

Chapter 11: Measuring patient perceptions of quality in health care: a structured review to inform service delivery for chronic disease

Summary

This review provides a structured synthesis of published evidence for the measurement and practical properties of patient-reported measures that communicate patients' experience of health care quality of relevance to long-term physical conditions or chronic disease management. The review aims to inform the future selection of multi-dimensional measures of patient-perceived health care quality.

BACKGROUND

a) Chronic disease

Chronic disease, defined as long-term conditions that can be controlled but not cured (DoH, 2004), represents the major cause of health problems in the United Kingdom (UK) (DoH, 2004). The growing demands to provide care appropriate to the needs of people with chronic disease are significant, representing a shift from the demands for acute health care: in the UK, 60% of all adults are diagnosed with one or more chronic condition, 60% of all hospitalisations are due to chronic disease or exacerbations, and 80% of GP consultations are related to chronic ill-health (DoH, 2004). It is evident that a high proportion of the UK's health service is currently devoted to health care provision for people with chronic disease; ensuring that the provision of health care is appropriate and of the highest quality is a major challenge, and an essential component of quality improvement efforts.

Many health care systems were designed for acute, episodic health care, and are, at best inappropriate for the management of chronic disease (Bodenheimer et al., 2002). Health care pathways for people with long-term chronic disease are often complex, and numerous shortcomings in the provision of quality health care have been described, including access to care (Davis and Wagner, 2000; Haggulund et al., 2005), continuity of care (Davis and Wagner, 2000; Thapar and Roland, 2005), integration of care between service providers (DoH, 2004), and respect for patients values, preferences and expressed needs (Hibbard, 2003; Davis and Wagner, 2000; Groves and Wagner, 2005).

Various strategies for improving care provision for people with chronic disease have been suggested, including patient involvement in decision making, care planning, and the regular monitoring of care provided (Groves and Wagner, 2005). The Chronic Care, or Chronic Disease, Model (CCM/CDM) was proposed to inform the provision of health care that embraced the needs of patients with long-term conditions (Bodenheimer et al., 2002). The model emphasizes a patient-centred approach to long-term health care, within which well-informed and self-motivated patients are supported proactive members of a multidisciplinary team. Moreover, a patient-centred approach should be responsive to the values, needs and preferences of patients (Hibbard, 2003); respect for and incorporation of patient values may be used to inform both the provision of care and evaluation of patient experience, providing a basis for improving service delivery. The multi-disciplinary nature of health care

suggests that care may often be provided across a range of different settings, by different members of the health care team, and often by more than one member from different disciplines over prolonged periods of time (Campbell et al., 2000). Hence, issues such as access to care, continuity of care, and co-ordination of care between team members become important requirements to ensuring care of the highest quality.

b) Quality health care

Modernisation of health care systems and associated advances in evidence-based healthcare has raised expectations of improvements in the quality of care (Powell et al., 2003; Sheldon, 2005). Moreover, the growing demand for health care, combined with rising costs and limited resources, has increased the emphasis on the efficient use of health care resources (Campbell et al., 2000). It is predicted that chronic disease will be the leading cause of disability by 2020; unless accompanied by good management, it will also become the most expensive health care problem (DoH, 2004). The drive for accountability and associated growth in quality improvement initiatives and performance measurement has ensued. Chronic disease management is now an essential component of quality improvement efforts within health care (Davis and Wagner, 2000). The provision of clinically effective, evidence-based health care, which is both acceptable and beneficial to patients, are important elements in understanding quality in health care (Jenkinson et al., 2002; Fitzpatrick, 1997).

Measuring and communicating health care quality requires rigorous and appropriate measurement of key and consensual variables that reflect the breadth and complexity of health care. Health care quality is, by necessity, a multi-factorial and broad ranging concept; the identification and appropriate measurement of key dimensions of health care service delivery of relevance to chronic disease management is a prerequisite to improving quality in health care (Hibbard et al., 2005). However, discrepant views between different stakeholders within the health care system, ranging from patients to providers, exist with regards to the definition and prioritization of quality issues (Campbell et al., 2002; Leatherman and Sutherland, 2003).

Numerous attempts to describe dimensions of relevance to a patient's experience of health care have been described. A patient's perspective of quality may include their desired health outcome (Mitchell and Lang, 2004; Swan and Boruch, 2004), their relationship with healthcare providers, the qualifications and performance of healthcare providers, and access to and choice of healthcare (Campbell et al., 2002; Hibbard, 2003). Exploring the concept of chronic disease management and patient-centred health care, the Institute of Medicine (IoM) (Committee on Quality of Health Care in America, 2001) engaged with health professionals and patients to describe nine core dimensions reflective of patient-centred quality health care: these include respect for patient values; attention to patient preferences and expressed needs; co-ordination and integration of care; information, communication and education; physical comfort; emotional support; involvement of family and friends; transition and continuity; and access to care. Intermediate outcomes, considered important intermediary steps in the achievement of improved health status, and reflective of key elements within the chronic care model, such as patient knowledge, self-efficacy and self-management skills (Hibbard et al., 2004), have also been described.

Other authors have described similar dimensions to those proposed by the IoM, reflective of central aspects of patient care (Gerteis et al., 1993): access; physical comfort / pain management; hospital environment; patient involvement; information and communication; co-ordination of care; and discharge planning. With the context of primary care, similar patient generated dimensions have also been described as important to the provision of good quality care (Coulter, 2005): fast access; trust in professional providing care; respect for patient preferences; patient involvement; information, education and support for self-care; attention to physical and environmental needs; emotional support; involvement of family and carers; continuity of care and smooth transition and coordination of care.

c) Patient reported quality in health care

Traditionally, health care quality has been assessed in terms of measures of structure, process and outcome (Donabedian, 1966; Campbell et al., 2000; Parchman et al., 2002): structure considers the accessibility and relative quality of the many components of health care, for example, how accessible was care for an individual with chronic disease?; process considers the appropriateness of care, location and timing, for example, did an individual with chronic disease receive care that was appropriate to their needs, at the right time, and in a suitable location? Measures of outcome assess the outcomes of health care, and may include functional and clinical outcomes, or clinical targets.

However, assessment has often focused on the perspectives of the care-provider or health care organization, such as cost, length of stay and patient mortality; within a chronic disease context few assessments have included the patient's experience of care (Groves and Wagner, 2005). Failure to sufficiently involve the patient perspective may reduce the credibility and relevance of assessment, particularly if used to support patient involvement and inform patient choice. Moreover, rigorous evidence of measurement reliability and validity is often lacking for more traditional measures or 'indicators' of care quality (Kendrick, 2001), and limited empirical evidence supports their contribution towards actually improving health care quality (Appleby and Devlin, 2004; Mitchell and Lang, 2004).

Patient-reported measures of health care quality aim to include the patient's perspective across a range of quality concerns in the assessment process. Well developed measures, particularly those that have involved patients in development and embrace the complex and multi-dimensional nature of health care, provide an important resource for assessing and communicating the quality of health care (Campbell et al., 2000). Although there may be occasions where a focus on specific elements of health care quality is important (Bredart et al., 2005), for example, a focus on the continuity of care, approaches that embrace individual dimensions may provide only a partial illustration of health care. Measurement that embraces the multi-dimensional nature of health care quality may be more meaningful to informing quality improvement initiatives.

d) Assessment of quality health care for chronic disease

Although evidence for measurement properties is important to ensuring scientific rigor in quality assessment, the appropriateness and relevance to the clinical setting and policy context, feasibility of incorporating such measures into routine practice settings, and relevance and interpretation of data to inform quality improvement initiatives, are also important issues in recommending measures for practice: ‘the true utility in quality measurement lies in its ability to inspire quality improvement’ (Kerr et al., 2001).

REVIEW AIM AND OBJECTIVES

Review aim

To provide guidance to policy-makers, clinicians and researchers on the most appropriate, valid and acceptable patient-reported measures of health care quality, of relevance to long-term physical conditions or chronic disease management, for use in routine practice, clinical audit and research settings.

Objectives

Structured review of published international evidence:

- a) to identify patient-reported measures of health service quality of relevance to long-term physical conditions or chronic disease management; measures that are broadly applicable across conditions, include key elements of health care quality, and have been applied in the settings in which care may be received / delivered will be reviewed.
- b) to extract and assess evidence relating to the development and evaluation of these measures in relation to pre-defined measurement and practical properties.
- c) to make recommendations for the application of patient-reported measures of relevance to health care and service delivery for people with long-term physical conditions or chronic disease. These recommendations will consider evidence for the practicability and viability of patient-reported measures as mechanisms for incorporating the patient voice in routine practice settings.
- d) to make recommendations for the further evaluation of measurement performance.
- e) to make recommendations for future development of measures where appropriate

METHODS

Search strategy

A structured, but pragmatic approach to identifying and retrieving references for the review was adopted.

The primary search strategy (‘main search’) was designed to retrieve studies exploring the evaluation of health care quality from the patient perspective, and of relevance to long-term physical conditions or chronic disease, including the development and testing of measures, and evaluation of both measurement and practical properties of particular relevance to ‘real-world’ application. All searches were restricted to English language publications.

Medline, accessed through Ovid software, was searched for the years 1980-2006 (August). For the main search, terms related to ‘health care quality’, ‘measurement (from the patient perspective)’, and ‘chronic disease’ were employed as illustrated in Table 11.1 below.

The reference lists of all included articles were reviewed for additional articles. The reference lists of existing reviews of patient reported measures or patient completed 'surveys' of relevance to the assessment of health care quality were also reviewed.

Table 11.1 Main search strategy (Medline via OVID software (020806); limits Humans, English)

| Health Care Quality / Elements of Health Care Quality (all joined by 'OR') | Measurement (all joined by 'OR') | Chronic Disease (all joined by 'OR') |
|--|---|---|
| **Quality of Health Care"/ | exp "Outcome and Process Assessment (Health Care)"/ | (chronic adj2 disease\$).kf,tw,ti,kw. |
| *Quality Assurance, Health Care/ | (patient adj report\$).kf,tw,ti,kw. | (chronic adj2 illness\$).kf,tw,ti,kw. |
| *Health Services Accessibility/ | (user adj report\$).kf,tw,ti,kw. | (chronic adj2 condition\$).kf,tw,ti,kw. |
| exp Patient-Centred Care/ | (client adj report\$).kf,tw,ti,kw. | (chronic adj2 ill-health).kf,tw,ti,kw. |
| exp Patient Satisfaction/ | (self adj report\$).kf,tw,ti,kw. | (chronic adj2 care).kf,tw,ti,kw. |
| *Patient Satisfaction/ | (consumer adj report\$).kf,tw,ti,kw. | (long\$term adj2 disease\$).kf,tw,ti,kw. |
| **Continuity of Patient Care"/ | (patient adj2 evaluat\$).kf,tw,ti,kw. | (long\$term adj2 disorder\$).kf,tw,ti,kw. |
| exp Professional-Patient Relations/ | (patient adj2 assess\$).kf,tw,ti,kw. | (long\$term adj2 illness\$).kf,tw,ti,kw. |
| *Health Facility Environment/ | (self adj2 assess\$).kf,tw,ti,kw. | (long\$term adj2 condition\$).kf,tw,ti,kw. |
| (quality adj4 measure\$).kf,tw,ti,kw. | (consumer adj2 assess\$).kf,tw,ti,kw. | (musculoskeletal\$ adj2 disorder\$).kf,tw,ti,kw. |
| (quality adj4 assess\$).kf,tw,ti,kw. | (patient adj2 question\$).kf,tw,ti,kw. | (musculoskeletal\$ adj2 disease\$).kf,tw,ti,kw. |
| (quality adj4 health care).kf,tw,ti,kw. | (consumer adj2 question\$).kf,tw,ti,kw. | (musculoskeletal\$ adj2 condition\$).kf,tw,ti,kw. |
| (quality adj4 service).kf,tw,ti,kw. | (patient adj complet\$).kf,tw,ti,kw. | (rheum\$ adj2 disorder\$).kf,tw,ti,kw. |
| (satisfaction\$ adj4 health care).kf,tw,ti,kw. | (consumer adj2 survey\$).kf,tw,ti,kw. | (rheum\$ adj2 disease\$).kf,tw,ti,kw. |
| (satisfaction\$ adj2 care).kf,tw,ti,kw. | (patient adj2 survey\$).kf,tw,ti,kw. | (rheum\$ adj2 condition\$).kf,tw,ti,kw. |
| (quality adj2 care).kf,tw,ti,kw. | (patient adj2 perspective\$).kf,tw,ti,kw. | |
| (satisfaction\$ adj4 service).kf,tw,ti,kw. | (patient adj2 appraisal\$).kf,tw,ti,kw. | |
| (patient\$ adj satisfaction\$).kf,tw,ti,kw. | (patient adj2 preference\$).kf,tw,ti,kw. | |
| (patient\$ adj experience\$).kf,tw,ti,kw. | (patient adj2 perception\$).kf,tw,ti,kw. | |
| (experience\$ adj4 health care).kf,tw,ti,kw. | (patient adj2 view\$).kf,tw,ti,kw. | |
| (expectation\$ adj4 health care).kf,tw,ti,kw. | (patient adj experience\$).kf,tw,ti,kw. | |
| (expectation\$ adj2 care).kf,tw,ti,kw. | (consumer adj2 perspective\$).kf,tw,ti,kw. | |
| (experience\$ adj2 care).kf,tw,ti,kw. | (consumer adj2 appraisal\$).kf,tw,ti,kw. | |
| (continuity adj2 health care).kf,tw,ti,kw. | (consumer adj2 preference\$).kf,tw,ti,kw. | |
| (continuity adj2 care).kf,tw,ti,kw. | (consumer adj2 perception\$).kf,tw,ti,kw. | |
| (access adj4 health care).kf,tw,ti,kw. | (consumer adj2 view\$).kf,tw,ti,kw. | |
| (access adj2 care).kf,tw,ti,kw. | (consumer adj2 experience\$).kf,tw,ti,kw. | |
| | AND | AND |
| | | Total: 679 |

Footnote: kf – XX; tw – text word; ti – title; kw – key word

These searches were further supported by personal knowledge of the field contributed by members of the review team, consultation with experts in the field, and reviews of web-sites for reviewed measures.

