M, Spillane A, Boyle F. (2011) Survivorship care after breast cancer treatment--experiences and preferences of Australian women *Breast* 20 (3): 271-277
- Burford B, Greco M, Bedi A, Kergon C, Morrow G, Livingston M, Illing J. (2011) Does questionnaire-based patient feedback reflect the important qualities of clinical consultations? Context, benefits and risks. *Patient Education and Counseling* 84 (2): e28-36
- Burgers J, Voerman G, Grol R, Faber M, Schneider E (2010) Quality and coordination of care for patients with multiple conditions: results from an international survey of patient experience. *Evaluation and the Health Professions*. 33 (3): 343-64
- Chishti T, Harris T, Conroy R (2013) How reliable are stroke patients' reports of their numbers of general practice consultations over 12 months? *Family Practice* 30 (1): 119-122
- Cochran V, Blair B, Wissinger L, Nuss T. (2012) Lessons learned from implementation of post discharge telephone calls at Baylor Health Care System. *Journal of Nursing Administration* 42 (1): 40-46
- Cornwell J and Goodrich J. (2011) Challenges for improving patients' experiences of health care *Journal of Health Services & Research Policy* 16 (1): 1-2
- Crosier M, Scott J, Steinfeld B. (2012) Improving satisfaction in patients receiving mental health care: a case study. *Journal of Behavioral Health Services and Research* 39 (1): 42-54
- Coulter A. (2006) Can patients assess the quality of health care? *British Medical Journal* 333 1-2
- Cronin E, Campbell S, Ashworth M, Hann M, Blashki G, Murray J, Tylee A. (2009) A tale of two systems: perceptions of primary care for depression in London and Melbourne *Family Practice* 26 (3): 210-20

- Crow R, Gage H, Hampson S, Hart J, Kimber A, Storey L, Thomas H. (2002) The measurement of satisfaction with healthcare: implications for practice from a systematic review of the literature. *Health Technology Assessment* 6(32): 1-244
- Damman O, de Boer D, Hendriks M, Meuwissen L, Rademakers J, Delnoij D, Groenewegen P. (2011) Differences between family practices in the associations of patient characteristics with health care experiences. *Medical Care Research and Review* 68(6): 725-39
- Davies E, Meterko M, Charms M, Seibert M, Cleary P. (2011) Factors affecting the use of patient survey data for quality improvement in the Veterans Health Administration *BMC Health Services Research* 11:334
- De Leon S, Silfen S, Wang J, Kamara T, Wu W, Shih S. (2012) Patient experiences at primary care practices using electronic health records *Journal of Medical Practice Management* 28(3): 169-176
- Dirocco D and Day S (2011) Obtaining patient feedback at point of service using electronic kiosks *American Journal of Managed Care* 17(7): e270-6
- Draper M. and Hill S. (1995) *The role of patient satisfaction surveys in a national approach to hospital quality management* Department of Human Services and Health
- Edwards A. Evans R. White P. Elwyn G. (2011) Experiencing patient-experience surveys: a qualitative study of the accounts of GPs *British Journal of General Practice* 61(585): 157-166
- Elder N and Barney K. (2012) "But what does it mean for me?" Primary care patients' communication preferences for test results notification Joint Commission *Journal on Quality and Patient Safety* 38(4): 168-176
- Entwistle V, Andrew J, Emslie M, Walker, Dorrian C, Angus V, Conniff A. (2003) Public opinion on systems for feeding back views to the National Health Service *BMJ Quality and Safety* 6(6): 435-42
- Foot C and Cornwell J. (2010) *Improving patients' experiences: an analysis of the evidence to inform future policy development* The King's Fund London
- Fung C, Lim Y, Mattke S, Damberg C, Shekelle P. (2008) Systematic Review: The Evidence That Publishing Patient Care Performance Data Improves Quality of Care *Annals of Internal Medicine* 148(2): 111-123
- Gardner K and Mazza D. (2012) Quality in general practice - definitions and frameworks *Australian Family Physician* 41(3): 151-4
- Gatehouse J. (2011) *Consumer Participation and Patient Experience - The Eastern Health Strategy Consumers Reforming Health Conference* 2011.
