

## ARTICLE

# Data systems for assessing quality of cancer care: are building blocks in place for person-centered care?

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## Abstract

**Introduction:** There is an urgent need to improve quality of care across many areas of health, including cancer care. Accurate and reliable measurement of current practice is an important first step toward this goal.

**Assessing quality of care data systems:** This paper proposes several criteria that may be used in order to judge the suitability of current data systems for measuring the quality of cancer care. These include characteristics of indicators of care; the capacity of the data system to provide data that are representative of patients, providers and practices and the capacity of the system to be used for quality of care improvement activities.

**How do current approaches to assessing quality of care measure up?:** Current data systems used in the assessment of quality of care include medical records, administrative systems, cancer registries and patient and clinician self-reporting. All these data systems have strengths and weaknesses and none performed well against all of the criteria described. Unlike other methods, clinician self-report, however, does have the advantage of allowing the collection of the 'fine grained' detail needed to judge the appropriateness of care.

**Conclusions:** This study suggests that it may be necessary to consider alternative ways of collecting data for quality improvement purposes. Advances in e-technology may allow for the development of flexible, specific self-report tools to assess clinical practice, allowing rapid feedback to stakeholders.

## Keywords

Assessment, cancer, data systems, evidence-based practice, evidence-practice gap, measurement, person-centered medicine, quality assessment, quality improvement, quality of care

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## Introduction

The gap between best available evidence and actual practice represents a failure to translate scientific efforts into meaningful benefits for cancer patients, their families and the community at large [1,2]. This gap has been termed the "quality chasm" [1]. Deficits in quality may relate to overuse, underuse and misuse of evidence-based treatments and therapies [1].

Quality deficits such as these occur in all areas of medicine [2], including across the whole spectrum of cancer control [3-5]. With respect to primary and secondary prevention, numerous opportunities for quality

improvement have been identified. Despite evidence for the benefit of providing cessation advice to adult smokers [6], only 21% [7] to 38% [8] of smokers receive this advice from their doctor. Similarly, the benefits of colorectal screening for people aged 50 or older have been well established [9], yet only about 28% of those invited to take part in screening actually do so [4]. Gaps in quality also occur in relation to receipt of recommended cancer treatments. Twenty per cent of women with breast cancer do not receive radiation therapy after breast conserving treatment, while 30-70% of women with a lymph node-positive cancer do not receive tamoxifen treatment [3]. Only 54% of stage III and IV colorectal cancer patients receive chemotherapy in accordance with current

recommendations [5]. Pain is potentially under-treated for 25% of advanced cancer patients who are currently receiving or identified as needing analgesic treatment [10]. These and the many other documented gaps in quality of cancer care suggest a pressing need for finding far more effective strategies to improve quality of care and the person-centeredness of clinical interventions.

## Assessing quality of care data systems

Measurement of current practice is a prerequisite to improving quality

There are multiple reasons for the failure to adopt practices shown to be effective [11,12]. An efficient mechanism for regularly measuring clinical care and comparing it to best practice is a necessary first step to achieving improvements in quality of care [13]. Such data allow efforts to be focused on relevant quality improvement activities and measurement of progress towards care improvement. Hence, accurate and reliable measurement of quality of care provides the basic building blocks of any quality improvement activity directed at increased person-centeredness. While the need for accurate and reliable data for measuring quality of care has been highlighted [3,14] less attention has been paid to the features of the measurement system that might be considered ideal for the task of quality assessment. We propose a set of principles for judging the suitability of a measurement system for the purpose of assessing and improving quality and increasing person-centeredness.

## Ideal characteristics of indicators of quality

Permit a judgement about the appropriateness of clinical decisions

Guideline recommendations should make it clear to the reader who should perform a specified clinical action, how it should be carried out, in what circumstances and for which patients [15]. Ideally, a similar level of 'fine grained' detail is needed in quality indicators to enable a judgment about the appropriateness of clinical care. This allows contextual factors, such as contraindications and the role of patient preferences, to be taken into account when judging care quality [16]. In addition to these features, a clinical indicator also needs to meet criteria related to accuracy, reliability and sensitivity.

