# ORIGINAL ARTICLE

# QUALITY OF INTEGRATED CARE FOR PATIENTS WITH HEAD AND NECK CANCER: DEVELOPMENT AND MEASUREMENT OF CLINICAL INDICATORS

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**Abstract:** *Background.* To improve the quality of integrated care, we developed indicators for assessing current practice in a large reference center for head and neck oncology.

*Methods.* We defined a set of indicators based on integrated care literature, national evidence-based guidelines for patients with head and neck cancer, and the opinions of professionals and patients. We tested this set regarding assessement of current practice and clinimetric characteristics.

*Results.* The final set consisted of 8 integrated care indicators and 23 specific indicators for patients with head and neck cancer. Current practice assessment produced high scores for the integrated care indicators, but the specific indicators showed room for improvement. The practice test showed that 9 indicators had good applicability.

*Conclusions.* The indicators, while based on evidence-based guidelines and the principles of integrated care, should incorporate patients' opinions and include a practice test. Our results show that the quality of integrated care for patients with head and neck cancer could be improved. © 2006 Wiley Periodicals, Inc. *Head Neck* **29:** 378–386, 2007

The management of care for head and neck cancer is very complex.[1,2] First, this common type of cancer has a very significant impact on the patient because of the location of the tumor. Patients often have problems with speech, eating, and physical appearance due to treatment.[3] Second, as head and neck cancers are heterogeneous and occur at several sites, they need to be managed by different disciplines in a multimodal treatment. Integration of care and integration of these disciplines are crucial for an optimal care outcome. However, many hospitals cannot guarantee such high quality.[4] Literature shows that integrated care programs can lead to higher patient satisfaction and

quality of life and less hospitalization. Effects on mortality are unclear.[5]

To improve the quality of integrated care for patients with head and neck cancer, current practice needs to be reliably assessed.[4] However, assessing the quality of integrated care is not straightforward, and selecting appropriate indicators to assess integrated care is difficult. Evidence-based guidelines for patients with head and neck cancer and reflective literature on the subject both provide recommendations for good-quality integrated care. To measure the quality of integrated care, key recommendations in these guidelines and the literature need to be translated into the so-called quality indicators.[6] Quality indicators are "measurable elements of practice performance for which there is evidence or consensus that they can be used to assess the quality of care."[7] Most indicators are derived from either evidence or professional expertise; they are seldom based on the experience and preferences of the patients.[7]

We undertook a study to develop indicators for measuring the quality of integrated care for patients with head and neck cancer. We were mainly interested in indicators regarding the process of care because they demonstrate clearly how providers can improve their outcomes. Besides, professionals are more accountable for the process of care than outcomes, which are affected by many other factors. The perspectives of both professionals and patients were used to develop the indicators and to test them empirically so that we could assess our current practice for patients with head and neck cancer and clinimetric characteristics of our set of indicators.

## MATERIALS AND METHODS

**Development of Indicators.** We used 2 strategies to develop the indicators (Figure 1). We systematically searched for integrated care recommendations in the literature, and we performed a systematic consensus procedure based on evidence-based guidelines and the opinions of professionals and patients.

This systematic procedure that combines expert opinions and evidence is called the "RAND-modified appropriateness method."[8] The following documents were selected as a starting point: the Dutch evidence-based guidelines for treatment and follow-up of patients with tumors of the larynx, oropharynx, and oral cavity; and the

guideline of the Dutch Cooperative Head and Neck group for optimal waiting and throughput time.[9–11]

Three specialists involved in the treatment of patients with head and neck cancer extracted 30 key recommendations from these guidelines, which were clinically relevant to patients' health benefits and/or to the continuity and coordination of care. This set of 30 recommendations was sent to an expert panel that included all 15 professionals involved in the care of patients with head and neck cancer at The Radboud University Nijmegen Medical Centre (RUNMC) (maxillofacial surgeons, radiotherapists, specialized nurses, pathologist, radiologist, consultant in nuclear medicine, dietician). The panel was asked to judge the 30 preselected key recommendations for potential indicators on a 9-point Likert scale on the basis of the same criteria as used in the preselection. Professionals could add new items. Descriptive analysis was used to process the results of this first round, and feedback in the form of means of all recommendations was presented in a face-to-face panel meeting. During this meeting, the panel members discussed the potential indicators and listed a personal top 5. The scores of the first round and the top-5 scores of the panel meeting were considered for inclusion in the final set of indicators.