Inclusion criteria

Titles and abstracts of all articles were assessed for inclusion/exclusion. Included articles were retrieved in full. All articles and patient-reported measures were required to satisfy certain criteria of relevance to the study question, patient population, elements of health care quality, type of outcome and language. Moreover, the appropriateness of measures to the UK context was an important consideration. Article and PROM inclusion/exclusion criteria are summarized in Tables 11.2 and 11.3 respectively.

Table 11.2 Article inclusion and exclusion criteria

| Articles | |
|--|---|
| Inclusion | Exclusion |
| <p>1. Published articles providing evidence in support of the development / evaluation / application of patient-reported measures of health care service quality of relevance to the receipt of care for long-term physical conditions or chronic disease management in an adult population</p> <p>2. Evaluation has relevance to current UK policy context for chronic disease management</p> | <p>1. Evidence of measurement and/or practical properties not reported</p> <p>2. Assessed outcomes focus on patient experience of disease and not on experience of health care.</p> <p>3. Focus on the evaluation of care for non-physical chronic conditions – e.g., mental or behavioural health problems.</p> <p>4. Focus on the evaluation of care for non-adult populations – i.e., paediatrics or adolescents.</p> <p>5. Non-English language</p> <p>6. Do not describe evaluative measures in sufficient detail to allow identification</p> <p>7. Non-published data</p> <p>8. Narrative reviews</p> |

Table 11.3 PROM inclusion and exclusion criteria

| PROM | |
|--|--|
| Inclusion | Exclusion |
| <p>1. Identifiable (and reproducible) multi-item patient-reported measures specific to the evaluation of health care service quality of relevance to long-term physical conditions or chronic disease management (1980-2006).</p> <p>2. Item content has relevance to the current UK policy context*</p> <p>2. Data synthesis will focus on PROMs with evidence of at least reliability or validity in the UK setting*</p> | <p>1. Not specific to the evaluation of health service quality</p> <p>2. Evaluations are specific to health care investigations or interventions – e.g., mammography service</p> <p>3. Single dimension measures of health care quality – e.g., interpersonal skills or care.</p> <p>4. Single item measures of health care quality</p> <p>5. Measure is specific to the experience of health care of relevance to non-physical long-term conditions – e.g.,</p> |

| | |
|--|--|
| | mental or behavioural health. 6. Clinician or proxy (or other) completed measures of health care quality. 7. No evidence of reliability or validity (in UK population)* 8. Measure not clearly identifiable |
|--|--|

Footnotes: * The appropriateness of measures to the UK context is an important consideration for inclusion in the review. Where item content has relevance to the UK policy setting, but measures lack evidence of measurement properties in the UK population, relevance to the current policy context will override formal exclusion criteria.

Flexibility in inclusion criteria was considered an essential requirement of the review. For example, where promising measures were identified that, although specific to condition or setting, addressed a wide range of dimensions of relevance to other conditions and appeared to address issues of relevance to current UK health policy, such measures were included in the review.

One reviewer (KH) assessed all returned titles and excluded clearly irrelevant or duplicate items. Borderline studies or measures were discussed with another member of the review team (RF).

Data extraction

Data extraction was informed by a form designed for the purposes of the review, and included both study-specific issues such as study design, and respondent characteristics such as type of chronic illness and age, and measurement specific issues, for example, type and description of measure including the dimension of health care quality covered, response format, extent of patient involvement in development, length, and evidence of measurement and practical properties, such as time to complete and ease of administration and scoring (Fitzpatrick et al., 1998; Haywood et al., 2004).

Evidence for the appropriateness of content to the UK policy context for people with chronic disease was extracted.

Format of the reviews

The summary of the evidence follows that of previous reviews (McDowell and Newell, 1996; Haywood et al., 2004). The following information is provided for each measure:

Title

The measurement title as given by the original developer. Instrument developers, year of original publication, and subsequent revision.

Description

The purpose and proposed application of each measure as defined by the developers.

Development, including item derivation, is summarized where available. Item content, the dimensions of health care quality covered, for example, patient involvement and continuity of care, the number of items, response options, and method of scoring are reported. Measurement modifications are described.

Measurement and practical properties

For all included measures published evidence of measurement properties (reliability, validity, and responsiveness, precision) and practical properties (acceptability, feasibility and interpretation) is summarized.

Review summaries (Discussion)

Reviewed evidence is summarized for each included measure. The nine core dimensions of patient-centred quality health care described by the IoM (Committee on Quality of Health Care in America, 2001) were used to inform a tabulated summary of core dimensions included in the reviewed measures, as shown in Table 11.4. To support comparison between measures, dimension coverage was reviewed against this general classification.

The number of studies in which the measures have been evaluated is provided.

Discussion and Conclusion

The discussion and conclusion to this chapter summarises the current state of health care quality assessment for chronic disease, and suggests areas for future evaluative work.

RESULTS

Search results

The main search returned 679 references. All abstracts were reviewed. When assessed against the inclusion criteria, 86 articles were retrieved and reviewed in full. Checking the reference-lists of included articles and websites generated a significant number of additional articles, and associated measures, that were read and considered for the review.

However, a relatively small final total of 22 articles contributed required evidence of development, measurement and/ or practical properties for the included measures.

a) Identification of patient-reported measures of health care quality

Eleven patient-reported measures of health care quality, of relevance to chronic disease were included in the review, as listed in section 11.5 and Tables 11.4 to 11.8. An additional oncology-specific measure was also included due to its relevance to the review. In addition, although not specific to chronic disease, the General Practice Assessment Questionnaire (GPAQ) was also included for its relevance to the UK policy context (not included in count).

Three organizations are significant within the field of health care evaluation for their development of a range of patient reported measures or surveys; these websites were reviewed for current (and future) developments:

- Consumer Assessment of Health Plans (CAHPS) (USA) <https://www.cahps.ahrq.gov/default.asp>,
- Picker Institute (USA and Europe) <http://www.pickereurope.org/>,
- Netherlands Institute for Health Service Research <http://nivel.nl>. (QUOTE measures)

The work of these groups, and relevance to the review, is summarized in the following sections.

b) Existing reviews of patient-reported measures of health care quality

Three structured reviews of patient-reported measures of health care quality and service delivery were identified (General practice – Wensing et al., 1994; Hospital surveys - Castle et al., 2005; Disease management industry - Sen et al., 2005); these reviews do not refer specifically to the evaluation of patient-reported measures of health care quality of relevance to chronic disease. Two further reviews of measures for the evaluation of quality of care and patient satisfaction were also reviewed assessed (van Campen et al., 1995; Weaver et al., 1997). A literature review of patient reported measures of general practitioner care was reviewed (Sixma and Spreeuwenberg, 2006).

Table 11.4 Dimensions of health care quality (informed by IOM: Committee on Quality of Health Care in America, 2001)

| Core dimensions of Health Care Quality | | | | | | | | | | |
|---|--|-----------------------------|---------------------------------------|------------------|-------------------|---------------------------------|------------------------|----------------------------------|-------------|--------------------|
| Measure (items) | Respect - patient values, needs / preference | Co-ordination / Integration | Information, Communication, Education | Physical comfort | Emotional support | Involvement of family / friends | Continuity /transition | Access to Care (include waiting) | Environment | Overall impression |
| <i>General application across condition and setting (Table 11.5)</i> | | | | | | | | | | |
| ICICE (>50) * | √ | | √ | √ | | | | (√) | | (√) |
| PACIC (20) * | √ | √ | √ | | | | √ | √ | | |
| QUOTE-generic | √ | √ | √ | | √ | | √ | √ | √* | |
| <i>General application across condition, but specific to setting (Table 11.6)</i> | | | | | | | | | | |
| <i>Primary Care</i> | | | | | | | | | | |
| CEP-Q (18) **Dr | √ | √ | √ | | √ | √ | √ | √ | √ | |
| GPAQ (25) ** DrNR | √ | √ | √ | | | | √ | √ | | |
| HSHQ (16) | √ | √ | √ | | | | √ | √ | | |
| SOSQ (21) | ?? | | √ | | | | | √ | | |
| <i>Out-patients</i> | | | | | | | | | | |
| OPEQ (26) | √ | √ | √ | | √ | | √ | √ | √ | |
| <i>In-patient</i> | | | | | | | | | | |
| I-PEQ (40) | √ | √ | √ | √ | √ | √ | √ | | | √ |
| PPE-15 (15) | √ | √ | √ | √ | √ | √ | √ | | | |

| Core dimensions of Health Care Quality | | | | | | | | | | |
|--|--|-----------------------------|---------------------------------------|------------------|-------------------|---------------------------------|------------------------|----------------------------------|-------------|--------------------|
| Measure (items) | Respect - patient values, needs / preference | Co-ordination / Integration | Information, Communication, Education | Physical comfort | Emotional support | Involvement of family / friends | Continuity /transition | Access to Care (include waiting) | Environment | Overall impression |
| <i>Specific to chronic condition and specific to setting</i> | | | | | | | | | | |
| Picker MSD (16) | √ | √ | √ | | √ | | √ | | | √ |
| I-PEQ (CHD) (38) | √ | √ | √ | √ | | | √ | √ | √ | |
| <i>Cancer-specific</i> | | | | | | | | | | |
| EORTC ^{**} DrNR IN-PATSAT32 (32) | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ |

Footnotes: Core IoM domains of quality care: respect for patient values; attention to patient preferences and expressed needs (first two domains combined for purpose of review); co-ordination and integration of care; information, communication and education; physical comfort; emotional support; involvement of family and friends; transition and continuity; and access to care.

- *Chronic Care Model informs item content
- ** includes sections specific to evaluation of doctor-related care^{Dr}, nurse-related care^{NR}, services and care organisation, and overall assessment.

INSTRUMENT REVIEWS

The following sub-headings were used to categorise the reviewed measures:

General application across condition and setting (Table 11.5)

Improving Chronic Illness Care Evaluation (ICICE)
Patient Assessment of Chronic Illness Care (PACIC)
(Assessment of Chronic Illness Care (ACIC))
Quality of Care through the Patients Eyes (QUOTE)

General application across condition, but specific to setting (Table 11.6)

Primary care

Clients Evaluate Practice locations Questionnaire (CEP-Q)
General Practice Assessment Questionnaire (GPAQ)*
Health care System Hassles Questionnaire (HSHQ)
Seattle Out-patient Satisfaction Questionnaire (SOSQ)

Out-patients

Out-Patient Experience Questionnaire (OPEQ)

In-patients (and ambulatory care)

Picker Institute
Adult In-Patient Experiences Questionnaire (I-PEQ)
Picker Patient Experiences Questionnaire (PPE-15)
Consumer Assessment of Health Plans (CAHPS)*

Specific application to condition and setting (Table 11.7)

Out-patients

Picker Musculoskeletal Disorder (MSD) Questionnaire
Picker I-PEQ Coronary Heart Disease (I-PEQ (CHD))

Cancer-specific (Table 11.8)

European Organisation for Research and Treatment in Cancer –
In-patient Satisfaction Questionnaire EORTC IN-PATSAT32

* *Measures not included in total number of reviewed measures*

GENERAL APPLICATION ACROSS CONDITION AND SETTING

a) Improving Chronic Illness Care Evaluation (ICICE) (Baker et al., 2005 a,b)

The Improving Chronic Illness Care Evaluation (ICICE) was developed in the USA as a comprehensive, patient-reported measure to evaluate the Chronic Care Model (CCM) of chronic illness care; the developers suggest that the model enables one – ‘to look inside the black box’ and see what elements of the CCM work (Baker et al., 2005a). The multidimensional measure was developed for the evaluation of quality of care across larger population groups to determine the effectiveness of quality improvement activities targeted specifically at groups with chronic illness; it may have particular relevance to research studies.