- Greaves F, Ramirez-Cano D, Millet C, Darzi A. (2013) Harnessing the cloud of patient experience: using social media to detect poor quality healthcare *BMJ Quality and Patient Safety* 22(3): 251-255
- Greaves F, Pape U, Lee H, Smith D, Darzi A, Majeed A, Millett C. (2012) Patients' ratings of family physician practices on the internet: usage and associations with conventional measures of quality in the English National Health Service. *Journal of Medical Internet Research*. 14(5): e146
- Greenfield D, Hinchcliff R, Westbrook M et al. (2012) An empirical test of accreditation patient journey surveys: randomized trial. *International Journal of Quality Health Care* 24(5): 495-500
- Haggerty JL. (2010) Are measures of patient satisfaction hopelessly flawed? *British Medical Journal*. 341(7777) 790-791
- Hancock RE. Bonner G. Hollingdale R. Madden AM. (2012) 'If you listen to me properly, I feel good': a qualitative examination of patient experiences of dietetic consultations. *Journal of Human Nutrition & Dietetics*. 25(3): 275-84
- Hanratty B, Addington-Hall J, Arthur A, Cooper L, Grande G, Payne S, Seymour J. (2013) What is different about living alone with cancer in older age? A qualitative study of experiences and preferences for care *BMC Family Practice* 14: 22
- Hargreaves D and Viner R. (2012) Children's and young people's experience of the National Health Service in England: a review of national surveys 2001-2011. *Archives of Disease in Childhood* 97(7): 661-666
- Harrison S, Watson E, Ward A, Khan N, Turner D, Adams E, Forman D, Roche M, Rose P. (2012) Cancer survivors' experiences of discharge from hospital follow-up. *European Journal of Cancer Care* 21(3): 390-397
- Heje H, Vedsted P, Olesen F. (2011) General practitioners' experience and benefits from patient evaluations. *BMC Family Practice* 12: 116-127

- Hendry T and Gatehouse J. (2013) In the patient's shoes: The eastern health patient experience of care program *Health Issues Centre*
- Hsu M and McCormack B. (2010) The experience of applying a narrative research approach with older people *Journal of Nursing Research* 18 (4): 249-57
- Hudon C, Fortin M, Haggerty J, Lambert M, Poitras M. (2011) Measuring patients' perceptions of patient-centered care: a systematic review of tools for family medicine. *Annals of Family Medicine*. 9 (2): 155-164
- Hudson S, Miller S, Hemler J, Ferrante J, Lyle J, Oeffinger K, Dipaola R. (2012) Adult cancer survivors discuss follow-up in primary care: 'not what I want, but maybe what I need' *Annals of Family Medicine* 10 (5): 418-427
- Hueston W and Carek S. (2011) Patients' preference for physician attire: a survey of patients in family medicine training practices. *Family Medicine*. 43 (9): 643-647
- Hush J, Cameron K, Mackey M. (2011) Patient Satisfaction With Musculoskeletal Physical Therapy Care: A Systematic Review *Physical Therapy* 91 (1): 25-36
- Ivers N, Jamtvedt G, Flottorp S et al. (2012) Audit and feedback: effects on professional practice and healthcare outcomes *Cochrane Database of Systematic Reviews* No: 7
- Iversen H, Andresen Ø, Groven G, Bukholm G. (2010) Usefulness of a national parent experience survey in quality improvement: views of paediatric department employees *Quality and Safety in Health Care* 19 (5) 1-4
- Jackson K, Oelke N, Besner J, Harrison A. (2012) Patient journey: implications for improving and integrating care for older adults with chronic obstructive pulmonary disease. *Canadian Journal on Aging* 31 (2): 223-33
- Kalucy L, Katterl R, Jackson-Bowers E. (2009). *Patient Experience of health care performance*. PHC RIS Policy Issue Review Primary Health Care Research and Information Service. Adelaide
- Kenten C, Bowling A, Lambert N, Howe A. (2010) A study of patient expectations in a Norfolk general practice *Health expectations* 13 (3): 273-284
- Kontopantelis E, Roland M, Reeves D. (2010) Patient experience of access to primary care: identification of predictors in a national patient survey. *BMC Family Practice* 11: 61-76
- Krishnasamy M, Ugalde A, Carey M, Duffy M, Dryden T. (2011) Patient expectations and preferences for follow-up after treatment for lung cancer: a pilot study *European Journal of Oncology Nursing* 15 (3): 221-225