### Accuracy and credibility

An indicator of clinical performance needs to provide an accurate representation of the clinical action that it is

supposed to reflect [17]. Indicators must also be perceived to be credible measures of performance. Credibility increases the chance that recommendations for change in practice will be implemented [18]. The following criteria have been identified to evaluate credibility of indicators for assessing quality of care: (i) the degree to which the clinical action of interest is based on evidence; (ii) the relationship of the clinical action to patient outcomes; (iii) the importance to practice; (iv) the applicability in multiple settings; (v) the appropriateness to provider accountability & (vi) the ability to justify non-adherence in specific cases [19].

### Reliability

The same clinical care should be scored or coded in the same manner if scored at two different time points or by two different assessors [17,20]. This is an important measurement property as it allows confidence in interpreting any changes in scores over time.

### Sensitivity

Measures of clinical performance should be sensitive enough to detect small changes in clinical performance over time [20]. This is needed adequately to evaluate the effectiveness of quality improvement initiatives.

### Predictive validity

Process of care indicators should have a demonstrable link to better outcomes for patients [20].

### Capacity of the data collection system to provide representative data

Data that are broadly representative of the key parties and processes involved are crucial to obtaining an accurate and complete picture of the quality of care available to patients.

### Representative sample of healthcare providers

Data that describe the performance of a representative sample of clinicians are needed for results to be generalized to the broader population of clinicians [16].

### Representative sample of patients from the population of interest

In addition, the data should also reflect the experiences of a representative sample of patients from each clinician within the sample [16], as these data are more likely to provide a strong rationale for change and have greater capacity for a widespread influence on practice.

## Representative of the spectrum of care available

Ideally, the data collection system should enable sampling of a representative range of the various therapies and care available [16]. This enables overall clinical performance to be judged not just on a single dimension, but across the range of care that reflects the overall experiences of the identified group of patients. Assessment of a range of dimensions of care also enables more reliable assessment of the performance of individual clinicians. Scholle and colleagues [14] demonstrated that reliable measures of quality could be obtained for a greater number of physicians when composite scores derived from a range of quality indicators were used rather than single indicators.

## Characteristics of the data collection system to maximize performance improvement

The best data on quality of care are suitable both for monitoring care and as drivers for changing performance.

## Capacity to provide feedback to individual clinicians

Indicators which measure only the endpoint of complex system interactions may be poor motivators for individual clinicians to change their practice. Therefore, data that directly reflect the actions of an individual clinician are a stronger motivator for change [21]. Such data need to be framed non-punitively [21], presented in concrete and specific terms [18] and reliably represent the performance of each individual clinician through a sufficiently large and representative sample of patients [22]. The number of patients required to provide reliable data depends on the number of patients the clinician sees with the particular condition of interest over a defined time period. The way in which the sample frame is defined needs to be carefully delineated. Rodriguez and colleagues [22] showed that less favorable ratings of primary care physicians' performance were found when the sample frame included patients presenting for *ad hoc* care, rather than from only the physicians' established patients.

The type of care provided will be influenced by the systems that operate within a given setting. Characteristics of the multidisciplinary team [23] and the presence of influential opinion leaders within the group, have also been shown to influence adoption of best practice care [24]. Therefore, in addition to providing feedback to individual providers, the system would ideally be able to provide group level feedback that could enable exploration of organizational factors that may contribute towards quality of care problems.

## Capacity for rapid and repeated feedback

In order to achieve practice change, performance feedback must be timely [25]. A long time lag between the

occurrence of a behavior and reception of feedback related to that behavior, limits the likelihood of behavior change. This, in turn, limits the scope for using feedback as a mechanism for improving quality of care. A Cochrane Review has indicated that feedback is likely to be more effective if it is provided more intensively, for example, in an ongoing or frequent manner [26].

## Resource efficiency

Monitoring systems which take a long time to construct or are expensive to implement and maintain may not be feasible for ongoing use. As fewer resources are diverted from care provision, finding low-cost mechanisms for data collection increases both the likelihood that the data will be gathered and the acceptability of the process to healthcare providers.

## Flexibility

Indicators and data collection systems need to be flexible enough to be developed and changed quickly in response to feedback or changing requirements. This allows indicators to be refined until they meet acceptable standards for validity, reliability and credibility. It also means that systems can be changed to accommodate new evidence or changes in practice guidelines. If this does not occur, data produced by these systems may be perceived as irrelevant and result in clinicians and healthcare organizations self-exempting from the findings.