To include the opinions of patients, 30 patients with head and neck cancer were individually interviewed for their opinions. Every third consecutive patient was selected from the consultation hours of 3 head and neck cancer consultants at the outpatient follow-up clinic of our university hospital. To ensure that a patient had the necessary experience, the follow-up period had to be at least 1 year starting from the patient's first visit to the clinic. The patients were asked to judge the recommendations on the basis of the same criteria that the professional expert panel used, except for the medical–technical items. The patients could also add new items. All 4 recommendations for integrated care were included in the final set of indicators (multidisciplinary patient care team, integrated care pathway, case management, patient involvement). To determine the specific indicators for the care of patients with head and neck cancer, the scores of the professionals on the potential indicators were compared with the preferences of the experienced patients. Recommendations were included in the final set when the combined, round mean scores of professionals and patients was 7 or more, or when the item was mentioned at
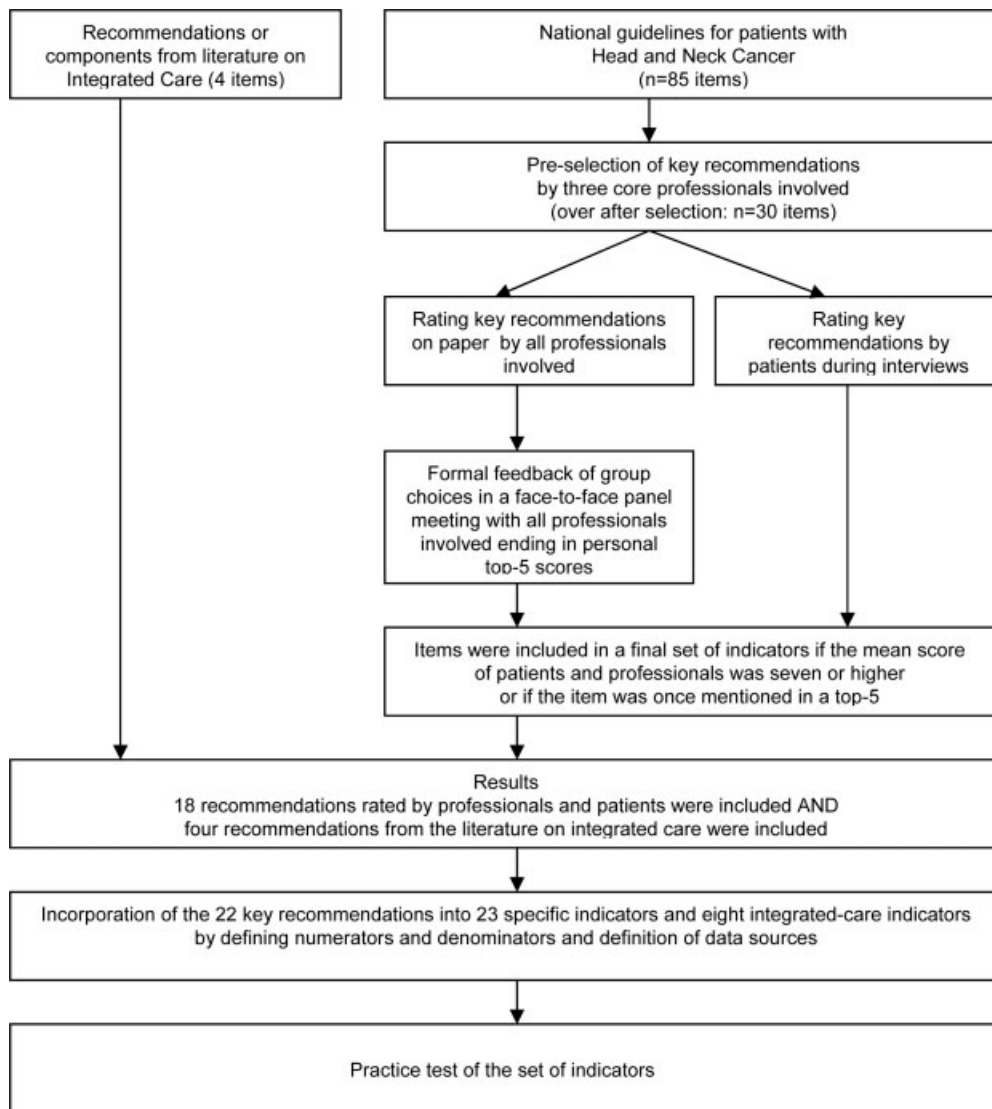
**FIGURE 1.** Process of indicator development.

least once in the professionals top 5. We incorporated the selected recommendations into indicators by defining numerators and denominators; data sources were also defined.