- Lawler S, Spathonis K, Masters J, Adams J, Eakin E. (2011) Follow-up care after breast cancer treatment: experiences and perceptions of service provision and provider interactions in rural Australian women *Supportive Care in Cancer* 19 (12): 1975-1982
- Lewis R, Neal R, Hendry M, France B, Williams N, Russell D, Hughes D, Russell I, Stuart N, Weller D, Wilkinson C. (2009) Patients' and healthcare professionals' views of cancer follow-up: systematic review *British Journal of General Practice* 59 (564): e248-59
- Lopez A (2012) What Patients Say About Their Doctors Online: A Qualitative Content Analysis *Journal of General Internal Medicine* 27 (6): 685-692
- Lundstrom L, Johnsen A, Ross L, Petersen M, Groenvold M. (2011) Cross-sectorial cooperation and supportive care in general practice: cancer patients' experiences. *Family Practice* 28 (5): 532-540
- Lyles R and Sarkar U. (2013) Additional considerations for 'Harnessing the cloud of patient experience' *BMJ Quality and Safety Published Online* 8 March
- Lyratzopoulos G, Elliott M, Barbiere J, Henderson A, Staetsky L, Paddison C, Campbell J, Roland M. (2012) Understanding ethnic and other socio-demographic differences in patient experience of primary care: evidence from the English General Practice Patient Survey. *BMJ Quality and Safety* 21 (1): 21-29
- Maben J, Peccei R, Adams M, et al. (2012) *Exploring the relationship between patients' experiences of care and the influence of staff motivation, affect and wellbeing* National Institute for Health Research Service Delivery and Organisation Programme NHS National Institute for Health Research
- Malus M, Shulha M, Granikov V. et al. (2011) A participatory approach to understanding and measuring patient satisfaction in a primary care teaching setting *Progress in Community Health Partnerships* 5 (4): 417-24

- Malterud K and Ulriksen K. (2010) Obesity in general practice: a focus group study on patient experiences. *Scandinavian Journal of Primary Health Care* 28 (4): 205-220
- Manary M, Boulding W, Staelin R, Glickman S (2013) The patient experience and health outcome *New England Journal of Medicine* 368 (3): 201-203
- Marcinowicz L, Konstantynowicz J, Godlewski C. (2010) Patients' perceptions of GP non-verbal communication: a qualitative study *British Journal of General Practice* 60 (571): 83-87
- Marshall M, Bazire F, Sullivan P, Garside E, Dugdale D. (2012) *Improving by listening – our plans to provide a better experience of care*. Lancashire Care Foundation Report
- Martino S, Kanouse D, Elliott M, Teleki S, Hays R. (2012) A field experiment on the impact of physician-level performance data on consumers' choice of physician. *Medical Care* 50 Suppl: S65-73
- Mavaddat N, Lester H, Tait L. (2009) Development of a patient experience questionnaire for primary care mental health. *Quality and Safety in Health Care* 18 (2): 147-152
- Mayer E, Gropper A, Neville B, Partridge A, Cameron D, Winer E, Earle C. (2012) Breast cancer survivors' perceptions of survivorship care options *Journal of Clinical Oncology* 30 (2): 158-163
- Mead N and Roland M. (2009) Understanding why some ethnic minority patients evaluate medical care more negatively than white patients: a cross sectional analysis of a routine patient survey in English general practices *British Medical Journal* 339: b3450
- McCann T and Lubman D (2012) Young people with depression and their satisfaction with the quality of care they receive from a primary care youth mental health service: a qualitative study. *Journal of Clinical Nursing* 21 (15-16): 2179-2187
- Menzies Centre for Health Policy (2012) *The Menzies-Nous Australian Health Survey* University of Sydney and The Australian National University
- Menzies Centre for Health Policy (2010) *The Menzies-Nous Australian Health Survey*. University of Sydney and The Australian National University
- Miller A and Archer J. (2010) Impact of workplace assessment on doctors' education and performance: a systematic review. *British Medical Journal* 341 (7775): c5064.