The ICICE was developed for the ICICE study, which sought to measure the impact of the CCM for several chronic conditions as part of a quality improvement initiative. However, the ICICE model reported by Baker et al., (2005a, b) is applied to the evaluation of a CCM for patients with heart failure only, and hence several items are specific to this condition. The CCM provides the conceptual basis to the measure, including core dimensions such as communication, patient education and information, support for self-management and patient goal setting, and links to community services. Items were generated from already existing measures, experts in the field, and reviews of the literature. Additional items are specific to chronic care management for people with heart failure. Specific involvement of patients and health care professionals is not reported.

The ICICE dimensions are: communication (4 items with 5-point scale; the mean of 4 items is calculated; 3 additional items have yes/no response options); satisfaction (4 modified items from the Consumer Assessment of Health Plans Study (CAHPS) instrument; each item has a 5–point agreement scale; the mean value is calculated); patient education (13 items across 3 condition-specific factors – pathophysiology and treatment; medication adherence; lifestyle modification and weight monitoring; yes/no response); patient knowledge (15 items across three condition-specific factors); and patient behaviours (items related to self-management for heart failure); self-efficacy (3 items relating to self-management relevant to heart failure; 5-point agreement scale; mean value calculated); and health status (generic health status assessed using the SF-12; condition-specific health assessed with the ICICE Heart Failure Symptom Scale; 7 items modified from several other heart failure-specific measures; 5 or fewer response options per item; score 0-100, where 100 indicates no symptoms), as shown in Tables 11.4 and 11.5. Access to care and overall quality of care (information accessed from patients’ medical notes) are also assessed; however, the methodology is not reported in the published literature. Although the total number of items is not clear, there are more than 50 items for the described dimensions.

Administration is via telephone, with an average completion time of 34 minutes. Relevance and comprehension to patients and / health professionals has not been reported. The complete version of the telephone survey is available on-line (<http://www.rand.org/health/ICICE/pdfs/chf.pdf>.)

Measurement and practical properties (Table 11.9)

There is acceptable evidence of internal consistency reliability, and some evidence of validity for several dimensions following completion by a large group of patients with heart failure, identified from hospital clinics and health plans in the USA. Evidence suggests that the communication dimension may support the detection of differences between groups and improvements in communication over time (although evidence for responsiveness to quality improvement initiatives are limited (Baker et al., 2005b)). The ceiling effects reported for the satisfaction dimension limits the ability of this dimension to detect group differences or temporal trends. The ICICE is a relatively long questionnaire, requiring a significant time period for completion; self-completion has not been assessed.

Discussion

The ICICE represents a generic model for the evaluation of chronic care for long-term conditions, congruent with the Chronic Care Model. Key dimensions are informed by the CCM model and, where appropriate to the model, made specific to the target condition. Hence, although the model is clearly generic across chronic conditions and the provision of care, measurement is specific to conditions.

Although the developers suggest that the number of dimensions included in the ICICE allow for the evaluation of specific elements of the CCM, the full questionnaire is long and resource intensive in completion. It may be more appropriate for health service research settings as opposed to routine practice settings. The ICICE is a relatively new model for evaluation, and evidence of measurement and practical properties are limited, and only assessed in a US population; feasibility in a routine setting has not been explored.

b) Patient Assessment of Chronic Illness Care (PACIC) (Glasgow et al., 2005)

The Patient Assessment of Chronic Illness Care (PACIC) was developed to evaluate the extent to which patients with chronic illness receive care that aligns with the Chronic Care Model (CCM) (<http://www.improvingchroniccare.org>) (Glasgow et al., 2005a). The developers suggest that there are no comparable patient-reported measures that evaluate the quality of patient-centred care, congruent with the CCM, for people with chronic illness. The measure was developed for application in a variety of health care settings, by individuals with one or more of a range of chronic illnesses.

The CCM emphasises an evidence-based approach to health care that is population-based, patient-centred, proactive and planned. Moreover, care includes key elements of self-management support such as collaborative goal setting, problem-solving and follow-up support (Glasgow et al., 2005a). In developing the PACIC, the CCM framework was evaluated by experts in the field of chronic disease management, and used to inform qualitative interviews with patients. The initial item pool was informed by interviews with national experts in chronic disease management and the CCM from the USA. Items, and earlier versions of the measure, were subsequently piloted and re-tested with patients with one or more chronic disease and further experts to ensure that items were both acceptable and representative of the underlying constructs in the CCM.

The PACIC includes 20 items across 5 dimensions: patient activation/involvement (3 items), delivery system design/decision support (3), goal setting (5 items), problem solving/contextual counselling (4 items), and follow-up/coordination (5 items), as shown in Tables 11.4 and 11.5. Although the CCM defines 6 dimensions of health care quality, issues such as organisation of health care and clinical information systems were omitted from the PACIC due to lack of specific visibility to patients. For each item, patients rate the frequency with which they experienced a particular event / action over the previous six-months, on a five-point scale ranging from 1 (no or never) to 5 (yes or always). Patients evaluate care delivered from their primary health care team for the chronic disease they perceive as impacting most on their life. Items scores are summed and a mean score for each dimension and a total mean score is produced (range 0-20, where 20 is best quality care).

Measurement and practical properties (Table 11.9)

Although a relatively new measure, the PACIC has been completed by large numbers of patients, aged 50 years and over, in the USA with one or more chronic diseases; most commonly hypertension, arthritis, depression, diabetes, asthma, and chronic pain (Glasgow et al., 2005a, b). Early evidence supports high levels of internal consistency reliability (greater than 0.77), but moderate levels of test-retest reliability (three-month retest: range 0.47 to 0.68; overall 0.58). Strong evidence of construct validity, supporting a priori hypotheses, was reported when assessed against other patient-reported measures of health care quality (subscales from the revised Primary Care Experiences Questionnaire; Safran, 2003), and a measure of self-activation which assesses the extent to which patients feel able to take responsibility for their care – an important consideration in chronic disease management (Patient Self-Activation Scale - Hibbard et al., 2004). Data quality was good across all patient groups, with evidence to support the proposed factor structure and no evidence of ceiling effects. The responsiveness of the measure to a quality improvement initiative has not been reported.

Self-completion reportedly required between 2 and 5 minutes; slightly longer for telephone administration (between 7 and 8 minutes). A copy of the PACIC is available from the ‘Improving Chronic Illness Care’ website:

<http://www.improvingchroniccare.org>

An earlier measure proposed by the development team is the ***Assessment of Chronic Illness Care (ACIC)***, completed by clinicians and health care team members to evaluate the extent to which the ‘team’ employs elements of the CCM in the routine care of patients (Bonomi et al., 2001). Evidence supports the reliability and validity of the ACIC, and indicates that it is responsive to improvements in the quality of care following CCM-based quality improvements (Bonomi et al., 2001; Wagner et al., 2001). It is recommended that the ACIC is applied alongside the PACIC, providing complementary provider and patient (‘consumer’) assessments of health care quality for chronic illness. The feasibility of completing and reporting on both measures has not been reported.

Discussion

Unlike other patient-reported measures of health care quality which report on the overall receipt of health care, or the experience of health care which may have relevance to chronic care, for example, including issues such as access and continuity

of care, the PACIC is the only multi-item measure that is specifically aligned to the provision of health care defined by the Chronic Care Model. As such, the measure has good face and content validity for the evaluation of quality in chronic disease management.

Development involved experts in chronic disease management, patients with one or more chronic diseases, and reference to detailed literature reviews, further enhancing content validity. Moreover, evidence of acceptability to patients, and measurement reliability and validity across these patient groups is good. There is limited evidence detailing the feasibility of application; however, it is a relatively brief measure with a simple scoring process.

There is no evidence of measurement responsiveness to change following quality improvement initiatives, and evidence of application in a UK setting is lacking. The PACIC, and the ACIC, are promising measures and warrant further consideration for application in the UK policy context.

c) Quality of Care Through the Patient's Eyes (QUOTE) (van Campen et al, 1998)

A team from the Netherlands Institute for Health Service Research (Nivel: <http://nivel.nl>) has developed a suite of patient-reported measures designed to understand the patients experience of health care 'through the patients' eyes' (van Campen et al., 1998). The original development of questionnaires took place during the late 1980's, and development continues to date. Both the structure (continuity of care, costs, accommodation, accessibility) and process (courtesy, information, autonomy and competence) of health care service delivery were considered important elements to understanding the patient experience of health care and are included as key dimensions in the multidimensional questionnaires developed.

The QUOTE questionnaires have two sections: the first evaluates patient expectations from health care (how important are specific aspects of care?); the second evaluates an individual's actual experience (perceived experience and problems?). First, patients are asked to rate the importance of several key indicators of health care quality ('Important or not?'). For example, '*Doctors ... should be conversant with my health problem*'. The four response options inform the 'importance score': Not important, Fairly important, Important, Extremely important. Second, patients are asked to score their actual experience. For example, '*Doctors ... were conversant with my health problem*'. The four response options inform the 'performance score': No, Not really, On the whole yes, Yes.

The measurement of importance acknowledges that patients do not value all aspects of quality similarly. For the purpose of statistical analysis, the quality judgment is equal to the importance score multiplied by the (perceived) performance score.

Each QUOTE questionnaire contains a core generic set of items applicable to a range of users of health care services; the four original QUOTE questionnaires (Rheumatology (Rheum), chronic non-specific lung disease (CNSLD), disabled and elderly) share the same generic set of items (van Campen et al., 1998). Core dimensions include access to care, coordination and integration of care, information

and communication, respect for patient values, preferences and expressed needs, continuity and transition of care, as shown in Tables 11.4 and 11.5.

Additional specific items support the evaluation of health care experience of relevance to specific conditions or patient groups, as listed below. Core and specific items for all questionnaires were informed by detailed qualitative interviews and focus groups with representative patients exploring patients concerns in relation to health care (for example, van Campen et al., 1998); health care professionals were also consulted, and detailed literature searches performed. Involvement of patients ('clients') ensures that the questionnaires are written in plain language that is understandable, supporting face content and acceptability.

QUOTE questionnaires are self-completed and are currently available for the following conditions or patient groups (www.nivel.nl/oc2/page.asp?PageID=5386) (Accessed August 2006):

- Breast Cancer
- Cancer (generic)
- Cataract
- Chronic non-specific lung disease (QUOTE-CNSLD) – asthma and chronic obstructive lung disease
- Diabetes (QUOTE-DM)
- HIV
- Inflammatory Bowel Disease (QUOTE-IBD)*
- Rheumatic Patients (QUOTE-Rheum)
- Elderly people
- Patients undergoing fertility treatment
- Disabled persons (QUOTE-disabled)
- Occupational Therapy Users (QUOTE-OT)*

All questionnaires were developed in Dutch; only the QUOTE-IBD and QUOTE-OT have English translations. Items referring to cost of health care have been removed from the English translations to improve relevance to the UK context. Published evidence of measurement and practical properties for these two measures has not been identified.

Several questionnaires have specific relevance to the current review: QUOTE-Rheum, CNSLD, DM and disabled. Published evidence reporting measurement and/or practical properties for the QUOTE-DM and QUOTE-disabled have not been identified. There is limited published evidence describing the development and initial evaluation (van Campen et al., 1997) or application (Temmink et al., 1999) of the QUOTE-CNSLD (evidence summarized in Table 11.9): high levels of internal consistency reliability and promising evidence in support of measurement validity has been reported (van Campen et al., 1997). The majority of evidence is available for the QUOTE-Rheum.

QUOTE-Rheum

Although several publications describe application of the QUOTE-Rheum in the Dutch population (van Campen et al., 1998; Temmink et al., 2000; Jacobi et al., 2004), few provide evidence of measurement and/or practical properties (van Campen

et al., 1998). The QUOTE-Rheum has been evaluated following completion by patients across a range of inflammatory and non-inflammatory conditions including rheumatoid arthritis (RA), osteoarthritis, low back pain, ankylosing spondylitis and osteoporosis (van Campen et al., 1998). High levels of internal consistency reliability and good evidence in support of measurement validity have been reported. The questionnaire is suitable for application across the range of health care services accessed by non-institutionalised patients with rheumatic conditions, including care provided by general practitioners, physiotherapy and nursing.