**Assessment of Current Practice.** The final set of indicators was next tested to assess current practice for patients with head and neck cancer in the RUNMC. The RUNMC is a university hospital in the southeast of The Netherlands, accommodating 1 of the main reference centers for head and neck oncology (approximately 425 new patients per year). We tested the integrated care indicators, except for the indicators "patient involvement" and "contact with the case manager," with questionnaires for professionals. All professionals

of the head and neck working group at the RUNMC were asked to complete a questionnaire. The Team Climate Inventory (TCI) was used to assess team functioning.[12] We used patient questionnaires and a survey of patient records to test the specific indicators for patients with head and neck cancer. After the medical ethics commission of the RUNMC gave their approval, we identified patients from clinic lists and sent a questionnaire accompanied by a letter from their consultants. All patients with head and neck cancer newly diagnosed in the period May to December 2003 were eligible to participate. These patients were approached regardless of disease stage or mode of treatment. Patients who had not responded within 2 weeks were reminded by telephone. The

**Table 1.** Indicators for integrated care and their results in practice.

| Indicator | Results |
|---|---|
| MDPCT | |
| 1. Availability of an MDPCT | There is an MDPCT with all professionals required: 3 head and neck surgeons, 2 maxillofacial surgeons, 2 radiotherapists, 1 pathologist, 1 nuclear medicine consultant, 1 medical oncologist, and 3 specialized nurses |
| 2. Functioning of the MDPCT according to the TCI | According the TCI, there was room for improvement (score 7 on 1–10 scale) in the areas of: information sharing, safety and influence of the members of the team, and a shared mission |
| Integrated care pathway | |
| 3. Availability of an integrated care pathway for patients with head and neck cancer | There are medical and nursing guidelines and protocols, but no up-to-date integrated care pathway that is used in the medical record of each patient |
| 4. The use of the clinical pathway for each patient with head and neck cancer | |
| Case management | |
| 5. Availability of a case manager | There are three specialized nurses that act as case managers |
| 6. The no. of patients that had interaction with the case manager(s) | 53% of the patients had interaction with a case manager |
| Patient involvement | |
| 7. No. of patients that feel involved in decisions regarding their treatment | 93% of the patients feel involved in decisions regarding their treatment |
| 8. The no. of patients that are well informed on all information items (see notes in Table 2 under ¶) | Only 44% state that they had been given enough information about all relevant items |
| Other items mentioned by professionals to improve the quality of integrated care: | |
| An electronic patient information system | |
| A budget of their own for the total chain of patients with head and neck cancer | |
| Support to improve the quality of integrated care | |

Abbreviations: MDPCT, multidisciplinary patient care team; TCI, team climate inventory.

medical records of the patients who completed and returned the questionnaire were examined.

### Assessment of Clinimetric Characteristics of the Indicators.

We examined the following clinimetric characteristics: feasibility, opportunity for quality improvement, and reliability. Feasibility was defined as the percentage of missing values per indicator. Feasibility was considered poor if this percentage exceeded 25%. Indicators must be capable of detecting changes in the quality of care. If indicator performance is already high, there is little opportunity for improvement. If there was less than 10% improvement potential on the indicators, there was considered to be too little room for improvement.[13] Reliability of the patient survey was tested on the data extraction of the patient records by calculating the percentage of agreement between 2 data reviewers expressed in κ coefficients. Two independent data reviewers collected both a sample consisting of 10 records, and scores of 0.6 or higher were considered to be good.[14]

## RESULTS

### Development of Indicators.

The researchers translated 4 recommendations about integrated care that were most often mentioned in the literature into 8 indicators, which were included in the final set to be tested in practice (Table 1). Regarding the development of the indicators specific to patients with head and neck cancer, the professionals gave 14 of the 30 recommendations a mean score of 7 or more. All recommendations scored by patients had a mean score of 7 or more. We combined the results of both professionals and patients to include 18 recommendations in the final set. The researchers incorporated 18 recommendations into 23 indicators (Table 2).