## How do current approaches to assessing quality of care measure up?

There are several data sources that can be used to assess quality of care. These approaches may be used separately or in combination.

### Medical records

Medical records data are commonly used to assess quality of care [3]. They provide person-specific records of care and are usually more detailed than other sources of data, thereby facilitating interpretation of appropriateness of care [27]. Disadvantages include the variable formats of the type and quality of medical records data across institutions [28]. Further, the level of detail provided in the medical record is highly dependent on the quality of recording by clinical staff. Certain types of care, particularly relating to interpersonal aspects of care, may be particularly poorly recorded [29], limiting the range of care that can be assessed via medical records.

## Tumor or cancer registry data

Population-based cancer registries record all incident cancer diagnoses for a defined geographic area [30]. They usually contain information about disease type, diagnosis date and patient characteristics such as age, gender and postcode [30]. Some staging data may also be collected [31]. Population-based cancer registries are subject to strict standards for completeness and quality of data [32]. Registries within the National Program of Cancer Registries in the US are expected to have 90% complete incidence counts within 12 months of the close of the calendar year in which the diagnosis occurred and 95% within 24 months [32]. Thus, registries provide comprehensive coverage of the target population. As limited data on treatment is recorded in most registries, registry data may be linked to medical records or claims data [3], in order to assess quality of care. Major disadvantages of this data source relate to the lag time for case ascertainment for quality assurance purposes [33], although this may be overcome with rapid case ascertainment procedures [30]. Even when linked to claims data, however, cancer registries may not provide sufficient detail on clinical features to enable quality assessment.

Many hospitals have tumor registries which keep more detailed data about the treatment provided to cancer patients within the organization than is available from population based registries [34]. When compared against quality of care data derived from medical records and supplemented with healthcare provider reports, the accuracy of staging and surgical procedures recorded on the breast cancer register has been shown to be high [35]. Sensitivity and specificity for staging and surgical procedures ranged between 0.91 to 0.97 [35]. Ambulatory care procedures were much less accurately recorded. Sensitivity was 0.58 and 0.27 for recording of radiotherapy and chemotherapy, respectively [35]. Similarly, Malin and colleagues found that when compared to medical records, gold standard tumor registry data demonstrated high sensitivity for surgical procedures (94.9 for lumpectomy to 95.9 for lymph node dissection) [3]. Sensitivity for ambulatory care procedures ranged from 9.8 for biopsy to 72.2 for radiotherapy [3].

## Routinely collected administrative data on health service use

Routinely collected data on hospital separations, procedures or claims data on healthcare services can also be used for quality of care assessment [36]. As these data are routinely collected, the costs associated with using them for quality assessment are often minimal compared to other methods [36]. Indicators are usually limited to services for which reimbursement can be claimed, limiting the types of care that can be assessed. Claims data may lack sufficient detail about co-morbidities and other clinical factors to enable accurate assessment of the appropriateness of care [27].

## Clinician self-reporting

Clinicians may be asked to complete surveys or interviews to indicate their adherence to particular indicators of quality. Several studies have examined doctors' self-reported practice patterns in order to assess aspects of quality of care [37,38]. As with all self-report data, clinician self-reporting may be subject to inaccurate recall [39] and social desirability biases [40]. Clinician self-reporting has the potential, however, to capture specific details of the clinical decision-making process and the context in which care was provided [41]. These details are unlikely to be captured by other methods and provide information critical to judging the appropriateness of care. Spies and colleagues [41] found that self-recording of clinical decisions enabled 95% of 206 quality criteria to be reviewed. In comparison, medical record review enabled 40% of the criteria to be reviewed, while observation allowed 72%. Clinician self-report may be retrospective or prospective. Prospective data collection decreases problems with recall biases; however, it may influence performance [42].

## Patient self-reporting

The usefulness of patient self-reporting may depend largely on the type of quality indicators which are being assessed. Patients are arguably the best source for assessment of interpersonal or patient-centered aspects of care [43]. For indicators such as information provision and quality of communication, they are the only people who can report on how effectively they were supported to be able to use, recall and apply information about their health condition [44]. Patient self-reporting may be less suited for technical aspects of care [45]. Several studies of self-reported screening behavior have demonstrated that accuracy is variable depending on the type of test being asked about [46].