There is little evidence of acceptability to patients (completion rates are not reported) or feasibility of application within a routine practice setting.

Discussion

The concept of a core set of generic items of relevance to the patient experience of health care has intuitive appeal: the needs of different patient groups are similar across a number of core aspects of care. For example, most patients want the opportunity to express their health concerns and to have these taken seriously. Moreover, a core set supports the comparison of health care quality across conditions, settings and hospitals.

However, the model also acknowledges the importance of recognising issues of relevance to specific conditions or population groups in the evaluation of health care quality. For example, access to care and continuity of care are important issues for people with long-term chronic conditions.

The QUOTE programme of work provides an important contribution to the evaluation of health care quality – and there are several interesting developments in the evaluation of health care quality of relevance to chronic disease. However, there is limited evidence of application in the UK setting. Modification of item content would be required to improve relevance to the UK policy context, particularly with reference to pay for service items. Further evidence for the performance of modules relating to chronic conditions, such as the QUOTE-CNSLD and QUOTE-disabled is also required.

Table 11.5. Patient-reported measures of health service quality: General application across condition and setting

| Measure (Developer) | Aim / Focus | Domains (no. items) | Response options | Score | Completion | Setting | other |
|---|--|---|--|--|---|---|--|
| <p>ICICE Improving Chronic Illness Care Evaluations Baker et al., 2005a,b</p> | <p>To evaluate the impact of Chronic Care Models of care Conceptual model – CCM</p> <p>‘model for a comprehensive instrument to measure all elements of the CCM’ – to ‘look inside the black box’ and see what elements worked</p> <p>Measuring quality of care for larger population groups; determine effectiveness of QI activities</p> | <p>1. a Communication (4) - participatory decision-making; encouragement; perceived interest in pt questions; regular review of mgt plan. 1. b 3 yes/no items re goal setting 2. Satisfaction (4) – modified from CAHPs – satisfaction with Dr / nurse 3. Patient education (13), 4. Knowledge (15) 5. Self-management, 6. Self-efficacy (3) 7..a Health status: generic (SF-12) and 7.b HF specific (7) 8. Access to Care – not reported NR 9. Quality of care – from notes** NR</p> | <p>Items 1a, 2, 6 use 5 point Likert agreement scale (1 strongly agree to 5 strongly disagree)</p> <p>Items 1b, 3,4 5 - Yes/No</p> | <p>1. a Mean of 4 items. 1. b Yes/No items 2. Mean of 4 items 3, 4 5 – % Yes/No 6 Mean of 3 items</p> | <p>Patient interview – telephone survey</p> | <p>Evaluation of CCM model of care – across all settings (tested in primary care)</p> <p>Initial development / evaluation in patients with Heart Failure (HF)</p> | <p>http://www.rand.org/health/projects/icice/pdfs/chf.pdf</p> <p>Single domain scores for domains 1 and 2 (but Sat scores very skewed); separate scores for 3 – 6 = considered critical elements of quality care for HF and other chronic diseases.</p> <p>USA only</p> |
| <p>PACIC Patient Assessment of Chronic Illness Care Glasgow et al., 2005a, b</p> | <p>To assess the extent to which patients with chronic illness receive care that aligns with the CCM</p> <p>To complement the ACIC – providing the patient perspective on receipt of CCM-related chronic illness care</p> | <p>Index: Overall PACIC (20 items) 1. Pt Activation/ Involvement* (3) 2. Delivery System Design / Decision Support (2) 3. Goal setting* / Tailoring items (5) 4. Problem-solving / Contextual* (4) 5. Follow-up / Coordination (5)</p> <p>Scales emphasise pt-HCT interactions – esp aspects of self-mgt support*</p> | <p>5 point categorical / Likert-type (almost never) to (almost always)</p> <p>extent to which actions / care received over past 6mths congruent with CCM</p> | <p>Mean for dimensions ; mean index 0-20</p> | <p>Patient self</p> | <p>All settings in which care can be received; tested in primary care setting</p> | <p>Copy; web-site (www.improvingchroniccare.org)</p> <p>From Improving Chronic Illness Care programme</p> <p>USA only</p> |

| Measure (Developer) | Aim / Focus | Domains (no. items) | Response options | Score | Completion | Setting | other |
|--|---|--|---|--|---|---|--|
| PACIC with 5 A's Glasgow et al., 2005b | Original PACIC plus 6 items to reflect 5 A's model of behavioural counselling: Ask, Advise, Agree, Assist, Arrange | | Addition of 5 A's | | | Supports evaluation of the receipt of patient-centred care in accordance to CCM framework | |
| ACIC Assessment of Chronic Illness Care *Compliments PACIC Bonomi et al., 2001 | Quality improvement tool to evaluate strengths and weaknesses of care delivery for chronic illness in 6 areas. Focus – organization of care for chronic illness. Aligned with CCM | 1.Community linkages 2.Self-management support 3.Decision support 4.Delivery system design 5.Information systems 6.Organization of care | | Sub-scales scores 0-11 (11 optimum care) | <i>*Completed by 'Team' NOT patient</i> | All settings in which care can be provided | Copy in appendix. web-site (www.improvingchroniccare.org/ACIC%20docs/ACICV3.5.pdf) |
| QUOTE 1.Generic core 2.Specific Rheumatic Patients Chronic non-specific lung disease (CNSPD) Diabetes (DM) Disabled population Netherlands Van Campen et al., 1998 | Measure quality of care from the perspective of the non-institutionalised patient. Consider needs, expectations and experiences Multi-dimensional taxonomy: focus structure and process | Total 32 indicators 1.General QUOTE** (16) as: Patient indicators (items 1-16) Structure quality (items 7-14) Process quality (items 1-6, 15, 16) • includes items relating to cost of care • 2.Specific items: Rheum-specific (16) (items 17-32) CNSPD DM Disabled | 1.Relative importance (I) rated 4-point scale (unimportant to extremely important) 2.Performance (P) rated 4-point scale (no; not really; on the whole yes; yes) | Q = I x P | Self (postal) | Focus on range of care services used by non-institutionalised patients with rheumatic conditions (RA, AS, OP, OA, LBP) (range home care to specialist care) | Contains common generic and condition-specific items (core of 4 measures developed**) Developed in collaboration with patients Non-English translation |

Footnote: ** QUOTE original four population-specific questionnaires have same generic items: Rheumatic patients (Rheum), chronic non-specific lung disease (CNSPD), Disabled (disabled) elderly (elderly).

Instrument Reviews

General application across condition, but specific to setting (Table 11.6)

Primary Care

The review process identified a large number of measures for the evaluation of health care within a primary care setting, for example, the Components of Primary Care Instrument (Flocke, 1997) and the Primary Care Assessment Survey (Safran et al., 1998). However, only three measures specifically considered health care quality from the perspective of an individual with long-term, chronic disease:

 Clients Evaluate Practice locations Questionnaire (CEP-Q)

 Health System Hassles Questionnaire (HSSQ)

 Seattle Outpatient Satisfaction Questionnaire (SOSQ)

a) Clients Evaluate Practice locations (CEP) Questionnaire (CEP-Q) (Wensing et al., 1996a, 1998)

The Clients Evaluate Practice locations Questionnaire (CEP-Q) was developed to enable patients with one or more chronic condition to assess several aspects of health care provided by their general practitioner (GP) within a primary care setting (Wensing et al., 1996a,b). It is suggested that the measure could be used to support a patients' positive or negative assessment of health care, and to stimulate physicians towards improving the quality and outcomes of their care.

The initial item pool was informed by a consensus study with 19 General Practitioners and 34 patients with chronic illness; a further evaluation of items and questionnaire performance involved 249 patients from six general practices within the Netherlands (Wensing et al., 1996a).

The CEP-Q includes 51 items across 9 core dimensions of health care (Vingerhoets et al., 2001): organization of care (9 items), availability for emergencies (3 items), premises/environment (3 items), continuity (4 items), cooperation (4 items), medical Care (6 items), relation / communication (10 items), information and advise (6 items), and support (6), as shown in Tables 11.4 and 11.6. Two broader dimensions are described: first, organisation of care includes items relating to access to care, the environment, continuity of care, and co-ordination between care providers. The second dimension includes items to evaluate the humaneness of the GP, patient involvement, the provision of information, emotional support and support for the patients' network. Patients respond to all items using 6-point descriptive scale ranging from 'poor' to 'very good'. Two items evaluating patients' needs for more care are evaluated on 3-point descriptive scales: 'yes, I like to'; 'it doesn't matter' and 'no, I'd rather not'. For each dimension item scores are summed and a mean score for each dimension produced (range 0-'x', where 0 is poor quality care). A revised 12-item questionnaire has been referred to (Sixma and Spreeuwenberg, 2006), but at the time of writing limited evidence of development and performance was identified.

Measurement and practical properties (Table 11.10)

The CEP-Q was developed in Dutch and has not been evaluated in the UK health care system. Extensive focus groups with patients with chronic illness and general practitioners were described to inform item content (Wensing et al., 1996a). However, limited published evidence of measurement and practical properties was identified.

Discussion

The CEP-Q was first published in 1996, and although early evidence for its measurement and practical properties was promising, there is limited evidence of its application in more recent published studies.

The General Practice Assessment Questionnaire (GPAQ) is recommended in the UK for the evaluation of health care quality of relevance to the primary care setting (<http://www.gpaq.info/about%20GPAQ.htm>). The GPAQ is summarized in the next section 11.5.2 (b); although not specific to the evaluation of health care for people with chronic disease, reference to the GPAQ in the current review is appropriate for completeness and to reflect the current status of health care quality assessment in the UK primary care setting.

b) General Practice Assessment Questionnaire (GPAQ) (Roland et al., 2006: www.gpaq.info/)

The General Practice Assessment Questionnaire (GPAQ) was developed in the UK and has recently been proposed as the successor to the original General Practice Assessment Survey (GPAS) questionnaire, on which it was based. The GPAQ is a patient-reported questionnaire to inform general practices of what patients think about care provided. It includes multiple aspects of general practice - specifically, including access, interpersonal aspects of care and continuity of care, and is the UK recommended assessment tool for general practice for the new GP contract to inform the 'Quality and Outcomes Framework' (<http://www.ic.nhs.uk/services/qof>).

Items for the GPAQ were informed by the GPAS, which in turn was developed from the Primary Care Assessment Survey (PCAS) (Safran et al., 1998); the PCAS has been widely used in the United States. The development team from the National Primary Care Research and Development Centre, Manchester, has led the development and validation of the GPAS and GPAQ. The GPAS was widely used in UK-based research to evaluate the quality of primary health care, as perceived by members of the general population attending primary care practices, during the late 1990's and early 2000's (for example, Campbell et al., 2003, 2005; Bower et al., 2003): the GPAQ is a shorter, more easily completed version of the GPAS.

Item content focuses on access, interpersonal aspects of care and continuity of care – items of health care quality not covered by other elements of the GP contract. There are two versions of the GPAQ: the postal version contains 25 items – receptionist (2 items), access (11 items), continuity (2 items), communication (8 items), and practice nurse (3 items). Items relating to the practice nurse are replaced in the 'consultation version' by items relating to enablement (3 items). The majority of items require patients to rate the level of 'excellence' of care on a 6-point adjectival scale ('very poor' to 'excellent'). Several items have 'time' related responses.

Computer software programmes are available to support scoring and data analysis. Mean scores are calculated for each question (each question has more than one item), and expressed as a percentage of the maximum possible score for each 'question' (where 100% is best possible score).

Measurement and practical properties

Evidence for the GPAQ is currently limited; however, the developers anticipate that the measurement properties will be similar to those established for the GPAS (www.gpaw.info/validation.htm). Measurement properties for the GPAS have been reported following completion by random samples of adults attending primary care practices in the UK, and evidence suggests acceptable levels of reliability and validity; there is limited evidence of performance specific to patients with long-term or chronic disease.

Discussion

The GPAQ is designed to be widely applicable to the general population accessing care from their general practice, and across a wide range of health states presenting in a primary care setting. Although not specific to the needs of individuals with chronic ill-health, the wide range of dimensions included in the questionnaire have clear relevance to this patient population group. Increasingly patients with chronic disease receive care within the primary care setting; the appropriateness of questionnaires to the evaluation of health care of relevance to patients with long-term conditions is important to future quality improvement initiatives. Further evidence of measurement and practical properties for the revised GPAQ is required.

c) Healthcare System Hassles Questionnaire (HSHQ) (Parchman et al., 2005)

The Healthcare System Hassles Questionnaire (HSHQ) was developed in the USA to enable patients with chronic illness to report difficulties experienced in accessing care within a primary health care setting; more specifically, to report how the receipt of care for chronic illness is facilitated by the primary care provider (Parchman et al, 2005).