Adding the patients' opinions led to the inclusion in the final set of 5 recommendations that would not have been included if the professionals had selected them alone. These 5 recommendations were support for reducing alcohol consumption, support to stop smoking, speech and swallowing

**Table 2.** Twenty-three specific indicators for patients (total $N = 158$) with head and neck cancer and their results in practice.

| Indicators | Results, % | Feasibility*, % | Improvement potential,[†] % | Reliability[‡] |
|---|---|---|---|---|
| **Patient-oriented items** | | | | |
| Coordination | | | | |
| 1. No. of patients who know who to talk to for information and questions | 87 (124/143)[§] | 10 | 13 | NA |
| Information | | | | |
| 2. Availability of an information protocol | None | | | |
| 3. No. of patients who were well informed on all information items applicable to their situation[¶] | 44 (67/153)[§] | 3 | 56 | NA |
| Emotional and social support | | | | |
| 4. No. of patients who said they were offered emotional support | 21 (30/143)[§] | 10 | 79 | NA |
| Contact with companion in distress | | | | |
| 5. No. of patients who were informed about the possibilities to contact companions in distress | 27 (41/150)[§] | 5 | 73 | NA |
| Reducing alcohol consumption | | | | |
| 6. Availability of a multidisciplinary alcohol abstinence protocol | None | | | |
| 7. No. of patients who had been asked about alcohol use | 94 (131/139)[§] | 12 | 6 | NA |
| 8. No. of patients with alcohol problems who were offered support | 25 (15/59)[§] | 63 | 75 | NA |
| Nonsmoking policy | | | | |
| 9. Availability of a multidisciplinary stop-smoking protocol | None | | | |
| 10. No. of patients who had been asked about smoking behavior | 97 (144/148)[§] | 6 | 3 | NA |
| 11. No. of smokers who were offered support to stop smoking | 35 (24/68)[§] | 57 | 65 | NA |
| **Organizational-oriented items** | | | | |
| Waiting time first consultation | | | | |
| 12. No. of patients who could see a specialist 1 day after referral | 24 (29/121)** Median: 5 d | 23 | 76 | 1 |
| Waiting time diagnostic procedures | | | | |
| 13. No. of patients who had all necessary diagnostic procedures on day of their first visit to the specialist | 7 (10/147)** Mean of all procedures: 11 d | 7 | 93 | 0.6 |
| Waiting time first treatment | | | | |
| 14. No. of patients who started their first treatment within 30 days after their first visit to the specialist | 29 (35/122)** | 23 | 71 | 0.7 |
| Operation | Median: 31 d | | | |
| Radiotherapy | Median: 56 d | | | |
| Chemotherapy | Median: 41 d | | | |
| Continuity of care | | | | |
| 15. No. of patients who said that transition went seamlessly: to the head and neck centre | 86 (112/130) | 18 | 14 | NA |
| within the hospital between departments | 83 (131/158)[§] | | | |
| from the head and neck centre returning home | 97 (126/130)[§] 77 (104/135)[§] | | | |
| **Medical/technical-oriented items** | | | | |
| Swallow revalidation | | | | |
| 16. No. of patients with swallowing problems after leaving the hospital who were offered arrangements about follow-up | 18 (10/56)[§] | 65 | 82 | NA |
| Speech revalidation | | | | |
| 17. No. of patients who had a radical neck dissection or radiation in this area and with whom arrangements were made about follow-up regarding their speech revalidation | 21 (18/84)[§] | 47 | 79 | NA |
| Nutrition support | | | | |
| 18. No. of patients who were monitored regarding their nutrition health status before, during, and after their treatment | 0 ($n = 0/149$)[§] | 6 | 100 | NA |

| Indicators | Results, % | Feasibility*, % | Improvement potential,[†] % | Reliability[‡] |
|---|---|---|---|---|
| Assessment of CT and MRI procedures | | | | |
| 19. Availability of a radiologist who had experience with patients with head and neck cancer | Available | | | |
| 20. No. of assessments of CT and MRI procedures by this radiologist | 66 (40/61)** | 61 | 34 | NA |
| Focus-consultation by a maxillofacial expert team | | | | |
| 21. No. of patients with cancer of the mouth or oropharynx who had been seen by a maxillofacial expert team | 95 (*n* = 76/80)** | 49 | 5 | 0.6 |
| Consultation pathologist | | | | |
| 22. No. of times clinicians had contact by telephone with the pathologist in case of a negative biopsy with suspicion of malignancies | Not measurable | | | |
| Previous results | | | | |
| 23. No. of times all results of diagnostic procedures performed earlier were available during the patient's first visit to the RUNMC | Not measurable | | | |