## Need to overcome shortcomings of current data systems

There are considerable shortcomings of current data sources for the assessment of quality of care. While these are sometimes overcome by linking multiple data sources to assess particular quality questions [33], this process makes assessment both cumbersome and expensive. Coory and colleagues [36] found that only 8 out of 243 guideline recommendations for cancer care could be assessed using either cancer registry or inpatient administrative data [36]. One hundred and nineteen recommendations could be assessed by a clinical registry, which included information about diagnostic and staging procedures, prognostic features and multidisciplinary assessment. Eighty-eight guideline recommendations required an expanded clinical registry data set and medical records review in order to assess quality, while 28 were related to communication and

Table 1 Summary of the adequacy of various available data sources for assessing quality of care

Requirement	Medical Records	Cancer Registry	Administrative Data	Patient Self Report	Clinician Self Report
<b>Measurement characteristics</b>					
Accurate	✓	✓✓	✓✓	*	**
Reliable	✓	✓✓	?	✓✓	?
Sufficient detail	*	**	✓	*	✓✓
Responsive	✓✓	✓✓	✓	✓✓	✓✓
<b>Capacity for representative sampling clinical performance for range of:</b>					
Clinicians	*	**	✓	*	✓✓
Patients	✓✓	✓✓	✓	✓	*
Care	✓	✓	*	✓	✓
<b>Capacity to provide feedback on clinical performance which is:</b>					
By Clinician	✓✓	*	**	✓	✓
Rapid	*	*	?	✓	✓
Ongoing	*	**	✓✓	✓	✓
Efficient	**	✓✓	✓✓	✓	✓
Flexible	**	**	**	✓✓	✓✓

Key: ✓✓= Little or no limitation, ✓ = moderate limitations, \* =major limitations, \*\* =not appropriate/inadequate, ?= unknown

informational aspects of care, therefore requiring patient report or observation [36].

As shown in Table 1, current data sources do not perform well across all the criteria that may be important for assessing quality of cancer care. Basic criteria, such as accuracy and reliability, needed for a robust measure, may be difficult to attain for many indicators of quality using available data sources. For indicators where accuracy and reliability are demonstrated, the available data collection systems are often limited with respect to their capacity to be used for rapid, ongoing, clinician or organization-specific feedback. This is of concern, because feedback incorporating these features may be more effective in producing improvements in clinical performance than other types of feedback [21,26]. Feedback may be coupled with other strategies to target systems within the organization of care in order to produce widespread and sustained improvements in care [47]. Before such initiatives can be credibly and effectively implemented, robust data are required on current care.

Several authors have suggested that current limitations could be reduced by augmenting existing data sets [34]. For example, it has been argued that registry data could be made more amenable to quality assessment through the addition of clinical data [3,34]. This may, however, carry with it significant costs, both in terms of initial set-up and ongoing collection of data, which may only be used sporadically for quality assessment. Advances in e-technology make the implementation of shorter-term, quality-specific data collection instruments feasible and also cost effective. These technologies also offer great flexibility in terms of being able to make changes to

quality assessment tools to improve relevance, specificity or accuracy of reporting. This feature also provides longevity, as the tool can change as new evidence on best practice is developed. Electronic data collection tools could be used to collect clinician self-report data, capturing specific details which could augment existing data to enable judgments about quality of care. Provision of automatic feedback is also possible. James [48] has suggested that essential elements of information systems for quality measurement must include the ability to ensure that data are only collected once; that data can be aggregated in different ways for different types of reports; that audit standards are incorporated within the measurement system and that patient privacy is protected. The implementation of such systems, however, would need collaboration from clinicians, hospital administrators, policymakers and other stakeholders.

## Conclusions

If quality of care is to improve and person-centeredness advanced, it is of paramount importance that robust data sets suitable for this purpose are available. The criteria outlined may be used to judge the suitability of current and future datasets for the purpose of quality of care assessment. Current systems for collection of data on care show significant limitations. Developments in electronic data collection systems offer much promise with respect to flexible and rapid feedback. If their potential is to be realized, considerable investment of effort and co-ordination of healthcare organizations and governments is

needed. Quality assessment and evaluation is only as good as the measure of quality applied. Without these basic building blocks, there is unlikely to be broad reaching improvement across the spectrum of cancer care and advances in the person-centeredness of healthcare interventions will be correspondingly inhibited.

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