The concept of ‘hassles’ is further defined as ‘troubles’ or ‘bothers’ that patients may experience during their numerous encounters with the health care service; qualitative focus groups with patients with chronic illness raised major concerns with health service interactions. Knowledge of the requirements and experience of people with chronic disease and the increasing role of primary care physicians in providing care highlighted key dimensions for consideration in the provision of health care: access to care, continuity of care, knowledge of the patient by the physician, coordination of care, and communication between patient and physician.

Items for the HSHQ were developed to reflect problems encountered by patients when visiting general health care providers; more idiosyncratic variables such as satisfaction with one specific clinic, provider or specific visit, or factors not amenable to change (e.g., cost or facilities) were avoided. ‘Hassles’ was operationalised as ‘the reporting of events’, as distinguished from the concept of ‘dissatisfaction’ which provides an evaluation of these events. An initial pool of 126 items (generation not clear) was piloted with a convenience sample of primary care patients (n= 132). Additional focus groups with 60 patients with two or more chronic illnesses further informed item development and comprehension. The final questionnaire contains 16 items coded on a 4-point descriptive scale, where 0 is ‘not a problem’ and 4 is ‘a very big problem’, as shown in Table 11.6; dimensions of care are listed in Table 11.4. Respondents are

asked to rate problems that may make it difficult for them to care for their chronic illness. Items are summed, 0-64, where 64 is the greatest level of hassle experienced.

Measurement and practical properties (Table 11.10)

Initial evaluation of the HSHQ involved participants from a larger study of US primary care (Parchman et al, 2005). Patients had one or more chronic illness. Initial evidence supports high levels of internal consistency reliability (greater than 0.90). Acceptable evidence of construct validity, supporting a priori hypotheses, was reported when assessed against the Components of Primary Care Instrument (CPCI), a patient-reported measure of primary health care quality. The CPCI includes dimensions to assess communication, preference for physician, knowledge of patient, and coordination of care (Flocke, 1997). The types of hassles experienced by patients with single or multiple morbidities was also assessed; patients with multiple chronic illnesses reported more problems with accessing information, problems with medication, and lack of time with clinicians. Evidence suggests that health care system hassles, as measured by the HSHQ, are inversely related to the level of communication and the extent to which care is coordinated within the primary care setting: as coordination and communication improved, the level of hassles also improved.

Data quality was acceptable, although a tendency towards end effects was reported; additional evidence supports the proposed factor structure. The responsiveness of the measure to quality improvement initiatives has not been reported. The questionnaire is brief and would appear to be simple to complete and score; the involvement of patients in item development supports the face validity and acceptability of the measure. However, response rates to the overall survey were low. Evidence of feasibility within a routine setting is not reported.

Discussion

The HSHQ provides a brief report of ‘hassle’ or difficulties encountered by patients with chronic illness when accessing care in a primary care setting. Development involved a large number of patients with a range of chronic conditions, and items were designed to be generic across conditions and across primary care providers.

Evidence suggests that key components of the HSHQ relate to communication and coordination of care, both essential elements of quality health care in a primary care setting, and for people with chronic disease. The measure may provide a useful resource to inform the reduction of patient ‘hassles’ during their interaction with the health care delivery system; in particular difficulties with communication and coordination of care in a primary care setting would be highlighted.

d) Seattle Outpatient Satisfaction Questionnaire (SOSQ) (Fihn et al., 2004)

The Seattle Outpatient Satisfaction Questionnaire (SOSQ) was developed to evaluate patient-reported satisfaction with health care provision from primary care providers and outpatient clinics for people with chronic disease (Fihn et al., 2004). The original development involved patients with one or more chronic conditions, including ischaemic heart disease, chronic obstructive pulmonary disease and diabetes. Patients were participants in the Ambulatory Care Quality Improvement Project; a project designed to evaluate if a comprehensive programme of sustained feedback to health

care providers about their patients' general and specific health, and their satisfaction with care, would result in improved health outcomes over time. It appears that the SOSQ was constructed specifically for this trial; all three publications refer to application of the SOSQ in this trial (Fihn et al., 2004; Reiber et al., 2004; Fan et al., 2005b).

The SOSQ has a total of 21 items and consists of two scales taken from available measures of patient satisfaction: 1) the Humanistic Scale (12 items) addresses the personal attributes of the primary care physician, taken from the 23-item American Board of Internal Medicine Patient Satisfaction Questionnaire (Webster, 1989); 2) the Organisational Scale (9 items) addresses issues related to the delivery and organisation of care, for example, access, waiting time, and choice of physician (Tables 11.4 and 11.6). This scale was modified from the RAND Patient Satisfaction Questionnaire. Clarity of item content across the two dimensions is not provided. The involvement of patients and health care professionals in item selection and initial questionnaire development is not reported; hence, evidence for the acceptability, face validity, and potential appropriateness of the questionnaire is unclear. Further detail pertaining to development and initial testing is limited (Fan et al, 2005).

Responses to each item are on a 5-point descriptive scale (from poor to excellent). Items scores are summed into two scales, and transformed to scores ranging from 0 (least satisfied) to 100 (most satisfied).

Measurement and practical properties (Table 11.10)

There is limited evidence for the internal consistency reliability of the SOSQ (Fan et al., 2005a), and only limited evidence of validity following completion by patients with one or more chronic conditions in the USA (Fan et al, 2005a,b). Evidence suggests that for patients with IHD, COPD and DM, patient education and ability to cope with their disease was more strongly associated with patient satisfaction with health care (as measured by the SOSQ), than disease severity. However, evidence for the acceptability of the questionnaire to patients and feasibility for completion in a clinic setting is limited.

Discussion

The availability of a measure to evaluate patient satisfaction with the provision of health care in a primary care setting for people with chronic disease has value and relevance to this review. Although the SOSQ is relatively brief and simple to complete, there is limited evidence supporting the involvement of patients or health care professionals in the initial development and testing of the questionnaire; evidence for the acceptability, content and face validity of the questionnaire is therefore limited. Minimal evidence for measurement and / or practical properties exists.

The SOSQ attempts to provide a multi-dimensional assessment of patient satisfaction with the provision of health care, in a primary care setting, for people with one or more chronic, long-term conditions. However, confidence in the performance of this measure is limited due to poor evidence of development and subsequent evaluation.

Out-patients

e) OutPatient Experiences Questionnaire (OPEQ) (Garratt et al., 2005)

The OutPatient Experiences Questionnaire (OPEQ) was developed in a Norwegian population to provide a patient-report of health care experience suitable for application across a range of out-patient clinic settings (Garratt et al., 2005). The measure was developed for application in a variety of health care settings, by individuals with one or more of a range of somatic conditions. The questionnaire was developed for application across a range of outpatient clinic settings, and was designed to be brief, acceptable to patients and easily completed.

Development involved extensive literature reviews of Anglo-American and Scandinavian literature of relevance to patients' experience of outpatient settings, and was further informed by earlier experience with a Norwegian measure of inpatient experience of health care quality (Patient Experience Questionnaire; Pettersen et al., 2004). Focus groups with health care professionals (doctors and nurses) across a range of outpatient clinic settings – cardiology, gynaecology, neurology, oncology, respiratory medicine, surgery – assessed items and dimensions of health care quality for their relevance to patient experience and the Norwegian setting. Relevance and comprehension was further assessed during qualitative patient interviews.

The OPEQ includes 26 items across 6 dimensions (Tables 11.4 and 11.6): clinic access (2 items), communication (6 items), organisation (4 items), hospital standards/environment (3 items), information (6 items), pre-visit communication (3 items). Each item has a 10-point scale with descriptive anchors (not detailed); patients report on their experience at the outpatient clinic. Items scores are summed and a mean score for each dimension ('scale') is produced (range 0-100, where 100 is the best experience).

Measurement and practical properties (Table 11.10)

The OPEQ has good evidence for internal consistency reliability, test-retest reliability and validity following completion by a large patient population sample (aged 16 years and above) identified from a range of outpatient clinics, and is recommended as an appropriate measure of patient experiences of outpatient clinics in Norway. Although only moderate survey response rates were reported (53.9%), low levels of questionnaire missing data were reported, suggesting high levels of acceptability.

Discussion

The OPEQ provides a multi-dimensional measure of outpatient experience across a range of clinic settings, and hence across a range of conditions. The views of a range of health care professionals and patients were central to questionnaire development. The OPEQ has been completed by a large number of patients representing a wide range conditions and age range; it appears that both acute and chronic disease populations were included in development and testing. The questionnaire is brief, simple to complete and evidence suggests high levels of patient acceptability. Good evidence of measurement reliability and validity is provided. Evidence of responsiveness to change in health care provision is not available.

Published evidence of a similar measure, generic across conditions and suitable for the evaluation of outpatient experience has not been identified in the UK setting.

Replication of the results for the OPEQ or similar measures specific to the evaluation of outpatient care, of relevance to chronic disease, in the UK health care system is required.

In-patients

f) The Picker Institute

The Picker Institute (USA and Europe) has developed a suite of patient-reported measures designed to seek detailed information relating to a patient's experience of health care. The original development of questionnaires took place in the USA during the late 1980's, funded by the Picker/Commonwealth Programme for Patient-Centred Care (www.pickereurope.org). The questionnaires have been used in postal surveys in the UK since 1994.

The questionnaires all address multiple dimensions of health care informed by detailed qualitative interviews and focus groups with patients exploring patients' concerns in relation to health care, consultation with experts, and systematic literature reviews (Gerteis et al., 1993; cited by Jenkinson et al., 2002a, b). These dimensions include access to care, coordination and integration of care, information and communication, respect of patient values, preferences and expressed needs, involvement of family and friends, continuity and transition of care. Items are phrased to explore if certain processes or events occurred during an episode of care, and hence reflect patient experience of health care; they do not assess patient satisfaction. Response options are generally 'Yes, completely; Yes, to some extent; No'. For the purpose of statistical analysis, all items are coded as dichotomous 'problem scores', indicating the presence or absence of a problem; a problem is defined as an aspect of health care that, in the eyes of a patient could be improved upon (Jenkinson et al., 2002a).

The Picker questionnaires are self-completed and are currently available for a range of hospital settings (website lists the following settings: outpatients, accident and emergency, maternity, day surgery, primary care, rehabilitation and home care – accessed 21/10/06) and conditions (website lists cancer, heart disease, hip replacement and back pain – accessed 21/10/06). Published evidence for the following questionnaires has been identified and used to inform the current review:

Picker Adult In-patient Experience Questionnaire (I-PEQ)

I-PEQ Coronary Heart Disease (I-PEQ CHD)

(detailed in section 11.5.3)

Picker Patient Experience questionnaire (PPE-15)

Picker Musculoskeletal Disease Questionnaire (Picker MSD Questionnaire)

(detailed in section 11.5.3).

Picker adult In-patient Experience Questionnaire (I-PEQ)

The original Picker adult in-patient experience questionnaire (I-PEQ) contains 40 items across seven dimensions of health care (Tables 11.4 and 11.7), and is suitable for the evaluation of in-patient hospital care across a range of surgical and medical conditions. The original I-PEQ was developed in the USA and has undergone multiple translations. The I-PEQ was modified for a UK population by the removal of items referring to payment for health care; the semantic equivalence of items for the UK audience was also evaluated (Jenkinson et al., 2002a). Good evidence in support

of measurement validity has been reported following completion by a range of UK, including those receiving in-patient care for medical (not detailed), orthopaedic, and surgical 27.9% conditions, and care for older people (Jenkinson et al., 2002a). However, published evidence in support of measurement reliability has not been identified. Acceptable survey response rates have been reported (range 46% USA to 74% Germany; UK 65%) (Jenkinson et al., 2002a) (Table 11.10).

Picker Patient Experience questionnaire (PPE-15)

A shortened version of the I-PEQ, the Picker Patient Experience questionnaire (PPE-15), was published in 2002 (Jenkinson et al., 2002b). The questionnaire contains 15 items and provides a core set of generic items suitable for the evaluation of in-patient health care across different settings (including both planned and emergency admissions); the developers suggest that optional ‘specific’ modules could be added to the core set of items. However, at the time of writing, published evidence of the development or evaluation of these ‘add-on’ components has not been identified. Evidence following completion by patients in the UK evaluating their experience of acute in-patient hospital care (conditions not detailed) supports high levels of internal consistency reliability, with promising evidence of both face and criterion validity. Survey response rates were acceptable (65%) (Table 11.10).