- Mold J, Lawler F, Schauf K, Aspy C (2012) Does patient assessment of the quality of the primary care they receive predict subsequent outcomes? (2011) An Oklahoma Physicians Resource/Research Network (OKPRN) study. *Journal of the American Board of Family Medicine: JABFM*. 24(5): 511-23
- Moore R, Yelland M, Ng SK. (2011) Moving with the times - familiarity versus formality in Australian general practice. *Australian Family Physician* 40 (12):1004-1007
- O'Brien R, Rose P, Campbell C, Weller D, Neal R, Wilkinson C, Watson E. (2010) Experiences of follow-up after treatment in patients with prostate cancer: a qualitative study. Prostate Cancer Follow-up Group. *BJU International* 106 (7): 998-1003
- O'Dowd A. (2012) New scoring charts for GPs are too crude, say doctors' leaders *British Medical Journal* 344: e3988
- Petroz U, Kennedy D, Webster F, Nowak A. (2011) Patients' perceptions of individualized care: evaluating psychometric properties and results of the individualized care scale. *Canadian Journal of Nursing Research* 43 (2): 80-100
- Quality Health (2012) *Quality of Life of Cancer Survivors in England* Report on a pilot survey using Patient Reported Outcome Measures (PROMS) Department of Health UK
- Raleigh V and Frosini F (2012) *Improving GP services in England: exploring the association between quality of care and the experience of patients* Data Briefing The King's Fund
- Rademakers J, Delnoij D, Nijman J, de Boer D. (2012) Educational inequalities in patient-centred care: patients' preferences and experiences *BMC Health Services Research* 12: 261-269
- Rao M, Clarke A, Sanderson C, Hammersley R. (2006) Patients' own assessments of quality of primary care compared with objective records based measures of technical quality of care: cross sectional study *British Medical Journal* 333: 19-22
- Reeves R and Secombe I (2008) Do patient surveys work? The influence of a national survey programme on local quality improvement initiatives *Quality and Safety in Health Care* 17: 437-441

- Ridd M, Shaw A, Lewis G, Salisbury C. (2009) The patient-doctor relationship: a synthesis of the qualitative literature on patients' perspectives *British Journal of General Practice* 59 (561): e116-33
- Robert G, Cornwell J, Brearley S. et al. (2011) *'What matters to patients'? Developing the evidence base for measuring and improving patient experience* The King's Fund London
- Robert G and Cornwell J (2011) *'What matters to patients'? Policy Recommendations* Department of Health and NHS Institute for Innovation & Improvement
- Roland M. (2012) Measuring and improving patient experience in primary care. *Primary Health Care Research & Development* 13 (2): 103-5
- Roland M. Elliott M. Lyratzopoulos G. Barbiere J. Parker RA. Smith P. Bower P. Campbell J. (2009) Reliability of patient responses in pay for performance schemes: analysis of national General Practitioner Patient Survey data in England. *British Medical Journal* 339: b3851
- Rowe J. (2012) Clients are central to any independent and rigorous evaluation of the services they use. *International Journal of Drug Policy* 23 (2):103-4
- Rozenblum R and Bates D (2013) Patientcentred healthcare, social media and the internet: the perfect storm? *BMJ Quality and Safety* 22:183186
- Salisbury C, Wallace M, Montgomery A. (2010) A Patients' experience and satisfaction in primary care: secondary analysis using multilevel modeling *British Medical Journal* 341: c5004.