Abbreviations: NA, not applicable.
Note: The following 9 indicators had both low percentages of missing values and high percentages for improvement: 1, 3, 4, 5, 12, 13, 14, 15, and 18.
*Percentage of missing data per indicator (should be <25%).
[†]Percentage of improvement potential per indicator (should be >10%).
[‡]Agreement between researchers expressed as κ coefficient: interobserver reliability κ.
[§]The absolute numbers of patient perceptions with a positive score on the indicator.
[¶]Information items and within parentheses are the positive scores on the separate items: course of diagnostic procedures and treatment options (94%), general information about hospital (92%), pros and cons of different treatment options (92%), narcosis (91%), side effects and complications (89%), course of the operation (88%), wound care (81%), mouth care and chewing problems (76%), possible course of the disease (73%), pain medication options (71%), diet prescriptions (68%), swallowing revalidation (66%), possible weight loss (65%), speech revalidation (52%), emotional and social support options (21%).
**The absolute numbers of patient records with a positive score on the indicator.

revalidation, and the wish to undergo all diagnostic procedures on the day of the first visit to the RUNMC. The patients added 2 information items to the professionals' set, namely, information about "the possible course of the disease" and "possible pain medication."

**Assessment of Current Practice.** We tested the set of indicators on a population of 189 newly referred patients with head and neck cancer at the RUNMC. A total of 158 patients returned the questionnaire (84% response). The patient characteristics are shown in Table 3. All medical records of the participants were examined. Thirteen of the 15 professionals completed the questionnaire. The mean age of the professionals was 48 years, 8 of them were men, and they had a mean clinical experience of 18 years.

Table 1 shows the integrated-care indicators and their realization in practice at the RUNMC. A multiprofessional patient-care team was available consisting of all professionals required. All new patients were seen, and their cases were discussed during the weekly meeting of this team. According to the TCI results, there was room for improvement within the team regarding information sharing, safety of team members, and task orientation.

Guidelines regarding care for patients with head and neck cancer exist, but they have not been translated into an up-to-date, integrated-care pathway. Three different specialized nurses perform case-management tasks, yet only 53% of the patients said they had interacted with them. The highest score was for patient involvement (93%). Despite the fact that only 44% of the patients stated that they were thoroughly informed about relevant information items, 93% of the patients

**Table 3.** Characteristics of patients (*n* = 158) included in the practice test.

| | |
|---|---|
| Mean age | 62 y |
| Men, % | 73 |
| Mortality, % | 9 |
| Education, % | |
| High | 23 |
| Regular | 23 |
| Low | 54 |
| Tumor location, % | |
| Larynx and hypharynx | 38 |
| Cavity of the mouth | 36 |
| Other | 26 |
| First treatment, % | |
| Operation | 56 |
| Radiotherapy | 37 |
| Chemotherapy | 7 |

felt that they were sufficiently involved in decisions regarding their care. The results of the assessment on the set of specific indicators for patients with head and neck cancer are shown in Table 2. The set of indicators could be divided into 3 dimensions of quality of care: patient-oriented quality of care, organizational quality of care, and medical/technical quality of care.

Regarding patient-oriented quality of care, the score was high for indicators for alcohol and smoking, and almost all the patients were asked about their alcohol consumption (94%) and their smoking behavior (97%). The score for support offered when necessary was low (25% and 35%, respectively). Patients knew who to talk to for information and to ask questions (87%), but the professions they mentioned were very different. The patients reported that they were often not well-informed about important issues, and only 44% said they were completely informed. Information about emotional and social support was especially lacking. One-day referral in the dimension of organizational quality was only achieved for 24% of the patients. Patients indicated they would like to have all the diagnostic procedures as soon as possible, preferably on their first visit or the day after. This was almost never the case (7%). The mean waiting times were 9 days for X-rays to 24 days for MRI scans. The median waiting time from the first visit until the start of first treatment was 31 days or more. Regarding medical/technical quality, "Focus consultation by a maxillofacial expert" had the highest score (95%). Fifty-three percent of the patients reported speech problems after operation or radiation, but in only 21% of the cases were arrangements made for follow-up. About one third of the study population (35%) had swallowing problems, and arrangements were made for 18% of them. None of the patients was structurally monitored for nutrition health status before, during, or after treatment. Although an experienced radiologist is part of the patient care team, she only evaluated 65% of all CT and MR procedures.