Discussion

The core dimensions of health care captured within the Picker questionnaires reflect the key elements of health care quality reported by a range of studies exploring health care quality from the perspective of patients (for example, Coulter, 2005). There is also a strong overlap with the nine core dimensions of care recommended by the Institute of Medicine, as shown in Table 11.4. The extensive involvement of patients and health care professionals in item development and subsequent testing of the range of questionnaires provides good evidence of face and content validity; there is acceptable evidence in support of patient acceptability. Limited evidence suggests acceptable levels of reliability. The extensive experience of Picker Institute Europe in running large scale surveys of patients experience in the UK is of note (www.pickereurope.org).

g) The Consumer Assessment of Healthcare Providers and Systems (CAHPS)

The Consumer Assessment of Healthcare Providers and Systems (CAHPS) programme represents a public-private finance initiative focused towards the development of a suite of patient-completed surveys for the assessment of patient and consumer experience of health care within the USA (<https://www.cahps.ahrq.gov/default.asp>). The original development of the CAHPS surveys commenced during the mid to late 1990’s, and were originally focused towards the standardized evaluation of health plans (CAHPS I). However, development has now extended to cover a wide range of conditions and settings (CAHPS II). The CAHPS programme is funded by the US Agency for Healthcare Research and Quality (AHRQ). Evidence of application of CAHPS surveys in the UK setting has not been identified. However, the extensive development of a range of patient completed surveys of experience within the health care setting is of relevance to this review.

The dimensions of the original CAHPS hospital survey were informed by the Institute of Medicines recommendations for key dimensions of health care: the included dimensions were nurse communication, nursing services, doctor communication, physical environment, pain control, communication about medicines and discharge information. The development of CAHPS surveys involves interviews and focus groups with patients, health professionals and a wide range of stakeholders, further supplemented by extensive literature reviews and information from web-chats and stakeholder meetings. Rigorous and scientific methods are applied to support the development of credible and relevant measures of health care quality (Darby et al, 2005). Patients are invited to report on their experience of health care, rather than the evaluation of satisfaction; response options generally encourage a response indicating whether or not an event / action occurred (most items have 4 or more response options).

Several CAHPS surveys are currently available (as listed on the website); several have specific relevance to the evaluation of health care for people with long-term or chronic disease:

CAHPS People with Mobility Impairments Survey: for the evaluation of health care experience by adults with mobility impairment. This survey may be used as a 'stand-alone' survey or as an additional module within the CAHPS Hospital and Ambulatory questionnaire. However, this is a relatively new survey and evidence of measurement properties is not yet published (website: accessed August 2006). These surveys are designed to inform health care providers of the needs and experiences of patients receiving health care within an ambulatory care setting.

CAHPS Hospital Survey: has been developed to provide a patient reported evaluation of health care experience within medical, surgical or obstetric hospital departments (Darby et al., 2005; Goldstein et al., 2005).

Table 11.6. Patient-reported measures of health service quality: general application across condition, but specific to setting

| Measure (Developer) | Aim / Focus | Domains (no. items) | Response options | Score | Completion | Setting | other |
|--|--|--|--|--|--------------|--------------|---|
| Primary Care | | | | | | | |
| CEP-Q Client Evaluates Practice location Questionnaire Wensing et al., 1996a,b | To measure patients opinion about aspects of treatment provided by their GP – of relevance to chronic disease Extensive involvement of health care professionals and patients | 51 items 1. Organization of care (9) 2. Availability for emergencies (3) 3. Premises (3) 4. Continuity (4) 5. Cooperation (4) 6. Medical Care (6) 7. Relation / Communication (10) 8. Information and Advise (6) 9. Support | 6-point descriptive scale (poor to very good) 2 items use 3 point scale: 'yes, I like to' to 'no, rather not' | Summation across dimensions (0 poor quality) | Patient self | Primary care | Completed by patients with range of chronic conditions to evaluate primary care service Netherlands only |
| GPAQ General Practice Assessment Questionnaire Roland et al., 2006 | Patient evaluation of 9 key areas of primary care activity – supersedes the GPAS Recommended for evaluation of UK primary health care | 9 domains, 25 items (2 versions: postal or clinic) 1. Access (11) 2. Continuity of care (2) 3. Communication (8) 4. Practice nurse (3) (postal only) 5. Enablement (3) (clinic only) | Range of response options. Descriptive scales: 'very poor' to 'excellent' Waiting / time for access etc. | Domain scores: summary expressed as percentage (100 best care) | Patient self | Primary care | Specific to evaluation of health care in UK primary care setting Developed under auspices of National Primary Care R&D Centre (www.gpaq.co.uk) |
| HSHQ Health Care System Hassles Parchman et al., 2005 | To measure the level of 'hassles' experienced by patients with regards to care for chronic illness in primary care – <i>how is receipt of care for CI facilitated etc by PC</i> | 16 items Include items relating to: information; access and waiting; communication; continuity; respect for patient values. Extensive involvement of health care professionals and patients | 4-point scale: 0 'no problem' to 4 'very big problem' | Summation 0-64 | Patient self | Primary care | Patient report experience; not evaluate experience (not a measure of dissatisfaction) USA only |

| Measure (Developer) | Aim / Focus | Domains (no. items) | Response options | Score | Completion | Setting | other |
|---|---|---|---|---|------------------------|--|--|
| SOSQ Seattle Outpatient Satisfaction Survey Fihn et al., 2004 | To assess satisfaction with primary care provider in relation to healthcare provision for chronic illness (IHD, COPD, DM) | 21 items 1. Organizational Scale – satisfaction with HC services in internal medicine (x) 2. Humanistic Scale – satisfaction with communication and humanistic qualities of physician (x) | 5-point descriptive scale (poor to excellent) | 2 summary scales. Transformed 0 to 100 (100 most satisfied) | Patient self | Primary care | USA only |
| <i>Out-patients</i> | | | | | | | |
| OPEQ OutPatient Experiences Questionnaire Garratt et al., 2005 | To assess patient experience of hospital out-patient care; completed by somatic patients (not specifically chronic disease) | 26 items Clinic access (2) Communication (6) Organisation (4) Hospital standards (3) Information (6) Pre-visit communication (3) | 10-point scale; descriptive anchors | Item scores and mean value across domains ('scales') | Patient self | Range of clinics – cardio, gynae, neuro, oncology, respiratory, surgery. Not specify acute / chronic | Developed and completed in Norwegian population only |
| <i>Picker Questionnaires</i> | | | | | | | |
| I-PEQ UK Jenkinson et al., 2002a,b | To measure adult experience of in-patient health care Surgical / medical | 40 items Information and Education (5) Respect for Patient Preferences (4) Emotional Support (5) Coordination of Care (6) Continuity and transition (4) Physical comfort (5) Involvement of family / friends (3) Overall impression (8) | 3 options – Yes (completely / always / to large extent); Yes (to some extent / somewhat); No 'Problem scores' – no problem / problem | 40 problem scores (index or item scores) | Postal self-completion | Evaluation of in-patient acute care | Evidence suggests sensitive to change over time, useful for setting priorities for quality improvement and measuring change in care delivery (www.pickereurope.org/) |

| Measure (Developer) | Aim / Focus | Domains (no. items) | Response options | Score | Completion | Setting | other |
|--|--|---|---|--|------------------------|-------------------------------------|-----------------------------|
| PPE-15 Picker Patient Experience Questionnaire UK Jenkinson et al., 2002b | Core set of items to measure patients' experience of in-patient care Surgical / medical | 15 items Information and Education (2) Respect for Patient Preferences (3) Emotional Support (3) Coordination of Care (1) Continuity and transition (3) Physical comfort (1) Involvement of family / friends (2) | 3 options – Yes (completely / always / to large extent); Yes (to some extent / somewhat); No 'Problem scores' – no problem / problem | 15 problem scores: score 0-16, where 0 is best quality care (index or item scores) | Postal self-completion | Evaluation of in-patient acute care | Short form version of I-PEQ |

Instrument Reviews

Specific application to condition and setting (Table 11.7)

a) Picker Musculoskeletal Disease Questionnaire (Picker MSD Questionnaire)

A questionnaire specific to the evaluation of patients' experience of out-patient health care for musculoskeletal disease (MSD) (mainly non-inflammatory neck and back pain), the Picker MSD Questionnaire, was developed in 2002 (Jenkinson et al, 2002d). As typifies development of Picker questionnaires, there was extensive patient involvement in item generation and development. Patients (n=13 patients with back or neck pain) and health care professionals (two physicians, two physiotherapists, a chiropractor and osteopath) contributed to initial item development. Reference was also made to an existing Picker out-patient questionnaire to inform item development; however, at the time of writing further evidence or detail pertaining to this questionnaire has not been identified.

A further 13 patients participated in two focus groups; cognitive interviews were subsequently run with 11 additional patients to explore the item content of the proposed questionnaire. The Picker MSD Questionnaire contains 16 items relating to the patient health care experience of relevance to musculoskeletal out-patient care, as summarized in Tables 11.4 and 11.7. The initial long-form version of the questionnaire included items across nine dimensions: access to care, information and education, respect for patient preferences, emotional support, coordination of care, continuity and transition, overall impression; the final version does not include items in the access to care (Table 11.4). An index score may be calculated, or individual scores across the 16 items.

Measurement and practical properties (Table 11.11)

The initial development and testing of the questionnaire was in a Swedish population (Jenkinson et al, 2002d); there is no published evidence of application and evaluation in a UK population. Initial evidence suggests high levels of internal consistency reliability (Kuder-Richardson 0.86), and promising evidence for measurement face and construct validity. However, survey response rates were relatively low (51%) (mean age 54 years (SD 13.84); range 16 – 88 years). Evidence for the feasibility of application is not reported. The low response rate to the survey is surprising; the small number of items, high level of patient involvement and associated evidence of face and content validity would have suggested a higher rate of completion, comparable to that of other Picker questionnaires. The authors suggest that the low response could have been influenced by the large number of questionnaires included in the survey package, or inaccuracies in the sample frame.

b) Picker In-patient Experience Questionnaire – Coronary Heart Disease (I-PEQ (CHD))

A version of the I-PEQ appropriate to the evaluation of in-patient care for patients with coronary heart disease (I-PEQ (CHD)) (Jenkinson et al, 2002c) has also been developed (Table 11.7). The questionnaire contains 38 items across seven dimensions of care, as shown in Table 11.4. Evidence following completion by UK patients who had received hospital in-patient care for coronary heart disease suggests high levels of internal consistency reliability, with good evidence to support the proposed seven measurement dimensions. There is evidence in support of construct validity. Good

acceptability as evidenced by high completion rates was reported (74%) (Table 11.11).

Discussion – Picker MSD and I-PEQ (CHD)

All but one of the reviewed Picker questionnaires, the Picker MSD, are specific to the evaluation of in-patient hospital health care. Although specific to the evaluation of health care experienced by patients with musculoskeletal conditions, several items in the Picker MSD are specific to neck and/ or back pain, and hence the questionnaire is not suitable for completion by patients with more general chronic or long-term physical conditions. Moreover, the questionnaire does not include items reflecting several core dimensions that, evidence suggests, may be important to people with long-term physical conditions or chronic disease, including access to care (Parchman et al., 2005; Haggulund et al., 2005), physical comfort and involvement of family and friends. At the time of writing, published evidence for the availability and performance of a musculoskeletal out-patient questionnaire referred to in the development of the MSD had not been identified. Although further reference to the availability of questionnaires to assess out-patient health care is made on the Picker Institute website (www.pickereurope.org), further contact with Picker Institute Europe is required to explore the availability and evidence for these measures.