- Saatci E. Tahmiscioglu G. Bozdemir N. Akpınar E. Özcan S. Kurdak H. (2010) The well-being and treatment satisfaction of diabetic patients in primary care. *Health and Quality of Life Outcomes* 8: 67
- Schoen C, Osborn R, Squires D, Doty M, Pierson R, and Applebaum S. (2011) Survey of Patients with Complex Care Needs in 11 Countries Finds That Care Is Often Poorly Coordinated *Health Affairs* 30 (12): 2437-2448
- Schoen C, Osborn R, How S, Doty M, Peugh J. (2009) In Chronic Condition: Experiences Of Patients With Complex Health Care Needs, In Eight Countries, *Health Affairs* 28 (1): 1-16
- Schoen C, Osborn R, Huynh PT, Doty M, Davis K, Zapert K, Peugh J. (2004) Primary Care And Health System Performance: Adults' Experiences In Five Countries. *Health Affairs (Suppl Web Exclusives)*: W4-487-503
- Shared Intelligence. (2010) Evaluation of the NHS Institute Patient Experience Learning Programme. London; Shared Intelligence.
- Sint Nicolaas J, de Jonge V, Korfage I, Ter Borg F, Brouwer J, Cahen D, Lesterhuis W, Ouwendijk R, Kuipers E, van Leerdam M. (2012) Benchmarking patient experiences in colonoscopy using the Global Rating Scale *Endoscopy* 44 (5): 462-72
- Sitza, J. (1999). How valid and reliable are patient satisfaction data: An analysis of 195 studies. *International Journal for Quality in Health Care* 11 (4) 319-328
- Sliwa M and Okane J. (2011) Service quality measurement: appointment systems in U.K. GP practices. *International Journal of Health Care Quality Assurance* 24 (6): 441-452
- Stenberg G, Fjellman-Wiklund A, Ahlgren C. (2012) "Getting confirmation": gender in expectations and experiences of healthcare for neck or back patients. *Journal of Rehabilitation Medicine* 44 (2): 163-171
- Suleman J, Anwar M, Weston C, Baker R. (2011) Use of outcomes in monitoring healthcare - how many outcome measures are needed in monitoring diabetes in primary care? *Journal of the Royal Society of Medicine* 104 (10): 413-20
- Szecsényi J, Goetz K, Campbell S, Broge B, Reuschenbach B, Wensing M. (2011) Is the job satisfaction of primary care team members associated with patient satisfaction? *BMJ Quality and Safety* 20 (6): 508-514
- The Intelligent Board (2010) Patient Experience Dr Foster Intelligence
- Tsianakas V, Maben J, Wiseman T, Robert G, Richardson A, Madden P, Griffin M, Davies E. (2012) Using patients' experiences to identify priorities for quality improvement in breast cancer care: patient narratives, surveys or both? *BMC Health Services Research* 12: 271-282
- Tsianakas V, Robert G, Maben J, Richardson A, Dale C, Griffin M, Wiseman T. (2012b) Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. *Supportive Care in Cancer*. 20 (11): 2639-2647

- Varley J, Delanty N, Normand C, Fitzsimons M. (2011) The health care journeys experienced by people with epilepsy in Ireland: what are the implications for future service reform and development? *Epilepsy and Behavior* 20 (2): 299-307
- Victorian Patient Satisfaction Monitor (2012) *Annual Report* July 2011 to June 2012 Department of Health, State Government of Victoria, Australia
- Waibel S, Henao D, Aller M, Vargas I, Vazquez M. 2012 What do we know about patients' perceptions of continuity of care? A meta-synthesis of qualitative studies *International Journal of Quality Health Care* 24 (1): 39-48
- Worth T. (2012) Practicing in a world of transparency. Online scores and comments about you can be painful, but they also provide an opportunity for improvement *Medical Economics* 89 (21): 52, 54, 57-8
- Zuidgeest M. Hendriks M. Koopman L. Spreeuwenberg P. Rademakers J. (2011) A comparison of a postal survey and mixed-mode survey using a questionnaire on patients' experiences with breast care. *Journal of Medical Internet Research* 13 (3): e68