**Assessement of Clinimetric Characteristics of the Indicators.** By following the "Rand-modified appropriateness method" based on evidence-based guidelines, the content validity of our set of indicators has been guaranteed. Besides, the indicators for which the reliability could be determined all had acceptable κ values of 0.6 or higher. Table 2 shows that the feasibility of 6 indicators was low because they had more than 25% missing values.

Fourteen indicators had an improvement potential higher than 10%. Nine indicators had both low percentages of missing values and high percentages for improvement. These indicators are reflected in a footnote to Table 2. Two indicators proved not to be measurable: clinicians never recorded whether they contacted the pathologist by telephone in case of a negative biopsy and while there still was suspicion of malignancy, and it was not noted whether all results of diagnostic procedures previously performed in other hospitals were available during the first visit.

## DISCUSSION

In order to improve the quality of integrated care for patients with head and neck cancer, we searched in this study for a valid set of indicators to assess current practice. Our set of indicators is founded on literature on integrated care, national evidence-based guidelines for patients with head and neck cancer, and opinions of professionals and patients. The present study shows that including the opinions of patients with head and neck cancer in the development process for indicators really makes a difference, especially for items like lifestyle support, information supply, and the wish for 1-day screening. The results that we found for the integrated care indicators in the reference center for head and neck oncology at RUNMC show that the care for patients with head and neck cancer was reasonably well organized according to the principles of integrated care. With regard to the specific head and neck indicators, low scores were found for waiting times for diagnostic procedures and treatment, information supply, emotional and social support, life style support, and paramedical support for swallowing revalidation, speech revalidation, and nutrition.

When we compare our findings with literature, we see that long waiting times for diagnostic procedures and treatment is a common problem for many cancer patients.[15] For patients with head and neck tumors, it is shown that delay in the initiation of radiotherapy is associated with a decrease in local control.[16] There is some evidence that process redesign interventions and diagnostic assessment units improve waiting times and in turn decrease patient anxiety and increase patient satisfaction.[17–19] Failure to provide sufficient information about the disease and its treatment is the most frequent source of patient dissatisfaction.[20] Patient information records and decision aids can have positive effects on patients' knowledge

and satisfaction with the decision process.[21–23] Literature shows that about one third of patients with head and neck cancer have psychological distress and emphasizes the need to identify high-risk patients through psychosocial screening in order to provide early intervention.[24,25] Alcohol abuse and smoking lead to more postsurgical complications, reinforce the side effects of radiotherapy, and increase the risk on secondary tumors.[26] Therefore, improvement should be made to implement an active nonsmoking and antialcohol policy. Loss of weight before an operation is a significant indicator for complications and prognosis. Nutritional support by a dietician during treatment and follow-up are recommended.[27,28] A significant part of patients with head and neck cancer undergoing radiotherapy develop speech and swallowing problems, and close follow-up is recommended.[29]

In addition, our study reveals the importance of subjecting a set of indicators to a practice test. The feasibility or usefulness of a quality indicator depends among others on the number of patients on which the indicator is applicable. Another criterion is "room for improvement"; indicators that have a score of 90% or higher do have little room for improvement. The most successful indicators for quality improvement are indicators with much room for improvement and that are applicable on a large part of the population. The strength of our study is the solid development and test process to define a valid set of indicators that is based on evidence and that includes the opinions of both professionals and patients. The literature provides few studies about indicator development,[13,30,31] and none of them includes the patient's perspective. However, it is known that professionals and patients have different opinions about good quality of care.[32,33] It is very important to engage patients to achieve high quality in integrated care.

The content validity of our indicators is guaranteed either because indicators have an evidence link to outcomes or they are judged by experts to be clinically relevant to patients' health benefits and/or to the continuity and coordination of care. However, by following our process, the final set of indicators consists mainly of so-called structure indicators (eg, the availability of a multiprofessional team) and indicators regarding the process of care (eg, speech revalidation). Information about these indicators is necessary to make changes to improve the quality of care. For quality improvement process indicators and structure indicators are more useful than outcome indicators because outcome indicators have a long-time horizon and are strongly affected by many other factors.[31] However, for studies directly interested in outcome indicators, adding a standard set of outcome indicators, such as mortality, morbidity, quality of life, functional health status, and patient satisfaction, could be considered.

In conclusion, an assessment of current practice based on a set of valid indicators should be made before attempting to improve the quality of integrated care for patients with head and neck cancer. Indicator development requires a solid procedure agreed upon in advance. The set of indicators should be based on evidence-based guidelines and the principles of integrated care and should include patients' opinions.

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