Table 11.7. Patient-reported measures of health service quality: specific application to condition and setting

| Measure (Developer) | Aim / Focus | Domains (no. items) | Response options | Score | Completion | Setting | other |
|---|--|---|---|---|------------------------|-------------------------------------|--|
| Picker MSD Q Picker Musculoskeletal Disease Questionnaire Sweden Jenkinson et al., 2002d | To measure experience of health care for patients with musculoskeletal disorders (neck or back pain) Monitor performance of providers; provide direction for improvements in health care delivery Provide info that can be acted upon by providers | 16 items Information and Education (2) Respect for Patient Preferences (3) Emotional Support (4) Coordination of Care (3) Continuity and transition (2) Overall impression (2) *Access to care not included in final version Validation only: Overall Satisfaction: 5-point scale (poor to excellent) Recommend clinic to others?: Yes / yes probably / No | 3 options – Yes (completely / always / to large extent); Yes (to some extent / somewhat); No Problem scores’ – no problem / problem | 16 problem scores: score 0-16, where 0 is best quality care (index or item scores) | Postal self-completion | For patients attending OP clinic | Interviews / FGs with HCPs and patients – important aspects of patient experience of HC for MSD Based on existing Picker OP questionnaire |
| I-PEQ (CHD) UK Jenkinson et al., 2002c | To measure adult experience of in-patient health care specific to Coronary Heart Disease | Total 38 items, 7 domains Information and communication (6) Patient involvement / respect for patient preferences (6) Hospital environment (8) Coordination of Care (7) Discharge and transition (6) Pain / Physical comfort (2) Access (1) | 3 options – Yes (completely / always / to large extent); Yes (to some extent / somewhat); No ‘Problem scores’ – no problem / problem | 38 problem scores (index or item scores) | Postal self-completion | Evaluation of in-patient acute care | Evidence suggests sensitive to change over time, useful for setting priorities for quality improvement and measuring change in care delivery (www.pickereurope.org/) |

Instrument Reviews

Cancer-specific (Table 11.8)

Several condition-specific measures of health care quality were identified in the review process, for example, the Diabetes Measurement and Evaluation Tool (Paddock et al., 2000) and the Osteoarthritis Treatment Satisfaction Questionnaire (ARTS) (Pouchot et al., 2005). However, most of these measures included an evaluation of the patient experience of disease as well as condition-specific health care, and were therefore excluded from further review. The EORTC IN-PATSAT32 questionnaire was included in the review due to the extensive involvement of health care professionals and patients with a wide range of cancer diagnoses, and the wide range of health care domains included in the final measure.

a) European Organisation for Research and Treatment of Cancer Quality of Care Patient Satisfaction Questionnaire (EORTC IN-PATSAT32) (Bredart et al., 2004, 2005)

The European Organisation for Research and Treatment of Cancer (EORTC) In-Patient Satisfaction with Care Questionnaire (EORTC IN-PAT32) was developed under the auspices of the EORTC quality of life group to provide a patient-reported evaluation of in-patient hospital based care for people with cancer, including perceived care from hospital doctors and nurses, and aspects of health care organisation and service delivery (Bredart et al., 1998, 2004, 2005). Development took place during the late 1990's and early 2000 and involved international collaboration with health care professionals and patients with cancer from across Europe.

The initial item pool was informed by interviews with oncology experts and patients with cancer from several North European countries including the UK. An existing patient satisfaction questionnaire was also utilised. Items, and earlier versions of the measure, were subsequently piloted and re-tested with patients with cancer and additional experts to ensure that items were acceptable and comprehensive.

The EORTC IN-PATSAT 32 includes 32 items across 11 multi-item and three single item dimensions or 'scales'. Patients are asked to rate doctors in terms of their technical skills (3 items), interpersonal skills (3 items), information provision (3 items) and availability (2 items). Nurses are similarly rated across the same dimensions, with items phrased to represent the nursing role (total 11 items). Additional items ask patients to rate other services and the care organisation, and include items relating to interpersonal skills and information provision (3 items), waiting time (2 items) and hospital access (2 items). The three single items refer to the exchange of information between carers, the level of comfort specific to the environment, and an overall rating of care received. All items use five-point categorical response options – 'poor' through to 'excellent'. All scores are linearly transformed to a 0-100 scale, where a higher score indicates a higher level of satisfaction. Patients are invited to complete the questionnaire at home, within six-weeks of discharge from hospital.

Measurement and practical properties

Although a relatively new measure, the EORTC IN-PATSAT32 has been completed by large numbers of patients from diverse cultural groups across Europe, including the UK; there are multiple translations available. Patients involved in measurement testing, aged 18 years and over, have included a wide range of oncology diagnoses, and experienced a range of medical and/ or surgical interventions (Bredart et al., 2005). Evidence supports high levels of internal consistency reliability (greater than 0.88 for all scales except Hospital Access (0.67)), and test-retest reliability (two-week retest >0.70; single item for general satisfaction 0.66). Strong evidence of construct validity, supporting a priori hypotheses, was reported when assessed against other patient-reported measures of health care quality and quality of life (EORTC Quality of Life Questionnaire (QLQ30)). Data quality was good across all patient groups, with evidence to support the proposed factor structure. There was some evidence of potential ceiling effects for several ‘scales’ (> 20% of respondents scoring the highest rating). The responsiveness of the measure to a quality improvement initiative has not been reported.

For the majority of patients, self-completion of both the EORTC IN-PATSAT32 and the EORTC QLQ30 required less than 15 minutes (Bredart et al., 2005); completion time for the EORTC IN-PATSAT32 alone has not been reported. Although the majority of patients did not require assistance with questionnaire completion, older patients were more likely to request assistance.

Discussion

Unlike other reviewed measures, the EORTC IN-PATSAT32 is specific to the evaluation of health care quality for patients receiving in-patient care for cancer. However, it supports the evaluation of surgical and / or medical in-patient care, and is appropriate for completion by patients with a range of cancer diagnoses.

Development involved a range of health care professionals in oncology and patients with a range of cancer diagnoses who had received medical and/or surgical treatment. The extensive involvement of patients and health professionals, from a wide range of cultural settings, in addition to reference to existing literature and an existing measure of satisfaction, contributes to the evidence for good levels of content validity. A wide range of dimensions important to the overall concept of health care quality are included in the measure. Moreover, evidence of acceptability to patients following self-completion, and measurement reliability and validity across these patient groups is very good. Although there is limited evidence detailing the feasibility of application, it is a relatively brief measure with a simple scoring process and has been completed across a large number of oncology settings. There is no evidence of measurement responsiveness to change following quality improvement initiatives.

The EORTC IN-PATSAT32 is a well developed measure of in-patient ‘satisfaction’, or experience, of health care specific to oncology in-patient care. The development and subsequent testing of the measure provides acceptable evidence of both measurement and practical properties. However, evidence of ceiling effects for some items may be a function of the request for respondents to rate levels or satisfaction with or excellence of care provided, as opposed to their experience of care. Although oncology-specific, items are not uniquely tied to oncology. The measure addresses a wide (the widest of all reviewed measures) range of dimensions considered important

in health care evaluation, and clearly of relevance to other long-term conditions; it also includes items of relevance to care provided by different members of the health care team. The measure also appears to address issues of relevance to the current health policy context in the UK.

Table 11.8. Patient-reported measures of health service quality: Cancer-specific

| Measure (Developer) | Aim / Focus | Domains (no. items) | Response options | Score | Completion | Setting | other |
|--|---|---|---|--|-------------------|--|---|
| EORTC IN-PATSAT32 Bredart et al., 1998; 2004 ; 2005 Cross-cultural development | Evaluate cancer in-patient perceptions of the quality of medical and nursing care, and the organisation of care and services received during admission to oncology unit | 32 aspects of care 1. Doctors: technical skills (3); information (3); interpersonal qualities (3); availability (2) 2. Nurses: : technical skills (3); information (3); interpersonal qualities (3); availability (2) 3. Services: interpersonal quality/information (3); exchange of information (1); waiting time (2); accessibility (2); comfort (1) 4. General satisfaction: global evaluation of care (1) Extensive involvement of health care professionals and patients | 5 point scale: poor, fair, good, very good, excellent | Linear transformation 0-100 scale: 100 is most satisfied | Self or interview | Relevance to hospital inpatient experience; completion once discharged to home | Interviews with patient, oncologists; review of satisfaction literature and available questionnaires. Cross cultural (European) development and evaluation. Multiple translations – include English Copy – Bredart 2005 |

CHAPTER 11: SUMMARY OF EVIDENCE

Table 11.9. General application across condition and setting - summary of evidence.

| Study/ Country | Population (N) Age (years) Method of administration Setting | Measurement and Practical properties | | | | | |
|---|---|--|--|----------------|-----------|---------------|-------------|
| | | Reliability | Validity | Responsiveness | Precision | Acceptability | Feasibility |
| Improving Chronic Illness Care Evaluations (ICICE) | | | | | | | |
| Baker et al., 2005a | Chronic heart disease (781) Age 62% older than 65yrs Telephone interview | Internal consistency ✓ Test re-test | Construct ✓ | | ✓ | ✓ | ✓ |
| Baker et al., 2005b | Chronic heart disease (828) Age Telephone interview | Internal consistency Test re-test | Construct ✓ | ✓ | | ✓ | ✓ |
| PACIC | | | | | | | |
| Glasgow et al., 2005a USA | Chronic illness/disease (266) All with more than 1 chronic condition (Hypertension, Arthritis, Depression, DM, Asthma, Pain) Age: mean 64.2 (10.5). 56% female Self-completed Primary Care | Internal consistency ✓ PACIC 0.93 Domains range 0.77 (Decision) to 0.90 (Contextual) Test re-test ✓ 3-months PACIC 0.58 Domains range 0.52 (Pt Activation) to 0.68 (Coordination) | Construct ✓ Hypothesised relations stated Health service use Number of conditions Other measures | | | | |
| Glasgow et al., 2005b Diabetes Care USA | Type 2 DM (363) Age: mean 64.1 (11.5). 47% female Self-completed Primary Care | Internal consistency ✓ PACIC 0.96 Test re-test | Construct ✓ Sociodemographic variables - no difference Number of conditions – no difference | | | ✓ | |

| <i>Table 11.9 continued</i> | | Reliability | Validity | Responsiveness | Precision | Acceptability | Feasibility |
|--|---|--|--|-----------------------|------------------|----------------------|--------------------|
| QUOTE measures | | | | | | | |
| QUOTE – Chronic Non-Specific Lung Disease (CNSLD) | | | | | | | |
| Van Campen et al., 1997 Netherlands | Total 357 with range of chronic non-specific lung conditions Mean 57yrs (sd 18.6) ; range 15 to 95 54% female Self (postal) | Internal consistency ✓ Index alpha 0.93 General QUOTE: Patient indicators 0.88 Structure quality 0.84 Process quality 0.80 QUOTE CNSLD-specific 0.90 Test re-test | Face and Content ✓ PCA supported factor structure ✓ | | | | Not clear |
| QUOTE – Rheumatic Patients (Rheum) | | | | | | | |
| Van Campen et al., 1998 Netherlands | Total 425 with range of rheumatic conditions (70% RA; 44% OA; 29% LBP; 25% other) Mean 62yrs (sd 14.5) ; range 15 to 95 Self (postal) | Internal consistency ✓ Index alpha 0.92 General QUOTE: Patient indicators 0.84 Structure quality 0.81 Process quality 0.74 QUOTE Rheum-specific 0.88 Test re-test | Face and Content ✓ PCA supported factor structure ✓ | | | | Not clear |

Table 11.10 General application across condition, but specific to setting

| Study/ Country | Population (N) Age (years) Method of administration Setting | Measurement and Practical properties | | | | | |
|--|---|---|--|---|-----------|--|-------------|
| | | Reliability | Validity | Responsiveness | Precision | Acceptability | Feasibility |
| CEP-Questionnaire | | | | | | | |
| Clients Evaluate Practice locations Questionnaire | | | | | | | |
| Wensing et al., 1996a Netherlands | Patients with 1+ chronic conditions (34); GPs (19) Age Focus Groups Primary Care | | Item development Face and Content ✓ | | | Extensive involvement of patients and GPs | |
| Wensing et al., 1996b Netherlands | Patients with 1+ chronic conditions (not severe illness or psychiatric disease) (n 345) Mean 59.5 (sd NR) rge 18- >70 Mail (202) or by hand in clinic (143): all self completed Primary Care | Internal consistency ✓ alpha range 0.54 to 0.94 | | | | ✓ Mail RR 63% Hand RR 72% No significant difference in completion of Q or evaluations of care | |
| Thoonen et al., 2002 Netherlands | Asthmatics (n= 193) Mean 39.5 (sd 11.5) Self Participants in RCT – tailored education vs. usual care Primary Care Only applied 3 domains (20): 1.Medical Care 2.Relation and Communication 3.Information and Advise | | | ✓ Stat. significant change in score over 6-mths for intervention group; and between groups | | | |
| Health care System Hassles Questionnaire (HSHQ) | | | | | | | |
| Parchman 2005* USA | Chronic illness/disease (422) Age: mean 64.2 (10.5). 56% female Self-completed Primary Care | Internal consistency ✓ >0.90 Test re-test | Face ✓ Construct ✓ Health service use Number of conditions Other measures – CPCI | | ✓ | ✓ | |

| | | Reliability | Validity | Responsiveness | Precision | Acceptability | Feasibility |
|---|--|--|--|---|-----------|---------------------|-------------|
| Seattle Outpatient Satisfaction Questionnaire (SOSQ) | | | | | | | |
| Fihn et al., 2004 and Reiber et al., 2004 USA | DM-specific population (completed DM-specific, SF-36, SOSQ) n= 1,593 (baseline and 2-yr data) Age mean 65 (SD 10) Self Primary Care - ACQIP | | | ✓ No statistically significant difference in score on either domain: between groups (at baseline or 2yrs) or over time (2 years) | | | |
| Fan et al., 2005a USA | Chronic illness (IHD, COPD, DM) (28,689 – returned SOSQ) Age mean 65 (SD 10) Self Primary Care - Ambulatory Care Quality Improvement Project (ACQIP)* | Internal consistency Test re-test | Construct ✓ | | | ✓ | |
| Fan et al., 2005b USA | Chronic illness (IHD, COPD, DM) (28,689 – returned SOSQ) Age mean 65 (SD 10) Self Primary Care - Ambulatory Care Quality Improvement Project (ACQIP)* | Internal consistency Test re-test | Construct ✓ | | | ✓ 61% response rate | |
| OutPatient Experiences Questionnaire (OPEQ) | | | | | | | |
| Garratt et al., 2005 Norway | Wide range of conditions. Age 55.5 (sd 17.4) Self-completed Hospital out-patient – range of departments | Internal consistency ✓ Test re-test ✓ > 0.70 | Face ✓ Construct ✓ | | | ✓ | |
| Picker In-Patient Experiences Questionnaire (I-PEQ) | | | | | | | |
| Jenkinson et al., 2002a UK | In-patients – acute medical / surgical Age range 60.9 (sd18) Postal Acute in-patient care | Internal consistency Test re-test | Face and Content ✓ Participation of patients and HCPs in development Construct ✓ Correlation with overall satisfaction and willingness to recommend | | | ✓ | ✓ |

| | Reliability | Validity | Responsiveness | Precision | Acceptability | Feasibility |
|--|--|--|-----------------------------------|------------------|----------------------|--------------------|
| Picker Patient Experiences Questionnaire (PPE-15) | | | | | | |
| Jenkinson et al., 2002b UK, Europe, USA | In-patients – acute medical / surgical Age range 60.9 (sd18) Postal Acute in-patient care | Internal consistency ✓ Test re-test | Face and Content ✓ Construct ✓ | | ✓ | ✓ |

Footnote:

* Ambulatory Care Quality Improvement Project (ACQIP): randomized controlled trial of feedback/no feedback to provider (Aim: could outcomes be improved by comprehensive feedback?)

Table 11.11 Specific application to condition and setting

| <i>Study/ Country</i> | <i>Population (N) Age (years) Method of administration Setting</i> | <i>Measurement and Practical properties</i> | | | | | |
|--|---|--|--|-----------------------|------------------|----------------------|--------------------|
| Picker Musculoskeletal Disease Questionnaire (Picker MSD Questionnaire) | | Reliability | Validity | Responsiveness | Precision | Acceptability | Feasibility |
| Jenkinson et al., 2002d Sweden | Patients with Musculoskeletal problems (mainly back/neck) Age 54 yrs (sd 13.84) Postal Patients attending MS clinics | Internal consistency ✓ KR-20 0.86 Test re-test | Face and Content ✓ Participation of patients and HCPs in development Construct ✓ Correlation with overall satisfaction and willingness to recommend | | | ✓ | ✓ |
| Picker In-patient Questionnaire - Coronary Heart Disease | | I-PEQ (CHD) | | | | | |
| Jenkinson et al., 2002c UK | Patients with Coronary Heart Disease Age range 25->75 Postal Following in-patient care for CHD | Internal consistency ✓ KR-20 range 0.60 to 0.74 Test re-test | Face and Content ✓ Participation of patients and HCPs in development Construct ✓ | | | ✓ | |

DISCUSSION

Long-term, chronic diseases can have a substantial impact on the well-being of patients. Ensuring the provision of good quality and timely care that is responsive to the needs of patients is essential to patient centred care, and an important challenge to quality improvement initiatives. Recent years have seen an increasing acceptance of the role of patients in evaluating health care; consequently an increasing number of surveys and questionnaires exploring patient satisfaction or experience of health care are now available.

A large number and wide range of patient reported measures were initially identified in the review process, including numerous condition and profession-specific measures, those specific to different health care settings, for example, primary care and hospital in-patient care, and those specific to single dimensions of health care quality, such as continuity of care and access. However, few multi-dimensional measures were identified that were specific to the evaluation of health care quality and of relevance to multiple chronic conditions. Furthermore, there was limited published evidence of application and measurement or practical properties for reviewed measures.

A range of measurement and practical properties were stated *a priori* to inform data synthesis and subsequent recommendations for patient reported measures of health care quality of relevance to a chronic disease setting. Four components were considered key to this review:

- 1) evidence of scientific rigour informed by published evidence of measurement properties;
- 2) the diversity and range of dimensions of relevance to chronic disease and health care evaluation;
- 3) evidence of, or perceived, feasibility of application within a real world setting;
- 4) evidence of, or relevance to, application within a UK health care setting.

Although no single measure was considered outstanding across these four components, several of the reviewed measures have evidence to commend them:

- The conceptual base of the Patient Assessment of Chronic Illness Care (**PACIC**) (Glasgow et al., 2005a, b) was informed by the Chronic Disease Model (CDM); hence, evaluation of health care is judged against a clearly defined conceptual framework. There was extensive involvement of patients with a range of chronic diseases and health care professionals in item generation and subsequent assessment of dimensions. The measure includes several dimensions reflective of key elements of the CDM. The PACIC is a relatively new measure: early evidence suggests acceptable levels of reliability and good evidence of validity as a measure of health care quality, where health care provision aligns with the CDM, following completion by patients with a range of chronic conditions. To date, the measure has only been applied in the US population. The extensive involvement of patients and health professionals is to be commended, resulting in a relatively short (20 item) and focused questionnaire, with good evidence of face and content validity, and acceptability. Although not reported,

these factors are likely to result in good completion rates. However, the strong theoretical background of the PACIC may influence the relevance of the measure to any future application in a UK population; the provision of health care would need to be closely aligned with the CDM. Further evidence of performance with a UK setting is required.

- The **Picker Institute** (Europe) have developed a range of patient reported questionnaires applicable to the evaluation of patients experience of health care within different health care settings, in particular patient experience of hospital in-patient care. Several measures are condition-specific. The range of Picker measures have been widely applied and evaluated within the UK health setting, with good evidence of patient and professional involvement in item development, and promising evidence of measurement properties, acceptability and feasibility. However, at the time of writing, there is little clear evidence of the availability and performance of measures applicable to the evaluation of health care for people with chronic disease, particularly for care received outside of a hospital in-patient setting.
- The Out-Patient Experience Questionnaire (**OPEQ**) provides a multi-dimensional measure of outpatient experience across a range of clinic settings, and hence across a range of conditions. Development and subsequent evaluation has involved large numbers of health professionals and patients representing a wide range acute and chronic conditions and age groups. The questionnaire is brief, simple to complete and with good patient acceptability. Published evidence of a similar measure, generic across conditions and suitable for the evaluation of outpatient experience has not been identified in the UK setting. Replication of the results for the OPEQ, or similar measure specific to the evaluation of outpatient care, of relevance to chronic disease, in the UK health care system is required.
- The **QUOTE** measures include both a patient's expectation from health care ('importance') and actual experience in the generation of a final score. A range of QUOTE questionnaires are available; each measure has a 'generic' set of common dimensions of relevance to a wide range of health care users. Additional condition-specific 'add-on' items are available, including those applicable to rheumatology, chronic non-specific lung disease and 'disabled' patient groups. However, limited evidence of measurement reliability and validity has been identified for the QUOTE-Rheum only; evidence of acceptability and feasibility is not reported. There is no published evidence of completion by a UK population; evidence suggests that modification of item content would be required to improve relevance to the UK policy context. Clarity is lacking with regards to the format of these measures.
- The **Healthcare System Hassles Questionnaire (HSHQ)** involved patients with a wide range of chronic conditions and health professionals in item generation. Although the broad concept of 'hassles' with the receipt of care within a primary care setting was proposed, evidence suggests that the measure more specifically addresses concerns related to communication and co-ordination of care. The HSHQ is a relatively new measure with limited evidence of measurement and practical properties. It has not been applied in the UK setting.

- Although specific to the evaluation of health care for in-patients (receiving medical and/or surgical care) with cancer, the **EORTC IN-PATSAT32** is commended for the extensive involvement of patients and health professionals, across a wide range of cultural settings, in item development and subsequent evaluation. The result is a relatively short measure (32 items) that includes the widest range of dimensions of relevance to health care quality of all reviewed measures; it also includes items specific to care provided by specific members of the health care team: doctor and nurse-specific items. There is promising evidence of measurement properties and feasibility of application, including evaluation within a UK setting. However, patients are asked to rate their level of satisfaction with health care; evidence of potential ceiling effects has been reported.

Although at this time it is impossible to recommend an ‘off the shelf’ patient reported measure of health care quality that could be recommended for a chronic disease setting, there are several promising developments in the field.

Dimensions of health care quality

The multi-dimensional evaluation of health care quality is recommended to support data interpretation (Weaver et al., 1997; Coulter, 2005) and to inform quality improvement activities (Cleary, 1999). There is clearly a convergence towards key dimensions of relevance to health care quality both generally, and specific to the evaluation of health care of relevance to chronic disease (as summarised in Table 11.4). All reviewed measures include a wide range of dimensions, embracing a broader understanding of health care quality, than was observed in some of the earlier reviews of measures of health care quality (for example, Wensing et al., 1994). Four dimensions are common to the majority of reviewed measures – 1) respect for patient values; 2) co-ordination/ integration of care; 3) information, communication and education, and 4) continuity/ transition of care.

The developers of all reviewed measures have made some attempt to include patients and health care professionals in item generation; several developers also make reference to theoretical and conceptual frameworks for chronic disease management and/or health care quality. The appropriate involvement of patients should enhance the comprehensiveness and relevance of questionnaire content, and is increasingly recognised as an essential component of questionnaire development (Fitzpatrick et al., 1998; Burke et al., 2006).

Types of measure – patient experience

There appears to be general consensus that measures which aim to extract evidence, or reports, of a patient’s experience within the health care setting are more reflective of health care quality than measures exploring levels of satisfaction or relative excellence. Evidence suggests that measures addressing satisfaction alone are generally unhelpful and lack discrimination (Wensing and Elwyn, 2003; Street, 2006). Several of the reviewed measures that require patients to indicate their level of satisfaction with elements of health care have evidence of potential ceiling effects; for example, the ICICE and EORTC IN-PATSAT32. Moreover, it is suggested that data interpretation for well developed measures of patient experience is easier and hence more actionable for quality improvement initiatives (Sixma and Spreeuwenberg, 2006).

Reviewed measures that aim to explore patient experience of health care include: the PACIC, the HSHQ, the OPEQ, the Picker suite of measures, the QUOTE measures, and the CAHPS survey questionnaires.

Questionnaire format – ease of completion

Evidence of response, or completion, rates, as a measure of acceptability was not readily available from the majority of publications. However, there is a convergence towards the type of questionnaire likely to be both acceptable and feasible: that is, simple to complete, of acceptable length, and with relevant and meaningful item content. Reviewed measures with better evidence of response rates had extensive patient and health professional involvement at all stages of development.

Measurement properties

The relevance of item content is important to interpretation, and hence to using information to inform quality improvement initiatives. However, few studies report evidence of measurement responsiveness to such initiatives. Further evidence of responsiveness is an important requirement if these measures are to be used to inform quality improvement activities.

CONCLUSION

Fundamentally, the use and interpretation of health outcomes, and associated health outcomes research, is concerned with the evaluation of health care quality (O'Connor 2004). Enabling patients to effectively communicate personal values, priorities and expectations for health care, within the context of long-term chronic disease, to health care providers and to evaluate the relative success of health care are important elements of patient-centred care.

People with long-term chronic conditions experience the receipt of health care across a range of settings. Well developed multi-dimensional measures that capture the range of health care dimensions of relevance to patient-centred care and the needs of people with long-term conditions are essential to informing quality improvement activities. However, the relative benefits of measures that are generalisable across conditions and / or health care settings, versus those that are more specific to condition and / or setting are not clear. The appropriateness of a measure should consider the underlying objectives of any quality improvement initiative, an overriding feature of which should be to facilitate quality improvement efforts (Cleary, 1999).

Overall, there is limited supporting evidence for the patient reported evaluation of health care quality of relevance to chronic disease; and where evidence is available this is generally not available within a UK setting. No single measure fulfilled all requirements of scientific rigour, content, feasibility and relevance to the UK policy context. However, there is growing convergence towards key dimensions of relevance to the provision of good quality health care for individuals with long-term chronic conditions. Moreover, evidence suggests that those measures that aim to evaluate a patients experience of health care provide a more rigorous and interpretable assessment of health care quality than those measures where patients are asked to rate their level of satisfaction with a service. Several measures have promising evidence of measurement and practical properties; the review should inform future development, or where appropriate modification, of patient reported measures. The current review

clearly highlights the need for a well-developed, multi-dimensional, patient-reported measure of health care quality of relevance to chronic disease and the UK policy setting.

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